The MiDerm App: A mixed methods approach to developing a complex digital behaviour change intervention for adults living with skin conditions

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Doctor of Philosophy

by

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Summary of thesis

Background

Skin conditions carry a substantial psychological burden, yet the biomedical model of care remains prominent in dermatology and psychological support for patients is lacking. Digital technology can support self-management. This thesis aimed to co-develop a complex digital behaviour change intervention (DBCI) for adults with skin conditions, with patient input.

Methods

Mixed methods research focused on intervention planning, which comprised of two phases. Phase 1 involved: (1) formation of a Patient and Public Involvement group; (2) a systematic review of digital psychological interventions in dermatology; (3) an online survey and group interview study to understand adults' (≥ 18 years) experiences of self-management, existing support and the perceived acceptability of a DBCI called MiDerm. Phase 2 prioritised the design, development and build of MiDerm. Studies were informed by the Common-Sense Model of Self-Regulation and the Theoretical Framework of Acceptability. Intervention development followed the Person-Based Approach and was informed by the Behaviour Change Wheel.

Results

Existing digital interventions were mostly web-based, educational and condition-specific. They were potentially acceptable and effective, but evidence was limited and barriers were identified. Overall, 413 people across 30 countries representing 24 skin conditions participated. Results emphasised the impact of self-management and limitations and inadequacies associated with medical care and psychological, social and peer support. Psychological support was needed and the idea of a smartphone app including informational, emotional, behavioural and peer support was generally welcomed as an adjunct to current care. Respecting personal autonomy seemed imperative for overcoming potential barriers. Results informed intervention development.

Conclusion

Quality and interdisciplinary research to develop and test DBCIs with adults with skin conditions was needed. Research findings supported and informed the development of MiDerm. Next is to evaluate, optimise and implement MiDerm for use among the target group.

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List of abbreviations

ACT	Acceptance and Commitment Therapy
AD	Atopic Dermatitis
App	Application
APPGS	All-Party Parliamentary Group on Skin
BAD	British Association of Dermatologists
BAI	Beck Anxiety Inventory
BBQ	Brunnsviken Brief Quality of Life Scale
BCT	Behaviour Change Technique
BCW	Behaviour Change Wheel
BeSci	Behavioural Science
BMI	Body Mass Index
BSA	Body Surface Area
CBT	Cognitive Behavioural Therapy
CFS	Chronic Fatigue Syndrome
CLCI	Cumulative Life Course Impairment
COM-B	Capability, Opportunity and Motivation – Behaviour
COPE	Coping Orientation to Problems Experienced
COSMIN	Consensus-Based Standards for the Selection of Health Measurement Instruments
CSM	Common Sense Model of Self-Regulation
CVD	Cardiovascular Disease
DALY	Disability-Adjusted Life Year
DBCI	Digital Behaviour Change Intervention
DIEPP	DIEt and Psoriasis Project
DLQI	Dermatology Life Quality Index
DSM-5	Diagnostic Statistical Manual of Mental Disorders 5
EASI	Eczema Area and Severity Index
EB	Epidermolysis Bullosa
eHealth	Electronic Health

ESDaP	European Society for Dermatology and Psychiatry
G	Group
GBD	Global Burden of Disease
GDPR	General Data Protection Regulation
GP	General Practitioner
GRIDD	Global Research on the impact of Dermatological Diseases
HADS	Hospital Anxiety Depression Scale
HECSI	Hand Eczema Severity Index
HRQoL	Health-Related Quality of Life
HPA	Hypothalamic–Pituitary–Adrenal
HS	Hidradenitis Suppurativa
IADPO	International Alliance of Dermatology Patient Organisations
IAPT	Increasing Access to Psychological Therapy
IBD	Inflammatory Bowel Disease
ICBT	Internet-based Cognitive Behavioural Therapy
IGA	Investigator Global Assessment
IMPACT	Identification and Management of Psoriasis Associated ComorbidiTy
ISDL	Impact of Chronic Skin Disease on Daily Life
ITCH RELIEF	Interactive Toolbox of Comprehensive Health Resources to Enhance Living with Itch – Educational Facilitation
JBI	Joanna Briggs Institute
JLA	James Lind Alliance
LS-PGA	Lattice System Physician’s Global Assessment
MEMS®	Medication Event Monitoring System
mHealth	Mobile Health
MI	Motivational Interviewing
MRC	Medical Research Council
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
NTSD	Neglected Tropical Skin Diseases

OSF	Open Science Framework
PANAS	Positive and Negative Affect Schedule
PASI	Psoriasis Area Severity Index
PBA	Person Based Approach
PC	Pachyonychia Congenita
PGA	Physician Global Assessment
PHQ-9	Patient Health Questionnaire 9
PHW	Public Health Wales
PICO	Population, Intervention, Comparison, Outcome
PICOS	Population, Intervention, Comparison, Outcomes and Study design
PIH&S	Post-Inflammatory Hyperpigmentation and Scarring
PIRIT	Public Involvement in Research Impact Toolkit
PIS	Participant Information Sheet
POEM	Patient-Oriented Eczema Measure
PPI	Patient and Public Involvement
PRIDD	Patient-Reported Impact of Dermatological Diseases
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROM	Patient Reported Outcome Measure
PROSPERO	International Prospective Register of Systematic Reviews
PSP	Priority Setting Partnership
QoL	Quality of Life
QoLS	Quality of Life Scale
RA	Rheumatoid Arthritis
RCT	Randomised Controlled Trial
SAPASI	Self-Administered Psoriasis Area and Severity Index
SCORAD	SCORing Atopic Dermatitis
SDT	Self-Determination Theory
SPIDER	Sample, Phenomenon of Interest, Design, Evaluation, Research type
TA	Thematic Analysis
TDF	Theoretical Domains Framework
TFA	Theoretical Framework of Acceptability

TIDieR	Template for Intervention Description and Replication checklist and guide
UK	United Kingdom
UoM	University of Manchester
URL	Unique Resource Locator
USA	United States of America
WHO	World Health Organisation
XP	Xeroderma Pigmentosum

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Publications and presentations on this work

Published articles

Hewitt, R. M. and Bundy, C. 2021. New technology use needs patient input. *British Journal of Dermatology* 185(5). doi: 10.1111/bjd.20634.

Hewitt, R. M., Purcell, C. and Bundy, C. 2022. Safeguarding online research integrity, concerns from recent experiences. *British Journal of Dermatology*. doi: 10.1111/bjd.21765.

Hewitt, R. M. et al. 2022. A mixed methods systematic review of digital interventions to support the psychological health and well-being of people living with dermatological conditions. *Frontiers in Medicine* 9. doi: 10.3389/fmed.2022.1024879.

Journal articles in preparation

Hewitt, R. M., Dale, C., Pattinson, R., Purcell, C. and Bundy, C. A qualitative exploration of the impact, management and existing support available for adults living with skin conditions. *(submitted).*

Hewitt, R. M., Dale, C., Pattinson, R., Purcell, C. and Bundy, C. A qualitative exploration of the perceived acceptability of the MiDerm App; a complex digital intervention for adults living with skin conditions. *(submitted).*

Hewitt, R. M., Dale, C., Thomas, B., Purcell, C. and Bundy, C. A global on-line survey of coping strategies and health behaviours performed by adults living with long-term skin conditions. *(in preparation)*.

Dale, C., **Hewitt, R. M.,** Purcell, C. and Bundy, C. "Feeling like a second-class citizen": Exploring the impact, self-management and existing support for adults living with acne and/or post-inflammatory hyperpigmentation and scarring. *(submitted).*

Published conference abstracts

Hewitt, R.M., Pattinson. R.**,** Dale, C. Purcell, C. and Bundy, C. 2023. Development of a novel, complex, digital psychological intervention for adults with skin conditions: a qualitative online group interview study with prospective users. *Congress of The European Academy of*

Dermatology and Venereology, Berlin, 11-14 October 2023. Available at: Psychodermatology.pdf (eadv.org).

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Hewitt, R.M. 2023. Digital Innovations in Psychodermatology: Development of a complex digital psychological intervention for adults with skin conditions (from 20th Congress of the European Society of Dermatology and Psychiatry, 22-24 June 2023). *Acta-Dermato Venereologica*, 103, doi: https://doi.org/10.2340/actadv.v103.12603.

Hewitt. R.M., Ploszajski. M., Purcell. C., Pattinson. R., Jones. J., Hughes. O. Wren. G., Ridd. M., Thompson. A., Bundy. C. 2022. A mixed methods systematic review of digital psychological interventions for people living with dermatological conditions. *Spring Symposium of The European Academy of Dermatology and Venereology,* Ljubljana, 12-14 May 2022. Available at: Symp2022_Abstract-Book_edit.pdf - Google Drive.

Meetings attended and presentations

Meeting	Date	Location	Title of Presentation	Format	Extra information
Congress of The European Academy of Dermatology and Venereology	October 2023	Berlin, Germany	Development of a novel, complex, digital psychological intervention for adults with skin conditions: a qualitative online group interview study with prospective users.	e-poster	
Congress of The European Academy of Dermatology and Venereology	October 2023	Berlin, Germany	'A global on-line survey of coping strategies and health behaviours performed by adults living with long-term skin conditions'	e-poster	
20th Congress of the European Society of Dermatology and Psychiatry	June 2023	Rotterdam, The Netherlands	Digital Innovations in Psychodermatology: Development of a complex digital psychological intervention for adults with skin conditions.	Oral	Invited speaker.
West of England, Clinical Research Network, NIHR, Education Event.	April 2023	Online	Psychological support for people with dermatological conditions: *Current issues and new developments.*	Oral	Invited speaker.
School of Healthcare Sciences (Cardiff University)	June 2022	Online	A mixed methods systematic review of digital psychological interventions for people living with dermatological conditions.	Oral	Won Dr Tina Gambling award

Postgraduate Research Symposium					for best oral presentation.
Spring Symposium of The European Academy of Dermatology and Venereology	May 2022	Hybrid	A mixed methods systematic review of digital psychological interventions for people living with dermatological conditions.	e-poster	Shortlisted for media activity.

Statement of contribution

This thesis was written by the PhD candidate, Rachael Hewitt (RH). Two PhD supervisors, Professor Chris Bundy (CB) and Dr Catherine Purcell (CP), reviewed and commented on the entire thesis. Other colleagues collaborated on the studies that form part of this PhD and co-authored related publications. These collaborations are justified in the context of team science (see Chapter 9) and individual contributions to each study are acknowledged below.

Chapter 4: Mixed methods systematic review

Contribution of candidate: RH led the conceptualisation, design and registration of the review protocol, as well as methodology, material development, database searching, article screening, data extraction, critical appraisal and data synthesis. RH wrote the thesis chapter and the published article.

Contribution of collaborators: Matthew Ploszajski (MP) contributed to database searching, article screening, data extraction, critical appraisal. RP contributed to the conceptualisation, methodology, article screening, data extraction, critical appraisal, discrepancy resolution, consensus checking. Dr Bethan Jones (BJ) contributed to the methodology, material development, article screening, data extraction, critical appraisal, and consensus checking. Ms Georgina Wren (GW) and Dr Olivia Huges (OH) contributed to the material development, article screening, data extraction, critical appraisal, consensus checking. Professor Matthew Ridd (MR) contributed to the consensus checking and discrepancy resolution for article screening, data extraction and critical appraisal. Professor Andrew Thompson (AT) contributed to the consensus checking and discrepancy resolution for article screening and data extraction. CP and CB contributed to the conceptualisation, methodology, consensus checks, discrepancy resolution for article screening, data extraction, critical appraisal, supervision, as well as reviewing and editing the thesis chapter. All collaborators contributed to reviewing and editing the manuscript prior to publication.

Chapter 5: Online group interviews

Contribution of candidate: RH led the study conception and design, material development, ethics application, participant recruitment, data collection and analysis, as well as drafting and finalising the thesis chapter and manuscript for publication.

Contribution of collaborators: RP supported data analysis and manuscript review and editing. CB and CB contributed to study conception and design, reviewed materials, supported data analysis, and reviewed and edited drafts of the thesis chapter and manuscript. Carys Dale (CD) contributed to editing the thesis chapter into a manuscript to submit for publication. Five patient organisations, including the Psoriasis Association, Global Skin, Eczema Outreach Support, the British Skin Foundation and Skin Care Cymru, supported recruitment.

Chapter 6: Online survey

Contribution of candidate: RH took a leading role in conceptualising the study, survey design and development, applying for ethical approval, recruiting participants, data cleaning and analysis, and preparing the thesis chapter and journal article.

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Chapter 8: Intervention development

Contribution of candidate: RH was responsible for conception, theoretical modelling of the intervention, and drafting the full thesis chapter. Took the lead on drafting and finalising the written content and conducted one online individual interview for the patient stories section of the app. Co-led app design.

Contribution of collaborators: CD, CB and CP all supported app development by reviewing and editing app content and design. CB and CP supported conceptualisation and theoretical modelling. CD conducted four online individual interviews for the patient stories section of the MiDerm app, and drafted the written content on treatment adherence, sleep and drinking alcohol, with support and supervision from RH. CD, CB and CP all reviewed and edited this chapter.

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Andrew Davidson co-led app design and was responsible for building the MiDerm app with support from other staff at Logic Software Ltd.

Several individuals and organisations contributed to the development of the content for the signposting page of the MiDerm app. Contributors are listed below by role or organisation.

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Glossary

Term	Definition
Acceptability	A theoretical concept referring to the appropriateness of an intervention.
Alexithymia	A term used in psychology to describe the inability to recognise and label emotional responses to a scenario.
Behavioural analysis	A structured process for identifying a behaviour(s) that a behaviour change intervention will target.
Behavioural science	The scientific study of human behaviour and the factors that influence it. Behavioural science is an integrative science that draws on several cognate disciplines that involve a behavioural component.
Behaviour change technique	An active ingredient of a behaviour change intervention which facilitates the performance of the desired behaviour and are observable, replicable and irreducible.
Code	A label that is assigned to a chunk of qualitative data which captures its meaning.
Code book	A set of codes and their respective definitions which are applied to analyse qualitative data. A code book can be developed a priori or generated from the data during the process of data analysis.
Complex behaviour change intervention	An intervention comprised of interacting components designed to change behaviour(s) and address a range of outcomes in at least one group of people.
Concept	A specific subject that relates to an overarching construct and can be measured using a single question or item.
Construct	A subject of measurement that is clearly defined. In psychology, the term construct is used to refer to phenomena that do not have a physical presence (e.g., emotions).
Content	General term used to refer to any written, visual or audio material that forms part of a digital intervention.

Cumulative Life Course Impairment	A theoretical concept that describes the increasing burden of long-term health conditions over time.
Deductive coding	A top-down approach to data coding where an existing framework or code book are applied to a qualitative data set.
eHealth	Use of information and communications technology to deliver and improve healthcare and services.
Guiding principles	A term associated with the Person-Based Approach to intervention development which collectively refers to the objectives and features of an intervention.
Implementation intentions	Also known as ‘if-then’ plans, are evidence-based self-regulatory strategies that can support goal attainment.
Inductive coding	A bottom-up approach to data coding whereby codes are derived from qualitative data. Also known as open coding.
Intellectual property	Something that is created, such as an invention. Intellectual property can be owned by an individual or multiple people, including businesses, and can be sold and transferred.
Item	A single question or statement (plus related response options) that form part of a measurement instrument or tool that can be answered to address concept.
Logic model	A visual depiction of the key components of a behaviour change intervention and the mechanisms of action and how these interact to produce the desired behavioural outcome.
mHealth	Use of mobile technology to deliver and improve healthcare and services.
Motivational Interviewing	An evidence-based and collaborative style of consultation developed by William R. Miller and Stephen Rollnick to facilitate personal motivation and capability for behaviour change by addressing ambivalence to change.

Patient and Public Involvement	The term used to acknowledge the role of non-academics who support the conduct of research.
Personal model	A psychological term that is used to describe a collection of beliefs, attitudes, feelings and experiences related to a phenomenon.
Prototype	A preliminary or original model of a product that can be tested or developed further.
Psychological processes	An overarching term that refers to cognitions, emotions and behaviour.
Push notification	A digital alert that is sent when an app is closed or not in use usually to draw the user's attention to a message or update.
Questionnaire	A series of questions on a particular topic that are administered to research participants to answer.
Stakeholders	Specific groups of people whose perspectives and experiences are deemed important to an intervention undergoing development.
Survey	The process of distributing a questionnaire to a specific group of people and collecting and analysing the data from it to answer a specific research question(s).
Theme	An overarching category that is comprised of a group of related codes.
Theoretical modelling	The process of mapping components of an intervention to existing theory.
Wireframe	Basic visual representations (usually line drawings) that depict the essential components and features of software.

Chapter 1: Introduction to skin conditions and their impact

Dermatology is a medical specialty of the skin and related structures, including the hair, nails and oral and genital mucous membranes (Chiang and Verbrow 2020). The British Association of Dermatologists (BAD) identifies over 2,000 known dermatological or skin conditions (BAD, 2018). Within the field of dermatology and across medical specialties more generally, the terms ‘condition’ and ‘disease’ are generally used interchangeably to refer to non-communicable health conditions of slow progression, that persist over time and require ongoing clinical and self- management (Bernell and Howard 2016).

Skin conditions can be classified by type, duration or according to their prevalence. They can be infectious, genetic, inflammatory or non-inflammatory, and cancerous or non-cancerous. Whilst some skin conditions are acute (short-term) in duration, others (e.g., acne, psoriasis, eczema, vitiligo) are chronic (long-term) conditions and many are currently incurable (BAD, 2013). Some skin conditions, such as eczema, are regarded as long-term conditions, but follow a cyclical timeline, which involves repetitive periods where symptoms flare, usually in response to a trigger, then subside (Ghio et al. 2020).

Skin conditions are the fourth most common health condition globally (Hay et al. 2014; Seth et al. 2017), affecting almost a third of the world’s population (Flohr and Hay 2021). Estimates indicate that up to 900 million people worldwide live with a skin condition at any time (Hay et al. 2014). In the UK, estimates suggest that 54% of the population experience a skin condition, and 24% visit their General Practitioner (GP) with a skin condition, each year (All-Party Parliamentary Group on Skin [APPGS] 2013).

Skin conditions are divided into common and rare types. Psoriasis, acne vulgaris and atopic dermatitis (AD/eczema) have a high prevalence globally. Ichthyoses and Pachyonychia Congenita (PC) are examples of rarer skin conditions for which prevalence rates are lower. However, prevalence data is often country- or condition- specific (Svensson et al. 2018). The prevalence of psoriasis in adults, for example, varies with age, sex, ethnicity, geographical location, genetic and environmental factors, and how prevalence is measured (Parisi et al.

2020). Thus, the prevalence of skin conditions is likely to be higher than current evidence suggests. Global estimates for the prevalence of some common and rare skin conditions are presented in Appendix 1.

A range of biological, physiological, environmental and psychological factors have been associated with the onset and development of skin conditions. Many ichthyoses, for example, are inherited due to underlying genetic mutations (Gutiérrez-Cerrajero et al. 2023). Other skin conditions, such as contact dermatitis, are most likely to be triggered by substances in the environment, including allergens and irritants, that react with the skin and cause physical symptoms (Williams and Grindlay 2010).

Inflammatory processes are implicated in many skin conditions, which has led to the distinction between inflammatory and non-inflammatory types (Lyman 2019). Inflammatory skin conditions, such as psoriasis, eczema, acne and vitiligo, are associated with impaired immune system function and thus are also classified as immune-modulated conditions (Lyman 2019). Skin conditions of this nature occur when the body's immune system becomes dysregulated, causing an inflammatory response that subsequently presents as visible symptoms on the skin's surface (Lyman 2019). This distinction is important because inflammation has been linked to other serious health conditions and psychological processes that are associated with skin conditions, which are covered in this chapter and Appendix 2.

The link between emotions and skin reactions is known as the 'brain-skin axis' (Marek-Jozefowicz et al. 2022). Psychological factors, including stress, can influence the onset and development of some, mainly inflammatory, skin conditions, although this link is complex as stress is both a cause and consequence of skin conditions, indicating a bi-directional relationship (Balieva et al. 2022; Marek-Jozefowicz et al. 2022). The term psychological stress is used to refer to physiological and psychological (cognitive, emotional and behavioural) responses that one experiences when the demands of a stressor (e.g., health threat or traumatic event) are perceived to outweigh the individuals personal ability to cope with it (Lazarus 1966).

The hypothalamic–pituitary–adrenal axis (HPA) controls the stress response including digestive, immune, sexual and emotional functioning and energy expenditure (Marek-Jozefowicz et al. 2022). Physiological changes occur in the body in response to stressful life events; the central and peripheral HPA axis and sympathetic nervous system is stimulated, commonly known for our ‘fight or flight’ response, and pro-inflammatory cytokines and cortisol, among other hormones, are released (Marek-Jozefowicz et al. 2022). These physiological changes are often revealed by our skin. Blushing, for example, is a common human experience wherein the skin flushes red in response to feelings of embarrassment. These physiological responses can cause and worsen symptoms of some skin conditions, such as psoriasis, because they are associated with increased production of localised inflammatory markers (i.e., C-reactive proteins, tumour necrosis factor alpha, and interleukin 1 and 6), which expedite the production of skin cells (Marek-Jozefowicz et al. 2022).

These physiological responses are also known to influence the presentation of psychological conditions, including depression (Marek-Jozefowicz et al. 2022). It seems psychological stress can promote an inflammatory skin response that can give rise to psychological comorbidities, including symptoms of depression and anxiety (Marek-Jozefowicz et al. 2022). However, psoriasis research also suggests that people with moderate to severe depression are at increased risk of developing psoriasis (Marek-Jozefowicz et al. 2022). This is evidence of the bi-directional relationship between emotions and the skin and justifies the need to offer emotional support to people with skin conditions.

Burden of disease

Skin conditions carry a substantial burden for people and their families, health services and societies across the world (Basra and Shahrukh 2009; Flohr and Hay 2021). Since 1991, the Global Burden of Disease (GBD) study has produced data on health trends and outcomes that is used to inform healthcare, research and policy at local, national and international levels (Murray 2022). The GBD study has reported morbidity and mortality rates for 396 health problems and 87 health risk factors across 204 countries (Murray 2022). The GBD study uses the disability-adjusted life years (DALYs) metric to calculate disease burden, where one DALY corresponds to the loss of one year of full health. To date, the GBD studies have featured 15 dermatological conditions and indicate the non-fatal burden is comparable to that of other long-term conditions, such as diabetes (Hay et al. 2014; Karimkhani et al. 2017), although variations have been observed across ages, countries and the availability of resources (rich versus poor) (Seth et al. 2017). However, the burden of dermatological conditions has, arguably, been systematically underestimated in research (Seth et al. 2017; Flohr and Hay 2021) given that DALY scores are based on physical symptoms only and do not account for the impact of these conditions on psychological health and well-being.

In the UK most skin conditions are managed by GPs in primary care settings; estimates indicate that skin conditions account for 15% to 20% of a GP's workload, with the majority of consultations addressing more common conditions, such as eczema, acne, psoriasis and skin allergies (Kerr et al. 2010; Hay et al. 2014; BAD, 2018). However, research indicates that 14% of people living with a skin condition in the United Kingdom (UK) do not seek medical treatment and 69% care for their condition by themselves (APPGS 2013). In addition, research on psoriasis and rosacea has shown that over 77% of people with these conditions do not seek medical treatment (Wehausen et al. 2016). Thus, whilst the management of skin conditions presents a challenge to health services, many people living with skin conditions are not engaging with the healthcare system and may need additional support to self-manage their condition effectively.

The economic cost of skin conditions is comparable to that of other serious non-communicable diseases, including cardiovascular disease (CVD; Lim et al. 2017). Since the early 2000's, there have been significant advances in the field of dermatology which has led to the development of new but expensive treatments (Lim et al. 2017). In 2013, the direct and indirect costs of skin conditions in the US were estimated at $75 billion and $11 billion, respectively (Lim et al. 2017). In the UK, skin conditions are estimated to cost the National Health Service (NHS) £723 million per year (Association of the British Pharmaceutical Industry 2018). The economic cost is only set to increase over time given that people are now living longer and the average life expectancy is increasing (Lim et al. 2017; Flohr and Hay 2021), although recent estimates show that life expectancy has dropped in countries such as Russia, the US and parts of the UK (England and Wales) due to the SARS-CoV-2 pandemic (Mazzuco and Campostrini 2022). The prevalence of skin cancer, for example, is increasing and this is likely to place additional demands on the workload of health services and the already high costs associated with diagnosis and treatment (Flohr and Hay 2021).

Although many skin conditions are now recognised as long-term conditions (BAD, 2013), they have not been given parity with other health conditions in the political sphere. In 2014, the World Health Organisation (WHO) committed to a resolution (World Health Assembly 67.9) that recognised psoriasis as a serious non-communicable disease and subsequently published a global report on psoriasis which sought to raise awareness of its impact and provide practical solutions for patient care (WHO, 2016b). Whilst this report helped to raise the profile of psoriasis globally, other skin conditions have not received the same level of attention.

In 2018, WHO published a pictorial training guide to help non-specialist health professionals to recognise Neglected Tropical Skin Diseases (NTSD; WHO, 2018b). The handbook focuses mainly on infectious tropical diseases but also covers eczema, a common, non-communicable, long-term skin condition and associated symptoms (i.e., itch and patches). This indicates that, at least in some, potentially lower-resource countries, there is still a way to go to improve the diagnoses and management of some of the world’s most common skin conditions. WHO have since launched a mobile application to facilitate this.

In 2021, the UCB Community Health Fund commissioned the King’s Fund to produce an independent report titled *innovation in treatment for people with rarer or less well-recognised long-term conditions* (The King's Fund 2021). The report stated that policy makers and health services currently prioritise common long-term conditions and typically overlook other long-term conditions which are rarer or less well-recognised, including inflammatory bowel disease (IBD) and spondyloarthropathies, as well as inflammatory skin conditions such as psoriasis. The report concluded that specialist and inter-disciplinary approaches, involving psychology, are needed to improve diagnoses, treatment and care for people living with these rarer and less well-recognised, but equally complex, health conditions.

The burden of skin conditions has been, and arguably continues to be, downplayed by research, medical and political groups across the world. This is likely to have resulted in fewer resources and sub-optimal healthcare and support for the people who live with these conditions, who, consequently, face delayed diagnoses, poor access to appropriate treatment and worsening of symptoms (The King's Fund 2013). Alternative approaches to caring for people with skin conditions are required.

The impact of skin conditions

Despite the historical neglect of skin conditions in research, it is now recognised that skin conditions are more than just a physical skin complaint and can impact all aspects of a person's life (APPGS 2003). Qualitative research involving people living with various skin conditions, including acne (Ra et al. 2021), psoriasis (Bundy et al. 2014), rosacea (Johnston et al. 2018), eczema (Teasdale et al. 2021), vitiligo (Thompson et al. 2002) and multiple skin conditions (Wheeler et al. 2021) attest this.

Quality of life

Quality of life (QoL) has been defined as:

> *"A concept which aims to capture the well-being, whether of a population or individual, regarding both positive and negative elements within the entirety of their existence at a specific point in time. For example, common facets of QoL include personal health (physical, mental, and spiritual), relationships, education status, work environment, social status, wealth, a sense of security and safety, freedom, autonomy in decision-making, social-belonging and their physical surroundings." (Teoli and Bhardwaj 2024)*

Improving the QoL of people with long-term conditions is now a major health priority as set out in the UK's National Service Framework for Long Term Conditions (Department of Health 2005).

A criticism of existing definitions of QoL are that they are largely subjective, and more recent definitions of this concept have sought to capture both subjective and objective assessments of factors known to influence QoL (Karimi and Brazier 2016). Many measures of QoL now exist, including ones specific to dermatology (Augustin et al. 2012; Pattinson et al. 2021). However, as QoL encapsulates different domains, it is a difficult concept to define and measure in a standardised manner (Megari 2013). Pattinson et al. (2021) conducted a systematic review of patient reported outcome measures (PROMs) in dermatology and found that not one of the measures that they reviewed included a definition of QoL.

Health-related quality of life (HRQoL) is a multi-dimensional concept that is used to understand how an individual perceives their physical, psychological and social functioning to be affected by an existing health condition(s) and/or treatment, as well as how satisfied they are with their level of functioning. Wilson and Cleary (1995) conceptualised HRQoL within a theoretical model comprised of five inter-related dimensions including: physiological factors, symptom status, functional health, general perceptions of health and QoL. This model is used most frequently, but a model by Ferran and colleagues has been recommended for use given that their model, which extends Wilson and Cleary's model, offers a clear definition of individual and environmental factors and thus, a more comprehensive explanation of HRQoL (Bakas et al. 2012). Pattinson (2021) used Wilson and Cleary's conceptual framework of HRQoL to inform the development of a new PROM called the Patient-Reported Impact of Dermatological Diseases (PRIDD), arguing that this model would show many aspects for consideration and obviate the need for a single definition. However, measures of HRQoL are often generic and fail to account for the nuances of specific health conditions and the social, ethical and cultural factors that can influence people who live with them (Megari 2013).

The negative effect of visible skin conditions on patients' QoL is widely recognised (Basra and Shahrukh 2009; Singh et al. 2019; Cortés et al. 2022; Montero-Vílchez et al. 2022). One of the main aims of dermatology care and treatment is, therefore, to improve patients' QoL (Chen 2012). However, a systematic review of 36 patient-reported outcome measures in dermatology found that none, including the widely adopted Dermatology Life Quality Index (DLQI; Finlay and Khan 1994), met the gold-standard Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) criteria and thus, could not be recommended for use (Pattinson et al. 2021). The authors reported the majority of existing dermatology-specific measures do not incorporate the patient perspective at the development stage and, therefore, fail to adequately capture the full impact of skin conditions (Pattinson et al. 2021).

Cumulative life course impairment (CLCI)

CLCI is a theoretical concept that is used to describe the increasing burden of long-term health conditions overtime (Ben-Shlomo and Kuh 2002). Kimball and colleagues (2010) investigated how the physical, psychological and social burden of psoriasis could influence the life course. People with psoriasis have previously reported that their condition altered the course of their life, affecting major life decisions and goals related to educational attainment, careers, relationships and starting a family (Warren et al. 2011). More recent studies show that CLCI is an issue across skin conditions (Pattinson et al. 2022) and that certain sociodemographic (e.g., age and gender) and clinical (e.g., disease severity and the presence of comorbidities) factors can increase people's risk of life-long impairment (Von Stülpnagel et al. 2021). The evidence for CLCI strengthens the need for the provision of psychological support for people with skin conditions, highlighting the importance of early assessment and intervention to prevent long-term impairment and allow people to lead meaningful and fulfilling lives. A new measurement tool has recently been developed to assess CLCI in people with skin conditions and identify at-risk individuals (Braren-von Stülpnagel et al. 2023).

Types of impact

In 2022, our research team published a global qualitative study exploring the impact of dermatological conditions to inform the development of a new measure called PRIDD (Pattinson et al. 2022). The study sample comprised of 65 participants representing 29 countries and 29 different dermatological conditions. We found:

- Impact is a complex and multifaceted construct that is both acute and cumulative across the lifespan.
- Impact occurs at the individual, organisational and societal level.
- Physical, psychological, social, financial and daily impacts were common across skin conditions, yet the psychological and social consequences were most profound.

The following section provides an overview of the psychological impact of skin conditions. Other types of impact were not the focus of this thesis and thus are described in Appendix 2.

Psychological impact

While skin conditions can pervade all areas of life, most people report the psychological impact to be the most profound, as well as the most overlooked aspect, of skin conditions (Pattinson et al. 2022). The term 'psychological' refers to cognitive, emotional and behavioural processes (Passer and Smith 2004).

Skin conditions are linked to a broad spectrum of psychological and psychiatric comorbidities (Lada et al. 2020). This spectrum ranges from primary psychiatric conditions, such as dermatillomania (skin picking), trichotillomania (hair pulling) and suicidality (Picardi et al. 2013; Parisi et al. 2019), to secondary responses to skin conditions, including common psychological conditions such as anxiety and depression (Koo and Lebwohl 2001; Gupta and Gupta 2003). This thesis is focused on the latter.

The variable nature of many skin conditions can result in uncertainty and individuals experiencing a loss of personal control over their condition and life more generally (Howells et al. 2019; Pattinson et al. 2022). People have described battling daily to lead the life they want whilst being restricted by, and forced to plan around, their skin condition, which can increase the pressure and cognitive load on the individual and leads to psychological fatigue (Bundy et al. 2014; Pattinson et al. 2022).

Skin conditions can elicit a range of strong emotions and negatively affect mood (Kanji 2019; Wheeler et al. 2021; Pattinson et al. 2022). Common emotional reactions to skin conditions include anger (Hughes and Hunter 2022), stress (Gupta and Gupta 2003), anticipatory worry (Pattinson et al. 2022) and feelings of hopelessness and loneliness (Kanji 2019). Visible skin condition(s) can evoke feelings of disgust (Schienle and Wabnegger 2022), which often leads to feelings of unattractiveness, shame (Sampogna et al. 2012), embarrassment and self-consciousness around others (Kanji 2019), and ultimately diminishes self-confidence (Kanji 2019), esteem and worth (Wheeler et al. 2021). However, people with skin conditions, such as psoriasis, often present with ‘alexithymia’ whereby they are unable or struggle to identify and name their emotional responses (Panasiti et al. 2020).

People with skin conditions tend to report significantly higher levels of distress than healthy controls (Balieva et al. 2022). Common psychological conditions, mainly depression and anxiety, have been widely observed in and self-reported by people living with a range of skin conditions (Gupta and Gupta 2003; APPGS 2020; Guo et al. 2020), such as vitiligo (Osinubi et al. 2018), alopecia areata (Toussi et al. 2021), rosacea (Dai et al. 2021), acne (Samuels et al. 2020), psoriasis (Dowlatshahi et al. 2014; Fleming et al. 2017), HS (Patel et al. 2020) and eczema (Rønnstad et al. 2018), to name a few.

The SARS-CoV-2 pandemic increased the emotional burden; many people reported social anxiety due to concerns over the general public confusing their skin condition for SARS-CoV-2 (APPGS, 2020; Lada et al. 2020). The fear of contracting SARS-CoV-2 was an additional source of distress and this was especially concerning given that distress can increase inflammatory markers and worsen symptoms associated with inflammatory skin conditions, including itch (Garcovich et al. 2020; Lada et al. 2020).

The Common-Sense Model of Self-Regulation (CSM; Leventhal et al. 1984) is an established and evidence-based psychological model, which explains how cognitive representations and appraisals can influence emotional and behavioural responses to illness specifically (see Chapter 3 for a full description). There is evidence to show that what people believe and feel about their skin condition can affect their ability to manage and cope. One study showed that beliefs about the controllability of primary cicatricial alopecia, and the perceived severity of its consequences (e.g., distress), were associated with higher depression scores and poorer QoL (Chiang et al. 2015). Another study demonstrated that beliefs about illness accounted for a greater proportion of the variance in depression, anxiety, and QoL in people with HS, compared to condition severity (Pavon Blanco et al. 2019).

In addition, low self-esteem was found to independently predict poorer coping in people living with vitiligo (Porter et al. 1979). One study involving people with different dermatological conditions reported that those who were fearful of judgement and rejection by others reported psychosocial consequences, including feelings of social anxiety, isolation and social withdrawal (Dalgard et al. 2018a; Germain et al. 2021).

Distress can impact on health behaviour. People with malignant melanoma, for example, who experience psychological distress, are less likely to perform health-protective behaviours, such as attending screening, seeking medical support, adhering to treatment and preventative behaviours (Kasparian et al. 2009). Distress has also been associated with increased engagement in health-threatening behaviours, such as treatment non-adherence (Richards and Fortune 2006), alcohol misuse (McAleer et al. 2011) and poor sleep (Gilhooley et al. 2021).

Two studies by Henry and colleagues (2017; 2019) illustrate the interaction between cognitions, emotions, behaviour and sleep in psoriasis. The first cross-sectional survey study found cognitive arousal and depression, along with somatic arousal, were the strongest predictors of poor sleep quality (Henry et al. 2017). The second qualitative study employed the CSM to analyse how the relationship between sleep-related thoughts, emotions and behaviours interact (Henry et al. 2019); participants in this study reported experiencing uncontrollable and intrusive thoughts and rumination about psoriasis, and these thought patterns, as well as anticipatory worry about sleep and frustration of being awake during the night, plus physical symptoms (i.e., itch), all disturbed sleep (Henry et al. 2019). The participants described coping strategies (i.e., caffeine consumption, increasing sleep opportunity, use of distraction techniques), which they perceived as helpful, but were in fact counterproductive and only perpetuated the sleep problems (Henry et al. 2019).

Chapter summary

Many skin conditions are common and highly complex long-term conditions with impact beyond the skin on social and psychological functioning. This burden often goes unrecognised and undertreated. The SARS-CoV-2 pandemic brought about additional practical, psychological and social challenges for people with skin conditions. The present chapter emphasises the need to support people to manage *all* aspects of skin conditions effectively, including the risk of associated co-morbidities and related health behaviours, to generally live well in their own skin across the lifespan.

Chapter 2: Management of skin conditions

The range and variability of symptoms, comorbidities and the multitude of triggers that are associated with skin conditions, plus the impact they can have on a person's life, make skin conditions challenging to manage for patients and health professionals alike. Skin conditions, such as psoriasis, are now considered to be complex long-term conditions (National Institute for Health and Care Excellence [NICE] 2017) that should be treated and managed as such (APPGS 2003; Picardi and Pasquini 2007). However, dermatology services do not currently meet the recommended standards for patient care, as outlined below.

To understand the current structure of dermatology services and approaches to the management of skin conditions, it is first important to consider the history of medicine, as well as definitions and models of health; the foundations on which healthcare provision, including dermatology, are built.

Defining health

In 1948, WHO defined 'health' as:

> *"A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."*

Although this definition acknowledged health as more than just a physical state, the idea of 'complete' health was criticised for being unrealistic and objectively immeasurable (Huber et al. 2011). It was also developed during a time when common illnesses facing society were acute rather than chronic whereas today the opposite is true and people are living longer with non-communicable health conditions that require ongoing management (Huber et al. 2011). WHO's definition of health is now outdated and new definitions accounting for the broader determinants of health, including psychological, cultural and economic factors, have since been proposed. This thesis defined health as:

> *"A state of well-being with satisfaction of physical, cultural, psychosocial, economic and spiritual need, not simply the absence of illness" (Marks et al. 2020, p. 5)*

Models of health and illness

In the 17th century, René Descartes proposed a philosophical theory known as Cartesian dualism, which viewed mental and physical health as distinct phenomena. This distinction was rooted in religious beliefs of the Christian Orthodox church and specifically, the idea of the human body as a vehicle for the soul; a view that greatly influenced scientific and medical practices of the time and led to a focus on physical causes of disease (Engel 1977).

The biomedical model of health and illness postulates that disease and illness are purely explained by biological factors (Johnson 2012). It was borne at the turn of the 19th century from Louis Pasteur’s Germ Theory of Disease, which explained and helped to banish infectious diseases, such as influenza, pneumonia and tuberculosis; the leading causes of death of that era (Johnson 2012). Critics claim the model endorses Cartesian dualism and thus, is reductionist by nature by excluding other determinants of health (Engel 1977; Johnson 2012; Farre and Rapley 2017). Despite this, the biomedical model has historically and successfully underpinned Western medicine and, arguably, remains the dominant model of healthcare today (Johnson 2012).

A landmark paper by Engel (1977) argued for a paradigm shift towards a new and integrated model of healthcare known as the biopsychosocial model, which expanded the traditional model to include psychological, social and environmental factors known to influence the cause, trajectory and outcomes of health and wellness.

The biopsychosocial model reflected key scientific advances that helped to improve understanding of health and its behavioural and social determinants. Longitudinal, prospective research was instrumental to this. The Framingham Heart study identified key ‘risk factors’ for CVD (e.g., obesity and smoking) that could be addressed to improve health (Wilson et al. 1987). The Alameda County study detected several health behaviours that were protective against morbidity and early mortality, including: avoiding smoking, limited alcohol consumption, regular physical activity, maintaining a healthy weight and sleeping seven to eight hours per night (Belloc and Breslow 1972). Additionally, the Whitehall Studies on British civil servants evidenced a social gradient in health (Marmot et al. 1978) that was influenced by workplace (i.e., job satisfaction and control) and lifestyle (i.e., smoking, diet and exercise) factors, the social environment, and early personal experiences (Marmot et al.

1991). These studies demonstrated that the biomedical model was outdated and supported the use of a biopsychosocial approach to address the changing and more prominent public health concerns, namely an ageing population living with complex long-term conditions influenced by biological, social and behavioural factors (Farre and Rapley 2017; Wade and Halligan 2017).

Improving the management of long-term conditions has been a major health priority since the 1990s and a collaborative approach to patient care is now best practice (The King's Fund 2010; Eaton et al. 2015). A collaborative model combines inter-disciplinary and person-centred approaches to ensure patients are directly engaged in decisions about their health and care and receive continued medical, psychological and practical support that enables them to live well with their condition long-term (Eaton et al. 2015). This approach reflects the biopsychosocial model by aiming to combine expertise to manage various factors that can influence health (Wade and Halligan 2017). Use of the biopsychosocial model as a framework for understanding and managing complex long-term conditions is increasing; long covid is a recent and pertinent example of this (Hussain 2022). This is a positive step in the right direction, yet barriers to the application of the biopsychosocial model remain at the level of health service structure, organisation and funding (Wade and Halligan 2017).

Medical education and training

The BAD previously recommended that undergraduate medical students complete a minimum of 10 half days of clinical experience (Dermatology Council for England 2017), although estimates suggest that medical students receive less than ten hours of core dermatology-specific training; the amount of training varies considerably and dermatology is not compulsory on some undergraduate medical programmes (Ulman et al. 2015; Dermatology Council for England 2017). Medical education is entrenched in the biomedical model (Moser and Stagnaro-Green 2009) and dermatology specialists receive little to no training in biopsychosocial approaches (Keyworth et al. 2014) and commonly report feeling unprepared to address psychological aspects, including behaviour change, effectively (Nelson et al. 2014; Nelson et al. 2016).

The Personal Models of Illness theory stipulates that an individual’s beliefs, attitudes, feelings and experiences of an illness collectively influence how they respond to it (Skelton and Croyle 1991). Thus, how medical students are educated will underpin their personal models of health and illness, and, in turn, influence their clinical practice. The concept of personal models is relatively new within dermatology. Emerging evidence shows that approximately 70% of health professionals recognise psoriasis as a complex condition but only treat the physical skin complaints (Chisholm et al. 2016). Another study (Hewitt et al. 2022a) found similar results; dermatologists in the UK and Germany reportedly valued a patient-centred approach to care but their clinical practice did not always reflect this and their beliefs about psoriasis and assumptions and stereotypes of patients influenced their consultation style, including the degree to which they engaged in shared decision-making. Health professionals should be educated on how their beliefs and emotions can influence their clinical practice.

Current dermatology service provision

The management of skin conditions generally adheres to the biomedical model and a biopsychosocial approach has yet to translate into clinical practice and service provision. In psoriasis, for example, the biomedical model of care remains (Trettin et al. 2021b) and dermatologists typically manage physical symptoms only (Richards et al. 2004), underestimate distress (Dalgard et al. 2018b) and do not routinely acknowledge the psychological impact of psoriasis or act on opportunities to address behaviour change with patients during consultations (Nelson et al. 2016).

UK dermatology service provision currently follows a stepped process; most people who present with a skin condition are managed in primary care and only at this point will they be referred to a dermatologist in secondary care settings, if considered necessary. Highly specialised tertiary care is available but only to a small minority of patients with complex medical and condition histories and who have experienced repeated treatment failures (APPGS, 2020). Patients who present with psychological comorbidities may be referred to mental health, liaison psychiatry or clinical psychology services that are separate from dermatology, although these services lack dermatology expertise, are over-stretched and have long waiting lists (APPGS, 2020). Very few dermatology services have integrated or even dedicated mental health service provision (APPGS, 2013; 2020).

Teledermatology forms part of dermatology service provision and includes two styles of remote consultation: the Store and Forward method, where patients send images of their symptoms to their clinician for review, and Live Video Conferencing, which facilitates synchronous patient-practitioner communication via video technology (Glines et al. 2020). Teledermatology was introduced in 1995 and has since been widely embedded within services to assess, diagnose, monitor and manage physical symptoms (Wurm et al. 2008; Glines et al. 2020).

However, dermatology provision can vary considerably between services and geographic location. An audit of UK dermatology services revealed that many were facing a shortage of specialist dermatology nursing staff, treatments, drug monitoring and dedicated psychological support for psoriasis management (Eedy et al. 2009). Specialist dermatology staff shortages is a persisting problem in the UK (Eedy 2015) and across other countries, including the US (Kimball and Resneck 2008). A report by the Association of the British Pharmaceutical Industry (2018) emphasised that much of dermatology resource has been dedicated to addressing the increasing global prevalence of skin cancer and this has overshadowed the management of other long-term skin conditions.

Many people with skin conditions report dissatisfaction with the current structure and approaches to healthcare. Patients often struggle to access medical care and cost-effective treatments in a timely manner and experience inaccurate or delayed diagnoses and poor communication with health professionals (Pattinson et al. 2022). Many feel unsupported and doubt professional competence due to a lack of empathy during discussions on the psychological and social challenges of psoriasis, which can lead to disillusionment and withdrawal from the healthcare system (Nelson et al. 2013). Young people with psoriasis and eczema reported feelings of frustration at the lack of structured and continued care and health professionals who offer uninformed, ambiguous or conflicting advice (De Vere Hunt et al. 2021). Despite calls for more proactive and preventative approaches to tackling long-term conditions and associated modifiable risk factors across England (NHS England 2019), Wales (Welsh Government 2022), Scotland (The Scottish Government 2010) and Northern Ireland (Department of Health 2016), patients have reported that some health professionals operate a reactive, rather than preventative, approach to managing flares, meaning patients endure severe symptoms before receiving medical support and have no clear plan for managing future flares (De Vere Hunt et al. 2021).

The SARS-CoV-2 pandemic placed a substantial strain on health services worldwide and resulted in significant changes to dermatology service provision. Many non-essential dermatology consultations and procedures were cancelled or postponed and services rapidly switched to mostly remote (telephone and video) and teledermatology consultations (BAD, 2020) in attempts to limit the spread of SARS-CoV-2 (Bhargava et al. 2021). The pandemic disrupted patient care and exacerbated patient dissatisfaction. A survey by our research group showed that people with psoriasis and psoriatic arthritis perceived the use of remote consultations during the SARS-CoV-2 pandemic as efficient and convenient, particularly for routine follow up appointments, but many struggled to communicate their emotions and discuss the psychological impact of their condition with a health professional via telephone due to a lack of emotional cues (Hewitt et al. 2022e). Some, but not all, people with eczema had difficulty accessing standard healthcare and treatments during the pandemic (Steele et al. 2021).

Overall, existing evidence emphasises several issues with current service provision from the patient perspective. A new approach including dedicated psychological support for patients and specialist training for health professionals is needed to ensure the effective whole person management of skin conditions.

New approaches to management in dermatology

Since the early 2000s, there have been political calls for biopsychosocial and inter-disciplinary approaches to managing skin conditions (APPGS, 2003; 2013; 2020). NHS England (2022) outlined principles for optimising the quality of patient care and the referral pathway, demonstrating the commitment to reducing inequities in access to appropriate and timely healthcare for patients.

There is widespread support from key stakeholders for a new approach within dermatology that includes psychological support. Qualitative research has shown that medical and other health professionals in dermatology now recognise the need for a holistic approach to condition management (Hewitt et al. 2021). People living with skin conditions also favour new approaches to support effective self-management; UK-based and cross-condition surveys highlight patient demand for dedicated psychological support (Wheeler et al. 2021) and the belief among patients that access to additional psychological support would benefit them (Kanji 2019). Qualitative research by our team demonstrated that globally patients value and need specialist, affordable and integrated psychological support (Pattinson et al. 2022).

This need was also recognised in the top research priorities decided through Priority Setting Partnerships (PSPs) funded by the James Lind Alliance (JLA) for the following conditions:

- Eczema (JLA 2012)
- Psoriasis (JLA 2018b)
- HS (JLA 2013)
- Vitiligo (JLA 2010)
- Acne (JLA 2014)
- Lichen sclerosus (JLA 2018a)

Research on psychological processes and interventions is a high priority for some skin conditions, including psoriasis and vitiligo.

Psychological interventions

Psychological intervention is important for supporting patients to successfully adapt to skin conditions (Zhang et al. 2019). However, psychological interventions are poorly defined across health fields (Hodges et al. 2011). A previous metareview on cancer care found various terms, including psychosocial, nonpharmacological, behavioural and psychoeducational, were used interchangeably to refer to psychological interventions and none of the 66 articles reviewed provided a clear definition (Hodges et al. 2011). The authors proposed that psychological interventions should encompass four key domains: intervention content, proposed mechanism(s), target outcome(s) and method of delivery, within a specified context (Hodges et al. 2011).

Attempts have been made to increase psychological support and services within dermatology and a meta-analysis described psychological interventions as those which:

> *"target psychological variables (e.g., beliefs and emotions) that influence skin severity, distress and related quality of life" (Lavda et al. 2012, p. 970).*

Mostly Cognitive Behavioural Therapy (CBT), habit reversal and arousal reduction resulted in significant moderate reductions in condition severity and psychosocial outcomes in people with different skin conditions (e.g., eczema, psoriasis, vitiligo, acne) and moderate to large effects on itch/scratch reactions were also reported (Lavda et al. 2012).

A systematic narrative review by Meneo and colleagues (2022) indicated the potential efficacy of mindfulness and self-compassion interventions for reducing disease severity and psychological distress and improving QoL in people with dermatological conditions. Most studies reviewed assessed mindfulness-based compassion therapy, which enhanced skills for mindfulness and self-compassion and reduced negative cognitions and physical symptoms. Rafidi and colleagues (2022) found similar results for psychological therapies and mind–body techniques (e.g., meditation/mindfulness, biofeedback, hypnosis, music therapy, multi-disciplinary approaches) in the management of dermatological conditions; specifically, CBT and habit reversal therapy in psoriasis and mindfulness-based interventions in eczema. Topp et al. (2019) systematically reviewed interventions aiming to reduce the stigma surrounding visible long-term skin conditions. Complex interventions involving counselling and skills building helped reduce self-stigma and improve QoL, psychological functioning, body image and self-esteem in people with leprosy, mainly from low- and middle- income countries.

Despite these benefits, methodological limitations are consistently reported, including heterogeneity in study designs, small sample sizes, high attrition rates and short follow up periods (Lavda et al. 2012; Topp et al. 2019; Meneo et al. 2022; Rafidi et al. 2022). In addition, research to date is mostly condition-specific with most interventions targeting common skin conditions (Lavda et al. 2012; Meneo et al. 2022; Rafidi et al. 2022), firstly psoriasis (Qureshi et al. 2019; Zill et al. 2019; Sijercic et al. 2020; Bartholomew et al. 2022) and secondly eczema (Lavda et al. 2012; Meneo et al. 2022; Rafidi et al. 2022). High quality research assessing psychological interventions for a range of skin conditions is needed.

Psychodermatology

Psychodermatology is a subspeciality of dermatology (Abdelrahman and Armstrong 2017) which concerns the relationship between the skin and the mind (Koo and Lebwohl 2001). Psychodermatology services bring together specialists in dermatology, psychology and psychiatry to facilitate a multi-disciplinary and biopsychosocial approach to condition management (Bewley 2017). Psychodermatology provision has traditionally focused on the treatment and management of the three following sub-groups of psychodermatological conditions: primary psychiatric disorders (e.g., trichotillomania), secondary psychological conditions (e.g., depression or anxiety following primary skin condition) and psychophysiological disorders (i.e., skin conditions affected by psychological stress) (Bewley 2017). It also concerns skin conditions induced by psychotropic drugs and psychological co-morbidity that develops following adherence to dermatological drug treatments (Bewley 2017). This model of care appears to be cost-effective for services and can lead to greater improvements in patient outcomes and coping than medical treatment alone (Mohandas et al. 2013; Kanji 2019; APPGS, 2020), although existing evidence is mostly anecdotal from a small expert group due to the cost, expertise and ethical issues associated with conducting research in this area (Bewley 2017).

Despite the promise of psychodermatology and a consortium of national and international organisations (e.g., Psychodermatology UK, the Association for Psychoneurocutaneous Medicine of North America and the European Society of Dermatology and Psychiatry) advocating for wider implementation (Bewley 2017), psychodermatology services are limited (APPGS, 2020) and where these services do exist, they are often not easily accessible to patients (Kanji 2019; Wheeler et al. 2021; Pattinson et al. 2022). A mixed methods cross-sectional survey of 166 specialist dermatology staff revealed that 76% did not have local access to a psychodermatology clinic and only 5% were involved with clinics that had a dedicated psychodermatology service (Massoud et al. 2021). Psychodermatology service provision differed between clinics in terms of structure, frequency and the support available; 80% of services were psychology-based, 37.5% ran on a monthly basis, over 50% were structured so that patients were seen by a dermatologist and psychologist or psychiatrist concurrently, and only 12.5% offered behaviour change support (Massoud et al. 2021). Given that many health behaviours are known to influence skin conditions and the associated CVD risk, current provision of behaviour change support is concerning.

Several barriers to the implementation of psychodermatology services exist. Barriers include a lack of robust supporting evidence (Bewley 2017), insufficient funding, poor support from service managers and commissioners, issues with referral pathways, the need for longer consultations and supervision for health professionals, and objections from patients

(Massoud et al. 2021). Another major barrier is poor availability of, and funding for, specialist training opportunities for health professionals (APPGS, Bewley 2017; 2020; Massoud et al. 2021). Action is needed to overcome these barriers and successfully and widely embed psychodermatology as part of routine service provision (Misery et al. 2023).

Specialist training for dermatology staff

PsoWell™ (Psoriasis & Well-being) is a unique and specialist one-day training programme and biopsychosocial approach to psoriasis management, which was developed by an interdisciplinary team at UoM as part of a five-year programme of research called The Identification and Management of Psoriasis Associated ComorbidiTy (IMPACT) funded by the National Institute for Health Research (NIHR). PsoWell™ aims to increase the opportunity, capability and motivation of health professionals involved in psoriasis management to address the psychological aspects of psoriasis and behaviour change during consultations with patients using Motivational Interviewing (MI) techniques.

MI is an established collaborative consultation style that can increase an individual's internal motivation and capability for behaviour change in four stages (engaging the patient, focusing the consultation, evoking reasons for change, and planning for change using goal setting and action planning) (Rollnick and Miller 1995). MI was first introduced by William Miller in 1983 to address problematic drinking behaviour and Miller and Rollnick subsequently developed and tested this communicative approach in health, sport and educational settings (Miller and Rollnick 2013). MI has proved beneficial for patients and health professionals alike (Szczekala et al. 2018). It can improve personal capability for behaviour change and self-management in people with psoriasis (Larsen et al. 2014b; Khoury et al. 2019; Qureshi et al. 2019) and other complex health conditions (Frost et al. 2018). Reported benefits for health professionals include a greater sense of satisfaction, self-efficacy, confidence and professionalism, and less perceived burnout and stress (Szczekala et al. 2018).

PsoWell™ training significantly improves health professionals' knowledge, confidence and MI skills (Chisholm et al. 2017) and is considered acceptable and feasible to implement within standard dermatology consultations (Chisholm et al. 2017) as well as a variety of primary and secondary care settings across the UK (Hewitt et al. 2021). The PsoWell™ approach has since been adopted within two flagship clinics in the UK, one in Salford, England and the other in Cardiff, Wales.

However, there are barriers to the widespread implementation of PsoWell™. Our research shows that health professionals' personal models of psoriasis and securing time away from clinic were potential barriers to attending the training (Hewitt et al. 2021). Participants believed insufficient funding to employ practitioner psychologists and a lack of time and clinic space, as well as the need for ongoing specialist training in the use of MI techniques, could prevent the uptake of this clinical approach within dermatology (Hewitt et al. 2021). Some barriers have since been realised as the PsoWell™ clinic in Salford is no longer operational due to a lack of funding and specialist staff.

PsoWell™ offers an effective and acceptable way to improve the provision of psychological support within dermatology services and barriers must be addressed to increase opportunities for health professionals involved in the management of psoriasis and other skin conditions to utilise this specialised training and clinical initiative.

Self-management

Given that many long-term skin and other health conditions are currently incurable, the role of the patient and their ability to self-manage their condition is important, not least because effective self-management can positively influence health outcomes and reduce health service utilisation (Panagioti et al. 2014). Patient self-management is now central to health policy and guidance specifies the need to manage the psychological and social impacts, promote healthy living through the adoption of lifestyle and other health-protective behaviours, in addition to controlling and monitoring physical symptoms (The King's Fund 2010; NHS England 2019).

The term self-management is poorly defined and several definitions exist (Barlow et al. 2002). In dermatology, early efforts to support and improve patient self-management were largely driven by nursing staff leading long-term condition management clinics (Ersser et al. 2010b). However, these clinics tended to focus on helping individuals to control the physical symptoms only and ignored psychological processes that can influence personal approaches to self-management (Ersser et al. 2010b) and inevitably, health outcomes. People with eczema, for example, have reported a high sense of personal control over their condition is important for improving their QoL (Howells et al. 2019). Beliefs about illness and treatments can also affect treatment adherence and, subsequently, condition progression and severity (Feldman et al. 2017).

The impact of skin conditions extends beyond the skin and thus the term self-management should, arguably, refer to the management of *all* aspects of skin conditions, including psychological and social factors. The following definition of self-management was, therefore, used for the purpose of this thesis:

> *"Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established." (Barlow et al. 2002, p. 178)*

Earlier sections of this chapter show appropriate medical and psychological support is lacking and the quality of care is inadequate for meeting the needs of patients. Often the responsibility of managing all aspects of skin conditions falls to the patient even though most want input and collaboration from health professionals to make informed and shared decisions about their health and care (Larsen et al. 2019).

People with skin conditions are rarely well-prepared to manage all aspects of their conditions and require support to cope effectively with their condition on top of other aspects of their lives. People with acne, for example, have expressed concerns and uncertainties about acne treatments and as a result, often seek advice online and adopt a trial and error approach to management as a way to feel in control of their acne (Ip et al. 2021a). Trial and error approaches, underpinned by insufficient knowledge of treatments and adherence, have also been reported by people with psoriasis lacking support from health professionals (Ersser et al. 2010a).

This is true of the psychological and particularly the behavioural aspects of skin conditions, which many patients find are challenging to deal with. People with eczema, for example, have reported uncertainties around health behaviours related to eczema and performing a cost-benefit analysis of changing their behaviour based on their own beliefs, preferences, experiences and social norms (Greenwell et al. 2021) rather than evidence-based information. In addition, some of the behavioural strategies (e.g., concealment) employed by people with rosacea as a means of coping can perpetuate unhelpful beliefs related to personal appearance and how others perceive them, and thus they are counterintuitive (Johnston et al. 2018). Treatment non-adherence is a significant problem in dermatology and people with psoriasis have previously reported lacking motivation to take their medicines as prescribed (Pathak et al. 2014). These are just some examples which demonstrate that many people need additional and especially psychological support to live well with a skin condition, although much of the cited evidence relates to medical treatment.

Research supports this and people living with a range of skin conditions have expressed a need and desire for psychological support (Kanji 2019). However, the current lack of professional support and services means that individuals tend to rely on other sources for support with self-management. They mainly seek advice from the internet and social media, family and friends, and the subjective experiences of other patients (Szepietowski et al. 2018; Kanji 2019; Barrutia et al. 2022). Whilst several benefits of using social media in dermatology have been reported (Barrutia et al. 2022), resorting to information online can be problematic because the information that is freely available is often unregulated, not evidence-based and comes from unqualified individuals, meaning patients are potentially following inaccurate and unsafe advice (West et al. 2014; Riddoch 2019; Barrutia et al. 2022).

Some interventions have been developed to support the self-management of dermatological conditions. Larsen and colleagues (2014a) systematically reviewed nine educational and self-management programmes for people with psoriasis, but definitive conclusions of effectiveness were limited by the poor methodological quality of included studies and personalised approaches were lacking, as was lifestyle behaviour change support. Ridd and colleagues (2017) found that most existing self-management interventions for eczema are face-to-face interventions for children and offer education on symptom management and treatment. The authors concluded that interventions were poorly reported and there was a lack of clarity around whether educational interventions could improve QoL and the cost-effectiveness of self-management interventions and their components. They recommended using established theory and frameworks to develop and test self-management interventions.

The recommendation by Ridd and colleagues relates to a wider issue with the development interventions supporting long-term condition management, which address behaviour change. Interventions of this kind are highly complex in nature, meaning they incorporate several interacting components and target behaviours, groups and outcomes (Craig et al. 2008). However, more often than not, complex interventions are developed without existing frameworks, theories or evidence of behaviour change, in a linear rather than iterative fashion, and with little or no input from key stakeholders from a range of backgrounds and expertise (Araújo-Soares et al. 2019). This is an issue, firstly because interventions that are grounded in theory and evidence are known to be more effective, acceptable and feasible than those that are not (Taylor et al. 2012), and secondly because theory-based interventions tend to specify behaviour change techniques (BCTs), mechanisms of action, and outcomes that can be replicated and evaluated (Michie and Johnston 2012).

It is, therefore, important that complex interventions in dermatology are developed in accordance with behaviour change theory and evidence if they are to be appropriate for patients and effective in supporting the uptake and maintenance of health and lifestyle behaviours that could help to mitigate the physical, psychological and social impact of skin conditions.

Digital health

Digital health is now a way of delivering health information, care and services. This concept first emerged in the 1990's in relation to digitised health information, although a standard definition was lacking for many years. Our understanding of digital health changed with the rise of the internet in the same decade and the subsequent, rapid and continual advances in technology (Fatehi et al. 2020). Digital technologies were also being widely adopted across a range of disciplines, which led to slight variations in meaning and the synonymous use of other related terms, including electronic health (eHealth) and mobile health (mHealth) (Fatehi et al. 2020).

eHealth and mHealth refer to the digital delivery of health information and care via the internet and mobile technologies, respectively. A clear definition of eHealth was lacking until 2001 when Eysenbach comprehensively defined eHealth as a novel approach involving the use of technology to improve healthcare that can be characterised by ten e's: efficiency, enhancing quality, evidence based, empowerment, education, extending, ethics, and equity (Eysenbach 2001). Fatehi and colleagues (2020) mapped the terms most frequently used in relation to digital health, plus their relevance scores, and found mobile health (mHealth) was the most commonly used and relevant concept. Now, the terms digital health and eHealth are often used interchangeably and are considered to be umbrella terms of which mHealth and remote health services, including telehealth and telemedicine, are subsets (Smits et al. 2022).

In 2018, WHO published a classification system of digital health interventions to help rectify the issues surrounding defining digital health and streamline the language used around this concept (WHO, 2018a). This classification system has since formed the basis of definitions of digital health that have been used to research digital health interventions for managing long-term conditions, such as musculoskeletal conditions (Hewitt et al. 2020). More recently, Fatehi and colleagues proposed the following comprehensive definition of digital health:

> *"The proper use of technology for improving the health and well-being of people and enhancing the care of patients through the intelligent processing of clinical and genetic data." (Fatehi et al. 2020, p. 71)*

Use of digital technology has transformed the organisation, delivery and quality of healthcare (Thimbleby 2013) and the demand for and use of digital health increased significantly during the SARS-CoV-2 pandemic (Smits et al. 2022). Computers, smartphones, applications (apps), wearable technologies and other hand-held devices are examples of digital technologies that are increasingly being used to facilitate healthcare (van Gemert-Pijnen et al. 2018b). Teledermatology and remote consultations are examples of how technology has and continues to shape dermatology service provision.

The provision of digital health is only expected to grow in future (Smits et al. 2022) and digital health now forms a major part of health policy. For example, WHO (2019) recently published a set of recommendations on digital interventions for health system strengthening, which demonstrates that digital technology will be integral to strategies for improving health globally. This is unsurprising given the many benefits of digital technology for health services, providers and patients (van Gemert-Pijnen et al. 2018b). Digital health can facilitate patient-centred care by improving personal choice and access to convenient, efficient and effective healthcare (van

Gemert-Pijnen et al. 2018b). Use of digital technology can support health professionals to make more accurate and timely diagnoses and tailor care to the patient based on their personal data (van Gemert-Pijnen et al. 2018b). It has the potential to reduce health service costs and utilisation and improve the overall quality of patient care (van Gemert-Pijnen et al. 2018b).

However, the application of digital technology is not without its challenges. The ‘digital divide’ is a major challenge associated with digital technology. This phenomenon refers to inequities in the availability, accessibility, affordability and usability of digital technology, as well as peoples’ personal capability to use it. We know that certain groups within society, including people of lower socio-economic status and literacy level, colour, older age and female gender typically have more difficulty accessing and using digital technology than others (White and Dorman 2001) and these difficulties were amplified by the SARS-CoV-2 pandemic (Local Government Association 2021). The digital divide contributes to existing health and social inequalities and increases the likelihood of poorer health outcomes in already vulnerable groups (Reddy et al. 2022). Furthermore, there are a plethora of existing digital health interventions and not all of the advantages stated above will be applicable to all technologies (van Gemert-Pijnen et al. 2018b). Several ethical, evidence and implementation barriers have also been identified (van Gemert-Pijnen et al. 2018b) and evidence for the long-term impact, benefits and harms of digital health interventions is currently limited (Jandoo 2020).

Despite these pitfalls, digital health is now recognised as a useful and convenient means for supporting people to self-manage their health and lifestyles effectively (Thimbleby 2013; Kelders and Howard 2018; van Gemert-Pijnen et al. 2018b). There is a growing body of evidence showing the promise of digital interventions in supporting the self-management of, and improving health behaviours (e.g., physical activity, medication adherence) and outcomes (e.g., QoL) associated with, long-term health conditions, such as CVD (Pfaeffli Dale et al. 2020), diabetes, osteoarthritis (Berry et al. 2018) and asthma (Morrison et al. 2014; McLean et al. 2016), without adverse effects. Digital interventions may also be effective across ages, as they can benefit children and young people with physical and psychological conditions, particularly with obesity and anxiety (Brigden et al. 2020). However, the evidence base is limited by mixed findings and there is a lack of clarity on the long-term impact of digital interventions, and, in some cases, which components make interventions effective (Morton et al. 2017).

Qualitative research involving key stakeholders, including patients, their relatives and health professionals, indicates that digital interventions are acceptable and beneficial for the people who use them. For example, Morton and colleagues (2017) conducted a meta-ethnographic review to explore experiences of using digital self-management interventions for people with long-term health conditions, including hypertension, CVD and asthma, and health professionals involved in their care. Digital interventions benefitted patients and health professionals and communication between them, as patients felt more reassured and able to take a proactive and informed role in their care, and health professionals felt a greater sense of clinical control and appreciated the increased understanding among patients (Morton et al. 2017). Brigden and colleagues (2020) reported that parents of children with long-term physical health conditions believed the use of digital interventions improved their condition-related knowledge and behaviour, which had a positive knock-on-effect on their child's behaviour. They also found that that digital interventions were a convenient medium for communicating with health professionals, although some were costly, difficult to use and lacked personalisation and relevance (Brigden et al. 2020), suggesting potential barriers to use.

Digital technology could provide a medium for delivering psychological support to people with skin conditions yet research on digital health in dermatology is currently limited. To date, existing studies have largely focused on specific conditions, mainly the use of health technologies for the primary prevention of skin cancer (Chuchu et al. 2018a; Chuchu et al. 2018b; Ferrante di Ruffano et al. 2018). There is, therefore, an opportunity to empower people to manage the impact of skin conditions using digital technology.

Structure of thesis

The remainder of this thesis is structured according to the two key phases of work that made up this PhD. The first phase concerned data gathering and generation to justify and inform the development of a new digital complex behaviour change intervention. MiDerm is the name of both the intervention and the new smartphone app which will deliver the intervention.

The second phase focused on the design and development of the new intervention using the findings from phase one and existing psychology and behaviour change theory.

For clarity, throughout this thesis the term ‘project’ is used to refer to the entire piece of work that formed this PhD. The term ‘phase’ relates to a particular block of work, which comprised of several tasks that (primarily) aimed to address the same research question, or aspects of it. The term ‘study’ is used to describe a specific piece of research that was carried out as part of this PhD.

Research aims and objectives

Chapter 1 and the present chapter emphasised the burden of skin conditions and the lack of appropriate support for people who live with them. Considering these issues, the overarching aim of this research was to work with adults with skin conditions to co-develop a new smartphone app (called MiDerm) to deliver a complex behaviour change intervention that meets the needs of this group. The intervention was intended to support adults globally to live well with a skin condition, addressing beliefs about their condition, manage mood and promote health behaviour change where relevant. The aims and objectives for the two phases of this project are stated below.

Phase 1 had two main aims: one related to secondary research and the other primary research. The first aim was to review the existing scientific literature on digital interventions in dermatology designed to improve psychological outcomes, including cognitions, emotions and behaviour. To meet this aim, a mixed-methods systematic review was conducted to answer the following questions:

1. What digital health interventions are available to support the health and well-being of people living with dermatological conditions?
2. What are the views and experiences of people living with dermatological conditions regarding the digital health interventions designed to support health and well-being?

The two research questions were broken down further into three specific objectives. The objectives of the review were to: (1) identify, (2) determine the effectiveness, and (3) explore adults' views and experiences of digital interventions designed to support their psychological health and well-being. The purpose of the review was to gather existing data to provide a rationale for developing MiDerm, inform its development, and direct future research questions and studies related to this project.

The second aim of Phase 1 was to conduct primary research to understand the impact of skin conditions and their self-management, as well as the perceived acceptability of MiDerm. To achieve this, two research studies, one qualitative and another mixed methods, were conducted in parallel to answer three research questions:

1. How do adults self-manage dermatological conditions?
2. What additional support do adults with dermatological conditions require from a new digital intervention designed to improve their psychological health and well-being?
3. Is the idea of a complex behaviour change intervention delivered via a new smartphone app acceptable to adults living with skin conditions?

As the two studies were intended to complement one another, they addressed the same objectives, which were to:

- Explore patient experiences of living with and self-managing skin conditions.
- Identify existing types of support that were available to adults in addition to standard medical care.
- Explore the perceived acceptability of MiDerm.

Two additional objectives were specified:

- Investigate how adults cope with skin conditions.
- Identify potential barriers and facilitators related to MiDerm.

The former objective was mainly linked to the online survey, as it included a validated measure of coping. The latter was more relevant to the online group interviews, as the interview topic guide included specific questions on barriers and facilitators. Whilst these two objectives were more aligned to a particular research study, the were not totally exclusive to either study and it was anticipated that both studies would cover the topics of coping and barriers and facilitators, but to different extents.

The main aim of Phase 2 was to develop a prototype of MiDerm. This aim was split into two objectives:

1. To define the theory underlying MiDerm.
2. To develop the MiDerm prototype, including content, features and design.

Chapter summary

Skin conditions can impact people in many ways, and the psychological impact is often reported to be the most profound. Despite the potential benefits of specialised psychodermatology services and psychological interventions, the availability of, and access to, psychological support is limited and there are currently several practical, psychological and financial barriers to implementing specialist psychology support, training and services that endorse a biopsychosocial approach, within dermatology. Most people receive little, if any, psychological support and are left to cope with and manage their skin condition alone; a problem which has been further exacerbated by the SARS-CoV-2 pandemic. Thus, there has never been a more urgent need to think creatively about how to provide psychological support to help individuals to self-manage all aspects of their condition effectively. Digital technology is increasingly being used to enable people to self-manage existing health conditions and could provide a medium for delivering psychological support with a focus on health behaviour change to people with skin conditions. However, little is currently known about digital psychological interventions in dermatology and quality research is generally lacking in this area. The contents of this chapter warrant further research in this area. This thesis will address existing gaps in dermatology service provision and the scientific literature through the development of a novel, theoretical, complex digital behaviour change intervention (DBCI) for adults with skin conditions, that reflects the views, experiences and needs of patients.

Chapter 3: Methodology

The present chapter outlines the philosophical perspectives and theoretical underpinnings of this research and the mixed methods approach that was employed across two project phases to meet this aim. Figure 1 presents a schematic map of the research project including the project phases, methodology and the respective chapters.

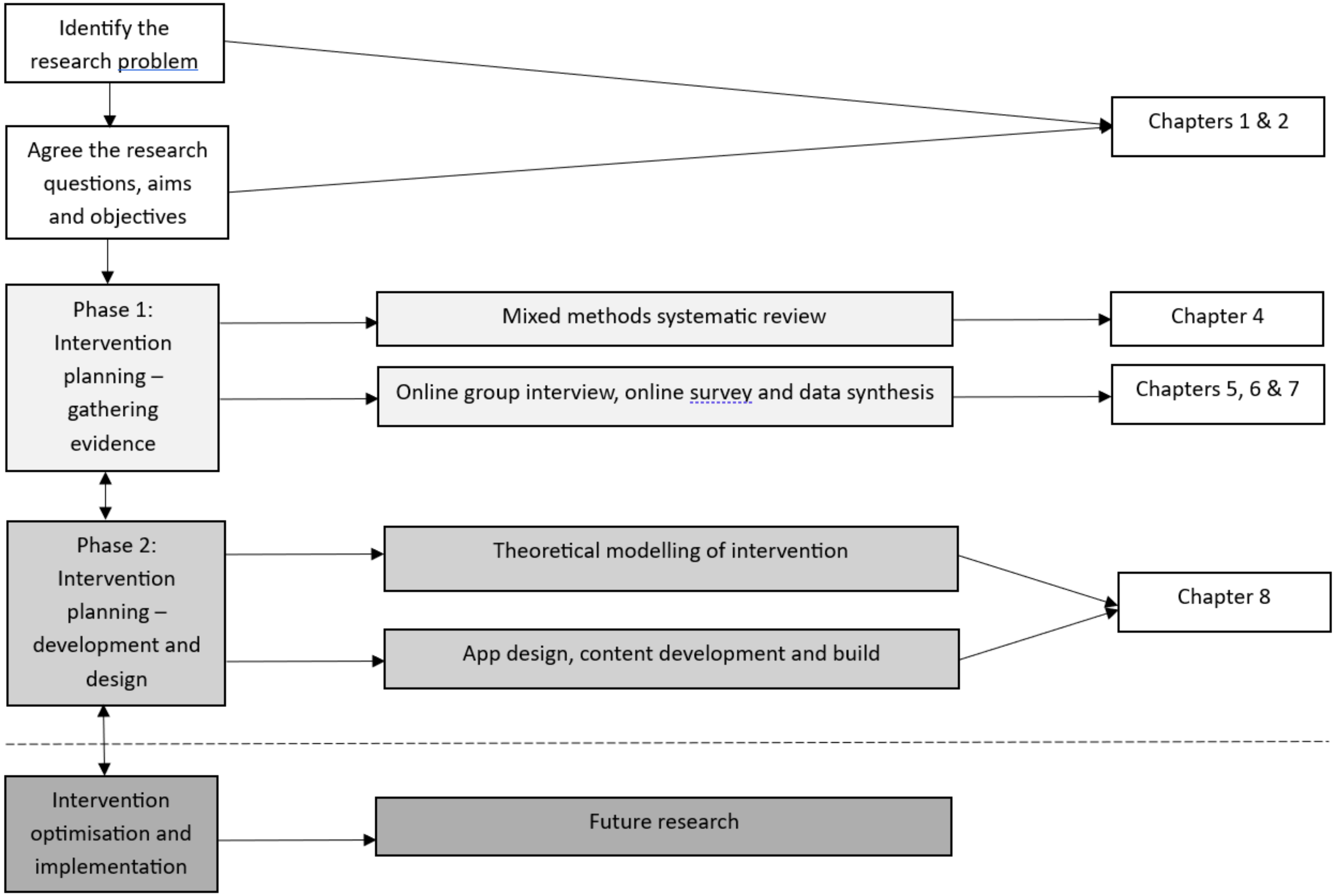

Figure 1: Schematic map of research methodology and thesis chapters

Philosophical principles

This section introduces key philosophical principles and their relevance in research, as well as the personal philosophical orientation that underpinned key methodological decisions in this research.

The importance of philosophy in research

At the simplest level, philosophy is the term used to describe the relationship between how we think and our state of being (Moon and Blackman 2014). Philosophy serves an important role in research, informing the perspective from which research is conducted and interpreted (Moon and Blackman 2014). Understanding the philosophical perspective from which a researcher operates is essential to make sense of what they have done and why, and whether their conclusions are valid and appropriate (Moon and Blackman 2014).

Philosophical worldview

A philosophical 'worldview' is a system of core beliefs, values and assumptions that influence action (Moon and Blackman 2014). This is also known as a philosophical 'paradigm' or 'perspective'. The term 'worldview' is preferred because it does not associate core beliefs with a specific discipline, specialism or area of expertise compared with other terms, such as paradigm, which do (Creswell and Plano Clark 2018).

One's philosophical worldview influences how they go about generating knowledge and make meaning of it. In the research context, this means that what a researcher assumes about the world will inform their approach to collecting and interpreting data. However, often researchers may be aware of their philosophical standpoint but do not communicate this explicitly (Creswell and Plano Clark 2018).

Philosophical worldviews are influenced by *ontological* and *epistemological* beliefs that a researcher subscribes to. The term 'ontology' refers to the beliefs one holds about *what* exists in the world that can be studied to generate new knowledge and understanding (Moon and Blackman 2014). A *realist* ontological perspective firmly supports the notion that one universal truth exists irrespective of the human experience. However, realism exists on a continuum and different realist perspectives have since emerged. A *critical realist* perspective, for example, subscribes to the idea that one reality exists to be discovered and explained, but also acknowledges that critical examination and interpretation is valid in understanding complex social phenomena (Hall 2013). The realist perspective contrasts with a *relativist* position, which acknowledges that people interpret their reality based on their subjective experiences and social, cultural and historical influences (Moon and Blackman 2014).

Epistemology concerns the beliefs one holds about knowledge, specifically *how* knowledge is generated and acquired (Moon and Blackman 2014). It is important to acknowledge that different epistemological approaches exist. An objectivist approach adheres to the idea that the truth exists and systematic and rigorous scientific methods can be employed to discover this truth and generate knowledge about it (Moon and Blackman 2014). Constructivism endorses the belief that we obtain knowledge as we experience the world around us, accounting for the social, cultural and historical context (Creswell and Plano Clark 2018). A subjectivist approach is aligned to the belief that individuals develop knowledge themselves and interpret the world around them in a way that is meaningful to them.

Common philosophical worldviews in mixed methods research

Later in this chapter I provide a rationale for conducting mixed methods research. This sub-section briefly outlines four philosophical worldviews that are aligned with mixed methods research specifically, as described by Cresswell and Plano Clark (2018):

1. Postpositivist.
2. Constructivist.
3. Transformative.
4. Pragmatist.

Before I introduce the postpositivist worldview, it is important to cover positivism, the worldview which postpositivism stemmed from. Positivism firmly aligns with a realist ontology and objectivist epistemology; fundamental to this is the use of quantitative scientific methods to observe or measure specific variables related to a phenomenon to determine or verify its truth (Moon and Blackman 2014). Postpositivism stemmed from positivism and is also objectivist and endorses using quantitative methods, although this stance recognises that determining a universal truth is unrealistic due to recognised human biases.

At the core of a constructivist worldview sits the belief that reality is open to personal interpretation and thus, multiple realities can exist (Creswell and Plano Clark 2018). Inductive, qualitative approaches are typically used to understand what reality is like for the individual and how the social and historical context contributes to their experiences (Creswell and Plano Clark 2018).

A transformative worldview focuses on the marginalisation of specific groups within society, such as racial and ethnic groups, and the pursuit of social justice and change using collaborative and community-based approaches to research (Creswell and Plano Clark 2018).

Unlike other worldviews, pragmatism is concerned with the specific research question being asked and the real-world application and implications of research rather than the methods employed. Pragmatists do not subscribe to the dichotomy between postpositivism and constructivism, nor do they endorse the concepts of 'truth' or 'reality' that other worldviews discuss (Creswell and Plano Clark 2018). Instead, they embrace the idea that, on one hand, the world around us governs our experiences and, on the other hand, our interpretations of our experiences influence our understanding of the world (Creswell 2009). Pragmatists instead focus on doing what 'works' in research and typically integrate qualitative and quantitative data to answer a specified research question. Pragmatism is commonly adopted by mixed methods researchers (Creswell and Plano Clark 2018) and is considered a useful perspective for researching complex social and behavioural phenomena (Tashakkori and Teddlie 2010).

Identifying a suitable worldview for mixed methods research is challenging because the approach combines quantitative and qualitative methods which, traditionally, sit in the two opposing camps of positivism and constructivism (Hall 2013). Some researchers hold different beliefs that reflect a worldview that does not 'fit' into one philosophical category (Creswell and Plano Clark 2018). It is, however, important to remember that worldviews are broad perspectives that are there to orientate researchers and guide inquiry, and they can be applied separately or together to inform one's approach to research (Creswell and Plano Clark 2018). In addition to this, Creswell and Plano Clark (2018) usefully point out that there is no 'hard and fast' approach to choosing a philosophical worldview and researchers have previously adopted different stances, including:

- Deciding on one worldview that they consider to be superior for mixed methods research.
- Opting for a dialectical perspective and combining two or more worldviews.
- Identifying a philosophical worldview that is suited to the design and context of the research being carried out.
- Adopting a worldview which fits with that of their wider research community.

Crotty (1998) produced a framework for contextualising philosophy in mixed methods research, which covers four key aspects to consider when designing a mixed methods study, including:

1. Paradigm worldview.
2. Theoretical lens.
3. Methodological approach.
4. Methods of data collection.

This sub-section explicitly outlines the philosophical, theoretical and methodological perspectives that informed the present research, according to Crotty's (1998) framework. These are also conceptualised in Figure 2.

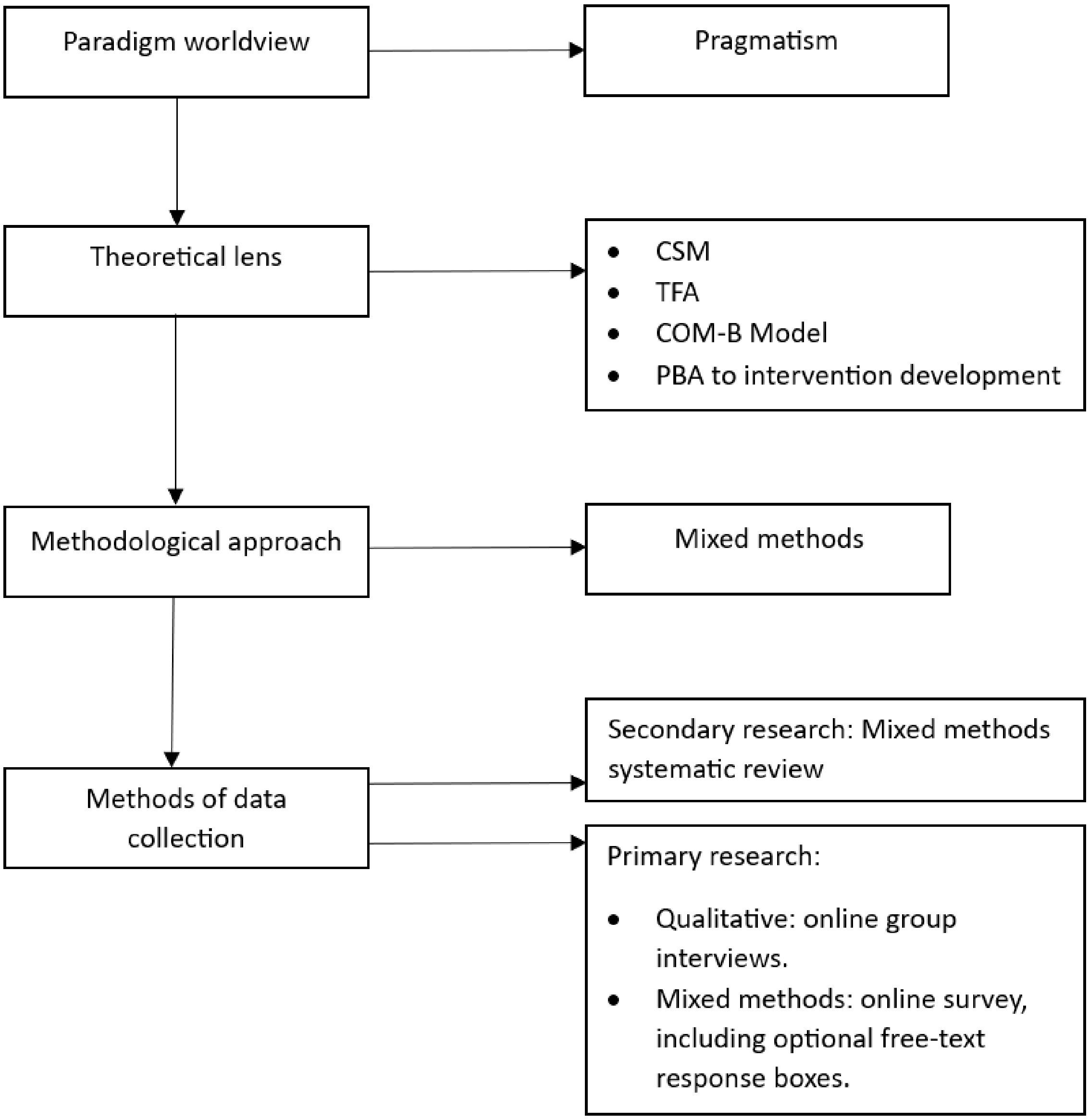

Figure 2: Conceptualisation of the current research design according to Crotty's (1998) four major elements of mixed methods research design

My philosophical worldview

This research was conducted from a pragmatic perspective appropriate for intervention research, which, at the most basic level, concerns developing or adapting and implementing solutions to overcome real-world problems. The purpose of this research was to develop a DBCI for adults with skin conditions. The MiDerm app is a potential solution to addressing the negative life impact of skin conditions and inadequate support.

Secondly, pragmatism is flexible in that it allows researchers freedom to explore different perspectives by combining qualitative and quantitative methods of data collection and analysis to better understand a phenomenon (Creswell 2009).

The pragmatic stance of employing qualitative and quantitative methodology (Creswell 2009) aligns with the biopsychosocial model of dermatology care (Chapter 2) and the Person-Based Approach (PBA; Yardley et al. 2015b) to intervention development that guided the development of MiDerm (Chapter 8). In contrast, a purely quantitative methodology is more in keeping with the biomedical model of health which focuses on pathological cause and effect mechanisms of illness. While this approach may be suited to studying the physiology of the skin or the effectiveness of pharmacological interventions in dermatology, it would fail to account for other psychological, social, cultural and historical factors that may influence health and illness. Qualitative research, on the other hand, can accommodate the rich exploration of cognitive, emotional, behavioural and social factors that influence the health and well-being of individuals, or groups. It involves engaging directly with the people from the target population to better understand their needs and circumstances. Qualitative methods, therefore, match the ethos of the biopsychosocial model and PBA, which consider the whole person, and should be employed in conjunction with quantitative methods.

Theoretical lens

Michie et al. (2017) published a set of recommendations for developing DBCIs in which they acknowledge the importance of theory. The authors recommend adopting a theoretical approach to data analysis and collection to maximise intervention effectiveness by accounting for potential drivers of behaviour, flagging barriers to use and implementation, and providing an overarching and systematic approach to development and evaluation (Michie et al. 2017). Theoretically informed research can also support the testing and advancement of existing theory and the authors argue that combining quantitative and qualitative research methods provides a well-rounded approach that generates insights into different aspects of a phenomena that can usefully inform existing theory (Michie et al. 2017). However, the theoretical underpinnings of digital interventions are often underreported and some lack a theoretical basis entirely, making it challenging to establish the mechanisms through which the intervention works (Michie et al. 2017). It is, therefore, important that MiDerm is informed by relevant theory and that its theoretical basis is made transparent from the outset. This sub-section outlines the theoretical foundations of this research, including the following psychological frameworks and models:

- CSM (Leventhal et al. 1984).
- The Theoretical Framework of Acceptability (TFA; Sekhon et al. 2017).
- The Capability, Opportunity, Motivation – Behaviour (COM-B) Model (Michie et al. 2011b).
- The Person-Based Approach to health intervention development (Yardley et al. 2015).

CSM (Leventhal et al. 1984)

The CSM (Figure 3) is an established psychological model, which posits that personal illness perceptions drive emotional reactions and behavioural responses to illness. It specifies five cognitive representations of illness (Table 1), which, together, form one's overall perception of illness.

Table 1: Cognitive representations from the Common-Sense Model of Self-Regulation (Leventhal et al. 1984)

	Cognitive representation	Definition
1	Identity	Personal definition of illness, including the label they assign to it and the symptoms they associate with it.
2	Cause	Factors that are perceived to cause or trigger illness.
3	Controllability / curability	The degree to which an individual believes their actions can influence their illness or it can be controlled using treatments, and whether an individual believes their illness can be cured.
4	Consequences	The perceived impact of illness on the individual and their life.
5	Timeline	Beliefs about the duration of illness, for example, whether it is acute, chronic or cyclical in nature.

The CSM is dynamic in that it explains how an illness is appraised can impact on the emotional representations a person associates with their illness and their behavioural response to it. The actions one takes to address their illness are then appraised and this creates a feedback loop which can reinforce or alter existing illness beliefs and, in turn, self-regulation (Leventhal et al. 2016).

The CSM also incorporates the concept of congruence, focusing on (in)consistency between illness beliefs and approaches to management. In addition, the CSM model accounts for the social context, encouraging consideration of how social factors might influence personal beliefs, emotions and behaviour related to illness (Leventhal et al. 2016).

The CSM provides a multi-level conceptual framework for understanding, investigating and predicting the psychological processes (cognitions, emotions and behaviour), and the relationships between them, that are relevant to illness self-management (Leventhal et al. 2016).

What adults believe about their skin condition(s) is likely to affect how they feel about their condition and respond by managing it. The CSM was used in this body of work to understand, and challenge where appropriate, adults' perceptions of their skin conditions, how these influence their emotional reactions and their behavioural approaches to self-management.

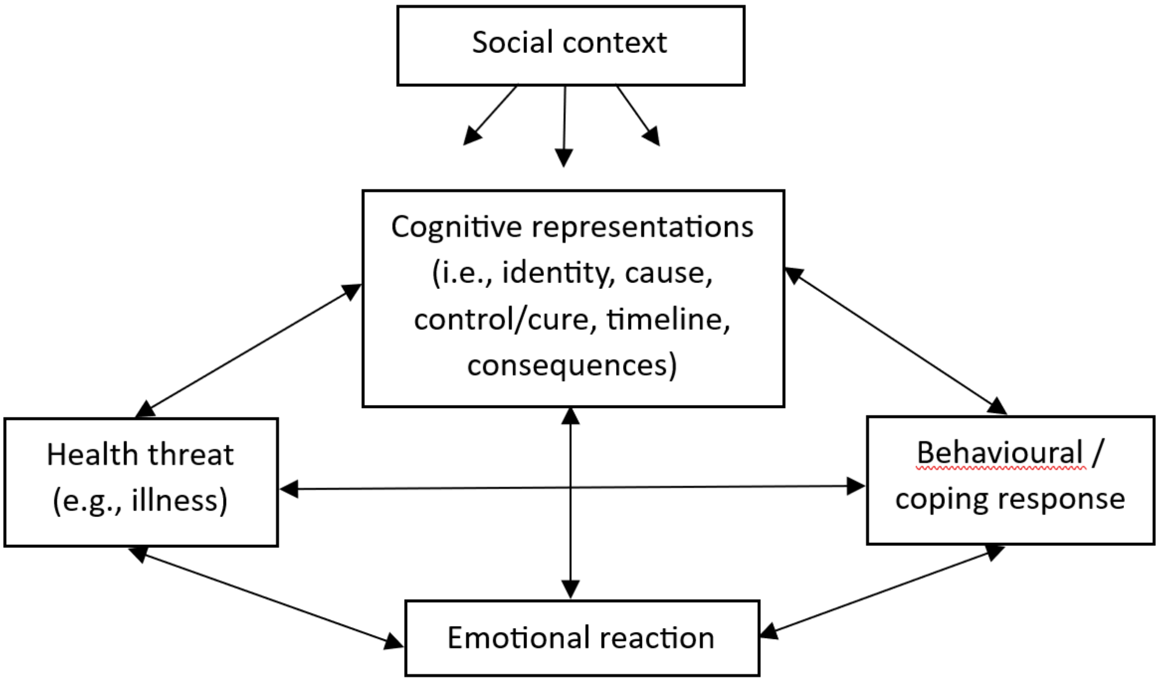

Figure 3: Common-Sense Model of Self-Regulation adapted from Leventhal et al. (1984)

TFA (Sekhon et al. 2017)

Sekhon et al. (2017) theorised the concept of acceptability to support a standardised approach to defining, investigating and measuring the acceptability (appropriateness) of health interventions and their related components. They developed the TFA (Figure 4) which defines acceptability as:

> *"A multi-faceted construct that reflects the extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experiential cognitive and emotional responses to the intervention" (Sekhon et al. 2017, p. 8)*

Intervention acceptability can be judged according to the seven domains in Table 2:

Table 2: Domains of the Theoretical Framework of Acceptability (Sekhon and Francis 2017)

	TFA domain	Definition
1	Ethicality	How aligned the intervention is to one's personal values.
2	Affective attitude	Personal feelings towards participating in an intervention.
3	Burden	The effort required to engage with an intervention.
4	Opportunity costs	Benefits, profits or values that are forgone to participate in the intervention.
5	Perceived effectiveness	Whether the intervention is perceived to have achieved its purpose.
6	Self-efficacy	Self-confidence to perform the behaviours required for the intervention.
7	Intervention coherence	Personal understanding of the intervention and how it works.

The TFA can inform quantitative and qualitative investigations of intervention acceptability from initial development through to evaluation and implementation, and can facilitate the exploration of three types of acceptability, including the:

1. *Perceived* acceptability of an intervention that has not yet been received or does not yet exist.
2. *Concurrent* acceptability of an intervention as determined during its delivery or use.
3. *Retrospective* acceptability of an intervention as determined following its use or completion.

How acceptable an intervention is in the eyes of the people who will deliver or receive it is likely to influence the degree of engagement and its effectiveness (Sekhon et al. 2017). Acceptability should be considered across the stages of intervention development and evaluation (Sekhon et al. 2017). The TFA was, therefore, used to assess the *perceived* acceptability of MiDerm.

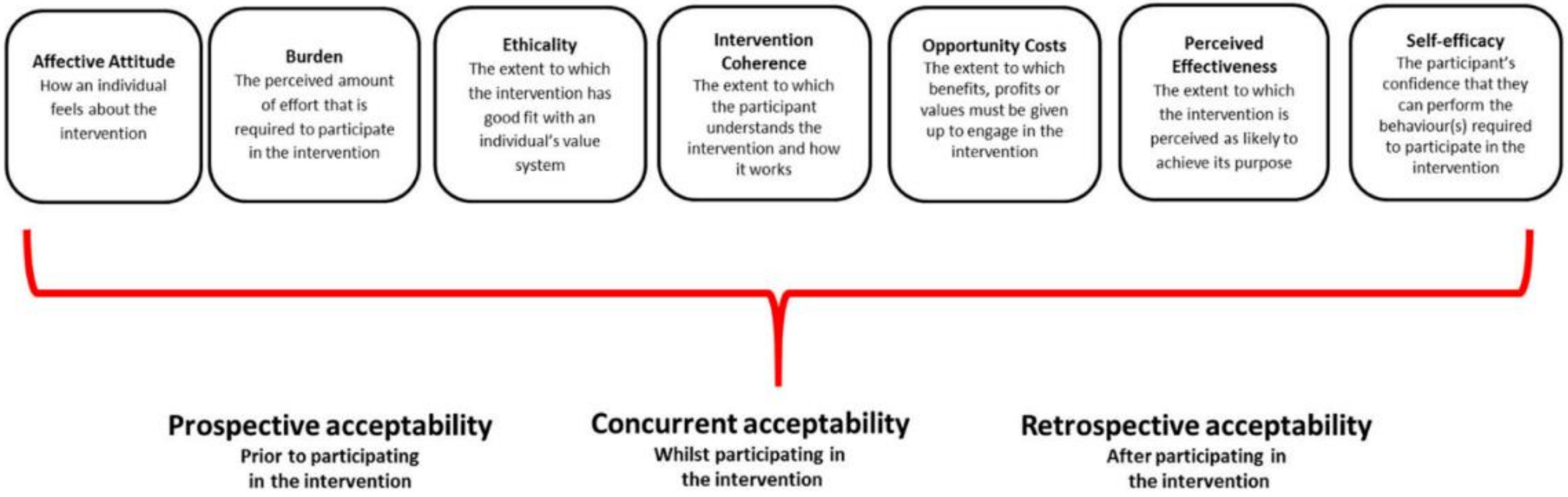

Figure 4: The Theoretical Framework of Acceptability reproduced from Sekhon et al. (2017, p. 8)

COM-B Model (Michie et al. 2011b)

The Behaviour Change Wheel (BCW; Figure 5) is an established and evidence-based framework for systematically designing behaviour change interventions (Michie et al. 2011b). The BCW specifies nine intervention types and seven policy categories that could aid the design and implementation of new interventions (Michie et al. 2011b). The BCW offers a person-centred approach to designing interventions because at the heart of this framework sits the COM-B Model (Figure 6), a behavioural hub which stipulates that engagement in a behaviour is dependent on and, in turn, can be influenced by, three interacting conditions (Michie et al. 2011b):

1. Capability.
2. Opportunity.
3. Motivation.

The term capability refers to people's physical and psychological ability to perform a behaviour, usually in the form of relevant skills and knowledge (Michie et al. 2011b). People also need to have the physical and social *opportunity* to perform a behaviour (Michie et al. 2011b). Physical opportunity includes personal finances and being in an environment that affords the desired behaviour (Michie et al. 2011b). Social opportunity relates to the social context and support available (Michie et al. 2011b). Behavioural change and maintenance are also influenced by personal motivation, the cognitive and emotional processes that underpin willingness to engage in a behaviour (Michie et al. 2011b). Motivation can be reflective and involve conscious evaluative and decision-making processes, or it can automatic, arising from our emotional and instinctive responses and desires (Michie et al. 2011b).

The COM-B model is commonly used to identify and understand behavioural factors that need to change in order for an intervention to be effective (West and Michie 2020). It informed this research by highlighting the factors adults need to change (risk factors for poor health outcomes), the helpful or unhelpful ways they engage with change (capability), as well as the facilitators and barriers to engaging with MiDerm and relevant health behaviours (opportunity and motivation), initially and overtime. Ultimately, COM-B informed the behavioural analysis to determine which behaviour(s) MiDerm would address.

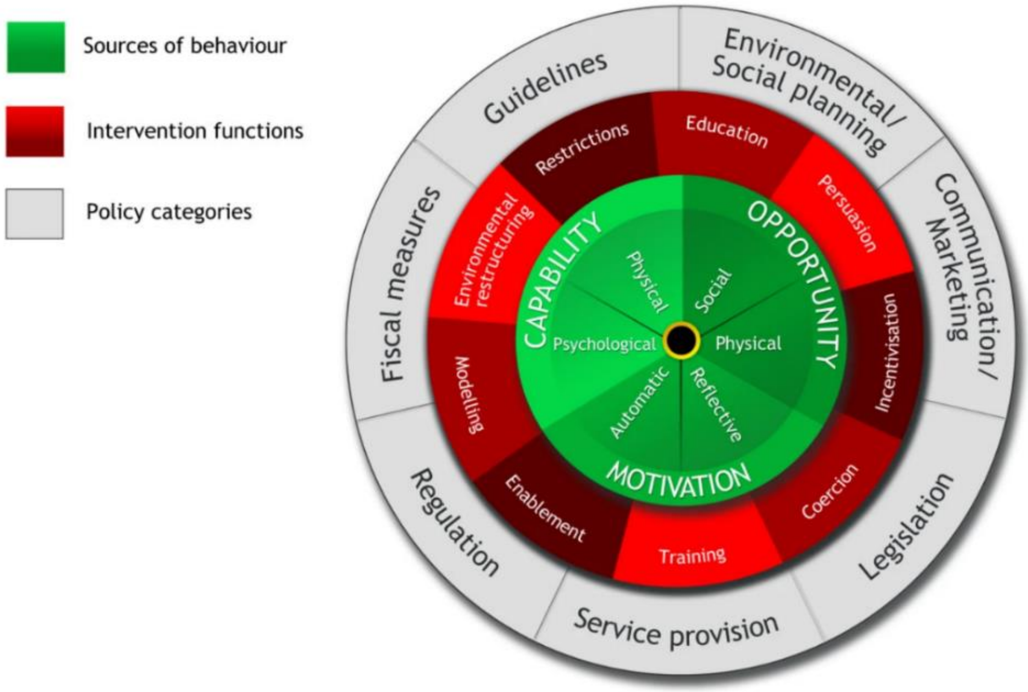

Figure 5: The Behaviour Change Wheel reproduced from Michie et al. (2011, p. 7)

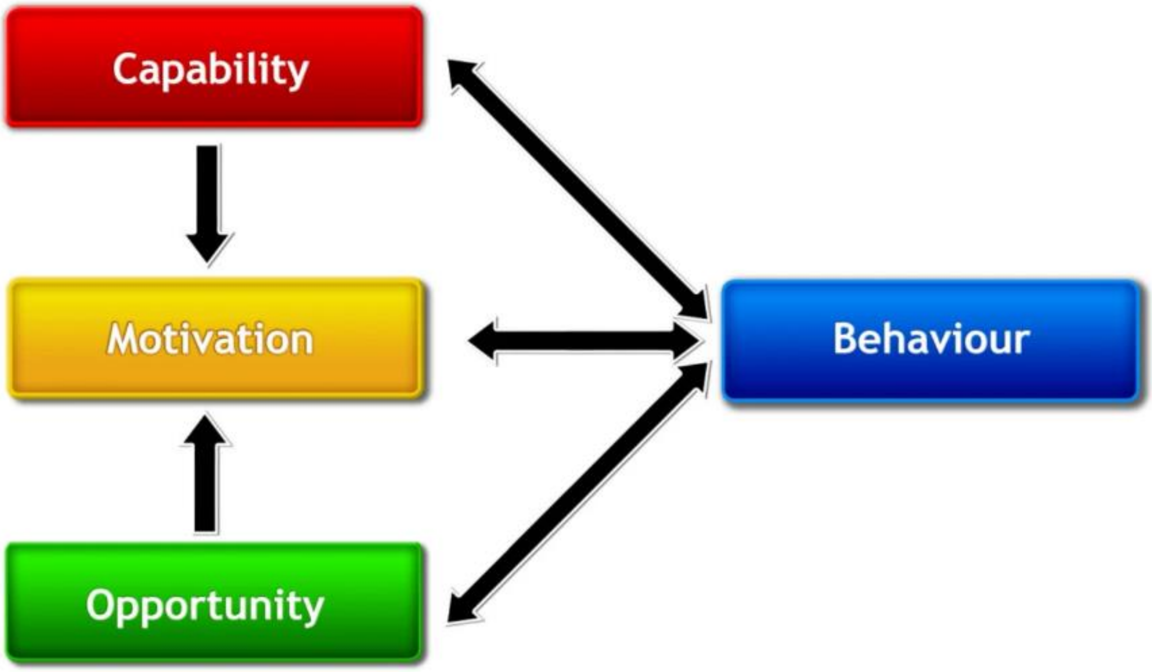

Figure 6: The COM-B Model of behaviour change reproduced from Michie et al. (2011, p. 4)

A framework for intervention development

Complex behaviour change interventions (see Chapter 8 for a full definition) are being increasingly used to address key health and social issues (Michie et al. 2016). The UK Medical Research Council (MRC; Skivington et al. 2021) and the Intervention Mapping approach help to develop theoretical and evidence-based health interventions (Bartholomew et al. 1998).

Theoretical frameworks support a systematic and transparent approach to development and evaluation that is traceable and reproduceable (Michie et al. 2016; Michie et al. 2017). They can enable developers to account for potential drivers of behaviour, and identify barriers to use and implementation (Michie et al. 2017). However, with many frameworks available, this increases the risk of conflicting guidance and confusion among developers (O'Cathain et al. 2019).

O’Cathain et al. (2019), therefore, conducted a consensus study which resulted in a taxonomy of eight categories of approaches to developing health interventions, including:

1. Partnership.
2. Target population centered.
3. Theory- and evidence- based.
4. Implementation-based.
5. Efficiency based.
6. Stepped or phased based.
7. Intervention-specific.
8. Combination.

The authors make it explicit that there is no right or wrong when it comes to selecting a particular framework for intervention development (O'Cathain et al. 2019).

With these considerations and current recommendations for developing and evaluating DBCIs (Michie et al. 2017) in mind, a person-centred and iterative approach, that endorsed the use of mixed methods research, was adopted to identify and address the needs and preferences of the target group.

The PBA (Figure 7) to intervention development (Yardley et al. 2015b) is recognised and defined in the existing taxonomy as a target population-centred approach (O'Cathain et al. 2019). It is an evidence-based and iterative approach for systematically developing complex behavioural interventions which advocates for gathering mainly qualitative data from prospective users so that interventions are relevant, appropriate and practical for the people they are intended for (Yardley et al. 2015a; Yardley et al. 2015b; Morrison et al. 2018). Intended to be used in conjunction with other theories and evidence-based approaches for developing behaviour change interventions, the PBA is comprised of three key steps to intervention development, including planning, optimisation and implementation (Yardley et al. 2015b; Morrison et al. 2018). A full description of the PBA and its stages is provided in Chapter 8. At this stage, it is important to acknowledge that the current research adopted the PBA as a guide for planning the MiDerm app. As current guidance for complex intervention development suggests, intervention implementation was a consideration from the outset (O'Cathain et al. 2019), but the optimisation, implementation and rigorous evaluation of MiDerm was beyond the scope of the current three-year project.

MiDerm was also developed in close collaboration with ten PPI contributors (see the section on Patient and Public Involvement, pg. 74), which is congruent with a partnership approach to intervention development (O'Cathain et al. 2019). A combination of target population-centred *and* partnership approaches were employed to develop MiDerm.

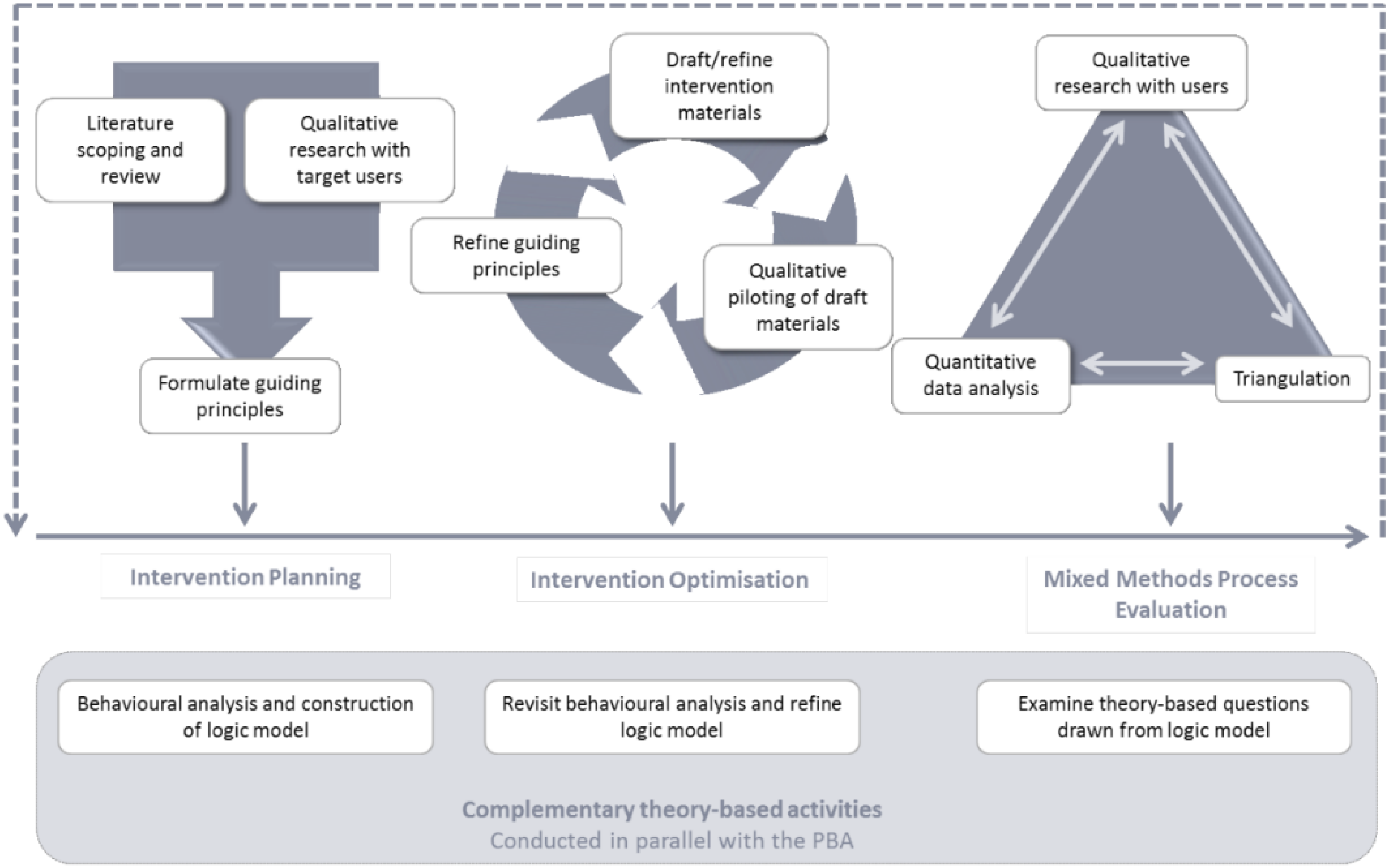

Figure 7: The Person-Based Approach reproduced from Morrison et al. (2018, p. 465)

Aligning theoretical approaches with philosophical world view

This research aimed to develop a complex DBCI with input from the target population (adults with skin conditions) to ensure its relevance, appropriateness and meaningfulness to them. It follows the PBA to intervention development (Yardley et al. 2015b), which sits within the category of target population-centred approaches to developing interventions (O'Cathain et al. 2019). Whilst these approaches use different terminology, they are essentially speaking the same language as both place the person at the centre of the development process. The people who MiDerm is intended for are, therefore, the fabric of this thesis and the theoretical approaches, models and frameworks that were used to develop MiDerm are the threads woven into this work.

Just like the BCW (Michie et al. 2011b), the PBA gives structure to the intervention development process in this thesis, the research methodology and methods that should proceed it (Yardley et al. 2015b).

Pragmatism and the CSM (Leventhal et al. 1984) are compatible because the CSM recognises the central role of beliefs in influencing how a person feels and subsequently how they react to health threats that they experience (Leventhal et al. 2016).

Amalgamating psychological theories

This PhD Used several compatible theoretical models and frameworks to collect and interpret the evidence to justify, inform and structure the development of MiDerm.

The TFA (Sekhon et al. 2017) was utilised in the first phase to explore the perceived acceptability of the proposed intervention and support a deductive approach to collecting and coding data on this specific topic. The data generated from it in phase one informed aspects of the development and design of MiDerm. For example, participants in the group interview study valued support from peers and expressed a desire for peer support to feature within the app. Some wanted the app to facilitate synchronous communication between users, but others reported some of the associated limitations and issues and proposed including patient stories instead. These findings indicated two potentially acceptable forms of peer support, one of which was more feasible to achieve within the current project and thus, became one of the main components of the MiDerm app. The TFA was also adopted with future work in mind as this framework could be revisited to explore either the concurrent or retrospective acceptability of MiDerm once the prototype is complete. The TFA will be used to explore concurrent acceptability within a cognitive interview study to establish the appropriateness of the app whilst users are engaging with it in real time and during implementation.

The CSM (Leventhal et al. 1984) was used to explore beliefs about living with and managing skin conditions. In phase one, the CSM was used to collect and analyse qualitative data from the online survey and group interviews participants. In phase two, these data were used to develop and design MiDerm, forming the basis of the guiding principles for the intervention and providing a clear steer for its design, content and functionality.

The BCW (Michie et al. 2011b) was used in a similar way across the two project phases to support the collection and analysis of data specifically on perceived barriers and facilitators related to the MiDerm app and in phase two to support the theoretical modelling of the intervention and to design and develop the app drawing on the solutions suggested by participants to overcome the perceived barriers, where possible. These data will inform the future implementation and evaluation.

The PBA (Yardley et al. 2015b) was used as a high-level guide that provided a structure both across the project as a whole and within the two main phases. It provided a steer for the current methodology and methods, all of which were aligned to the ethos of this research; person-centredness.

Figure 8 presents a visual depiction of the theoretical underpinnings of this research.

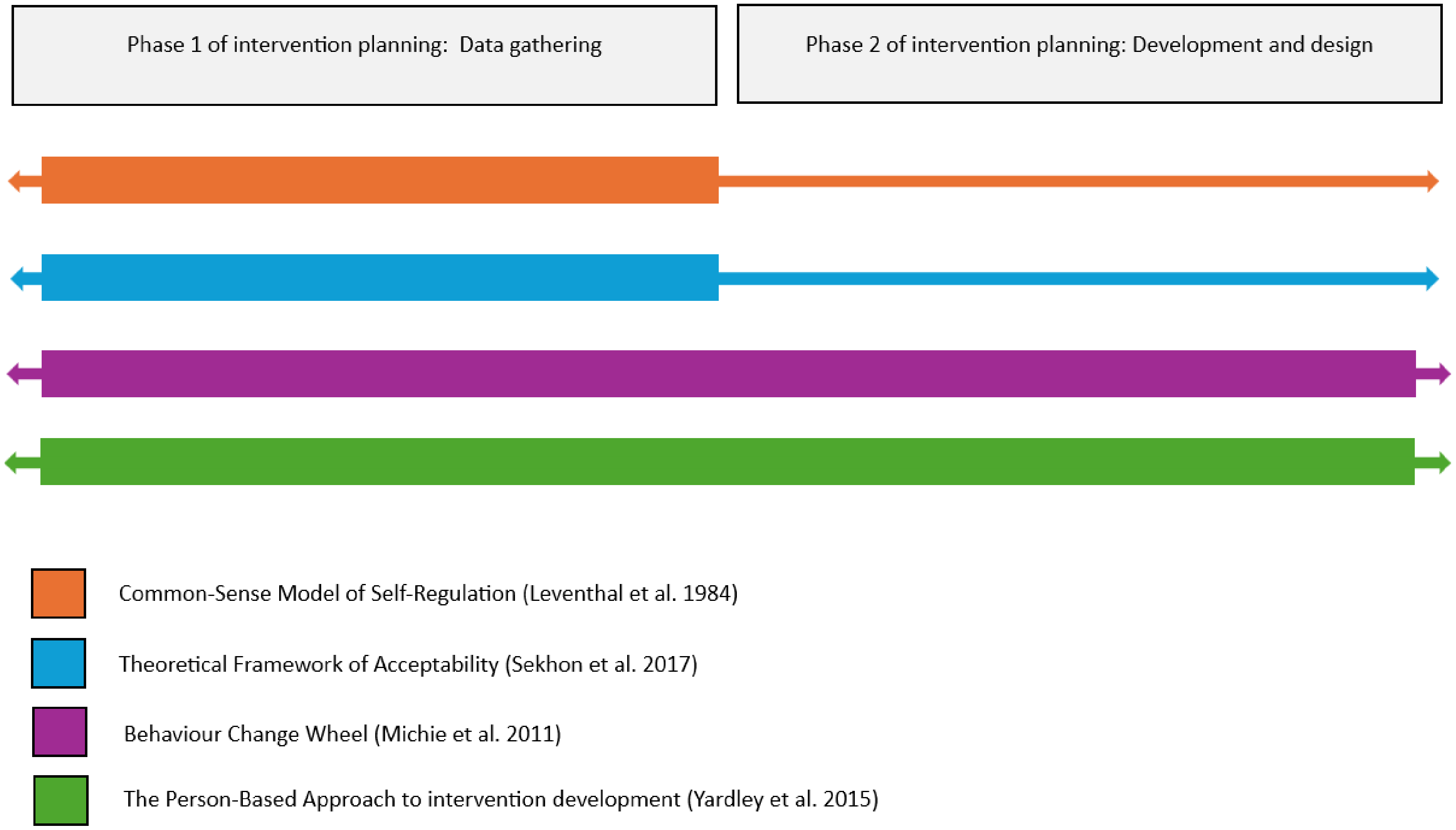

Figure 8: Visual representation of the theoretical underpinnings of this research

Methodological approach

Mixed methods research

This PhD involved mixed methods research combining qualitative and quantitative methods to gather data on a phenomenon (Hall 2013). Qualitative research is useful for exploring complex psychological processes of individuals or groups within socio-cultural contexts (Tenny et al. 2023). Quantitative methods are more suited to research aiming to collect numeric data to test 'a priori' hypotheses using established statistical analyses (Watson 2015).

Definitions of what constitutes mixed methods research vary from the philosophical paradigm to methodology (the research process) and methods (ways to collect data) (Creswell and Plano Clark 2018). Cresswell and Plano Clark (2018) characterise mixed methods research as that which utilises both qualitative and quantitative methods for data collection and analysis, and synthesises these two distinct types of data to answer a research question, through a theoretical and philosophical lens.

The mixed methods approach emerged in the 1980's out of the necessity for a means of addressing increasingly complex research questions (Creswell and Plano Clark 2018) mainly in the social and behavioural sciences for which broad and pragmatic approaches are needed to explore different perspectives (Tashakkori and Teddlie 2010). One of the main advantages is that using both qualitative research with quantitative methods enables researchers to develop a more comprehensive understanding of the topic under investigation compared to using one method only (Tashakkori and Teddlie 2010). Qualitative and quantitative methods both have their own limitations but combining these methods, arguably, helps to offset the limitations of each, leading to a deeper understanding of a topic (Tashakkori and Teddlie 2010). Another advantage is that a variety of philosophical paradigms can be used with mixed methods research, a belief coined as 'paradigm pluralism' (Tashakkori and Teddlie 2010).

However, whilst some view mixed methods research as a useful 'third methodological movement' (Tashakkori and Teddlie 2010), others firmly believe that the epistemological viewpoints that underpin qualitative and quantitative methods are incompatible, which has made it challenging for researchers to justify combining these methods leaving them open to scrutiny (Hall 2013). Conducting mixed methods research is also time and resource intensive compared to using qualitative or quantitative approaches alone (Creswell and Plano Clark 2018). Finally, simply employing qualitative and quantitative methods to collect data is not sufficient and integrating or triangulating the data generated is an important step in the process, but can be challenging to do (Tashakkori and Teddlie 2010).

Mixed methods were used here to understand complex psychological and social phenomena, the personal lived experiences of skin conditions and their management against the backdrop of existing support within healthcare and social settings. It aimed to give precedence to the voices of adults with a range of skin conditions globally to understand their needs and preferences for additional support, and qualitative methods, which are currently underutilised in dermatology (Pascual et al. 2023). Quantitative methods provided the opportunity to gain more perspectives.

Research Methods

Research design

Research designs provide a systematic guide for answering research questions and supporting key decisions by offering insights into potential problems that may arise and solutions for overcoming these (Creswell and Plano Clark 2018). Designs are not mutually exclusive and different designs may be adopted across different phases of research.

The authors outline three core design classifications that are applicable in mixed methods research. A *convergent* design involves employing qualitative and quantitative methods of data collection and analysis in parallel and combining and comparing these data to interpret them. An *exploratory sequential* design occurs when qualitative research precedes and informs subsequent quantitative research. An *explanatory sequential* design begins with quantitative research that is later built on with qualitative research.

I employed a convergent design, as qualitative and mixed methods of data collection and analysis were conducted simultaneously to achieve both a high quantity and quality of data to fully understand the experiences, needs and preferences of adults living with a range of skin conditions and provide a concrete foundation of data on which to develop MiDerm.

Future research will adopt an exploratory sequential design and involve more qualitative research to verify whether the initial design and content of the app are appropriate and gather more data to optimise it. Quantitative methods will be used to test the effectiveness of the intervention against patient health outcomes.

Online research methods

The development of digital technologies has provided useful opportunities for researchers and changed the ways and pace at which research is conducted (Coulson 2015). Coulson (2015) explains that use of the internet for research purposes began in the late 1960's to support university- and lab- based projects commissioned by the Advanced Research Projects Agency within the US Department of Defence. By the 1990's, significant technological advances meant that the internet was easier to access and use than ever before, establishing the internet as a research tool and resulting in different approaches to its use, including:

- A translational approach – traditional research methods and materials are adapted for online use.
- A phenomenological approach – how people interact with the internet and behave online becomes the subject of interest.
- A novel approach – using methods and platforms that are unique to the online environment, such as online music libraries.

The increasing use of online research methods has key advantages and disadvantages (Coulson 2015): by providing an opportunity for researchers to use novel approaches to investigate complex psychological phenomena where other more traditional methods may be limited; by allowing for greater flexibility, convenience and efficiency for those involved whilst reducing research costs including those for printing materials and renting interview equipment (Coulson 2015). It facilitates more direct access to the target population and improves access to hard-to-reach groups, such as those with existing health conditions, as well as those who face stigma, prejudice, or discrimination by others in society (Coulson 2015).

Whether online study samples are representative of the wider population given that access to the internet and technology is not equal and a digital divide exists (Chapter 2 and 6) is questionable. Furthermore, it can be limited by technical problems and poor response and dropout rates (Coulson 2015). There is also the challenge of verifying the identities of participants and dealing with automated (Hewitt et al. 2022d) and duplicate responses; researchers, arguably, have less control over online research processes than they do with traditional research methods (Coulson 2015).

Despite these limitations, the use of online methods throughout this PhD extended the global reach of adults living with different skin conditions and the opportunity for them to participate in studies that they would not have otherwise been able to if conducted in person. This PhD began one month after the SARS-CoV-2 pandemic was officially declared and thus, going online was the only option at that time to continue the project and avoid significant delays. However, the latter does not overshadow the main advantage of supporting the conduct of global research, it merely reinforces the convenience and flexibility that online research affords.

An overview of the two project phases and the methodology and methods used in each are presented in Appendix 3.

Triangulation

Triangulation is the process in which different research methods are employed to study a phenomenon (Carter et al. 2014). It is closely related to the idea of 'integrating' qualitative and quantitative data in mixed methods research (Tashakkori and Teddlie 2010) and a convergent research design. Carter and colleagues (2014) distinguish between four types of triangulation, which are listed and described below in Table 3.

Triangulation offers a way to gain multiple perspectives and supports the validation of data (Carter et al. 2014), potentially increasing the overall credibility of research findings (Thurmond 2001).

Table 3: Type of triangulation according to Carter et al. (2014)

Type of triangulation	Definition
Methodological	Use of different research methods to answer a research question or objective related to a particular phenomenon. Facilitates the generation of more data on a topic to build a comprehensive data set that can be used to validate and confirm existing findings, establish whether findings are consistent across a population, and improve general understanding of a topic.
Investigator	Applicable to research where two or more researchers contribute to a study, bringing together their independent knowledge, skills, observations and reflections to corroborate results and form more robust conclusions about a topic.
Theoretical	Draws on different theories to inform data collection, analysis and interpretation.
Data source	Involves gathering data from different people to gather a broad range of perspectives on a particular topic.

The present research incorporated methodological, theoretical, data source and investigator triangulation. Quantitative and qualitative research methods, including a survey and group interviews, were employed (methodological) and this supported the collection of data representing lived experience of different skin conditions (data source), which were used to address the key aims and objectives. This research drew on the concepts of existing psychological theory, models and frameworks to support a systematic and evidence-based approach to gather and analyse participant data (theoretical). Lastly, whilst I was responsible for leading and running all of the studies that form part of this research project, colleagues with relevant knowledge and expertise were involved throughout to support the research and facilitate a team approach to research (investigator).

Methods used throughout this PhD

Participants

The target group for this research was English-speaking adults (18≥ years) living with a recognised skin condition(s) anywhere in the world. Adults who had the ability to provide informed consent and could access the internet were eligible to participate. There were no exclusion criteria.

Recruitment

Participant recruitment is a fundamental step in the research process, as it can influence the richness and robustness of research findings (Negrin et al. 2022). Recruiting participants can be challenging because it involves some degree of anticipating the motivations and reactions of the people in the target group (Negrin et al. 2022). It is important to establish a clear recruitment strategy, which offers some flexibility, at the outset and researchers should critically reflect on their recruitment strategy throughout the process to help maximise recruitment (Negrin et al. 2022). Negrin and colleagues (2022) describe several factors that can influence participant recruitment in qualitative research, although some are applicable to research generally. These factors include:

- How well the researcher understands the target group, including their context, environment, needs, desires and concerns.
- Rapport and trust between the researcher and participants.
- How flexible the researcher is and how accommodating they are to the preferences and schedules of participants.
- How broad or narrow eligibility criteria are. For example, strict inclusion and exclusion criteria could negatively impact recruitment.
- The type and number of recruitment methods used. For example, the use of active (e.g., direct contact with a person) versus passive (e.g., flyers and newsletters) methods and whether two or more methods are used together.
- Incentivisation. Offering money, vouchers or food may increase motivation for participation.

Use of new (social) media is considered by many to be a cost-effective and efficient strategy for recruiting participants, particularly for cross-sectional and non-intervention studies

(Darko et al. 2022). Use of paid and targeted advertisements can be especially helpful for accessing typically hard-to-reach groups, including people who are socially disadvantaged due to being stigmatised, on low income, have health complications, lack literacy skills or belong to an ethnic minority group (Darko et al. 2022). However, new media may be less appropriate for recruiting older adults, who report barriers to use and tend to engage less in new media compared to younger people (Darko et al. 2022). In addition, it can be difficult to verify the identities of potential participants on new media platform, which raises ethical and safety concerns for researchers and their participants (Darko et al. 2022). Researchers need to carefully consider the pros and cons of recruitment via these methods in the context of the aims and objectives of their research to determine the best approach and practice (Darko et al. 2022).

Whilst acknowledging the limitations of this approach, given that the present research was all planned to be conducted online, and the aim was to engage adults with skin conditions across the world, advertising the study on new media platforms was deemed appropriate. The following strategy was adopted to recruit adults to the research studies.

Details of the research were publicised on four new media platforms (Twitter [now known as X], Facebook, Instagram and LinkedIn). The use of social media was useful in that it helped to widely disseminate key information about the study (passive method), but it also enabled me to engage with potential participants and respond to their queries in a timely manner (active method).

Professional network colleagues and acquaintances who were working as leaders of organisations representing people with skin conditions were invited to support the recruitment process. All five patient organisation leaders agreed to advertise the PPI and research opportunities. The patient organisations involved included:

- The International Alliance of Dermatology Patient Organisations (IADPO; aka Global Skin).
- The British Skin Foundation.
- Skin Care Cymru.
- The Psoriasis Association UK.
- Eczema Outreach Support.

These organisations also shared information on their social media pages, websites, via email and in member magazines or newsletters. Each organisation received a financial gift (400 euro) for their contributions to the three-year project, which was paid in two instalments.

Throughout the recruitment period, leaders or trustees of other patient organisations emailed me volunteering to promote the studies. These organisations included:

- HS Ireland (Hidradenitis Suppurativa Association).
- Alopecia UK.
- Ichthyosis Support Group.
- Vitiligo Society UK.
- Beautifully Umblemished Vitiligo Support Group.
- Outer Shell Africa Communications.

Attempts were made to offset the limitations of using online recruitment methods. This mainly included producing targeted advertisements and inviting PPI contributors to review the written and visual content of these advertisements to check appropriateness and comprehensibility. It was important to determine whether the language and images used with the advertisements were relevant, clear and understandable to people they were aimed at, including people operating at lower literacy levels and people in other countries whose first language was not necessarily English.

No incentive was offered to research participants. Despite the lack of incentive being made clear to participants in the Participant Information Sheet (PIS), some people emailed to ask whether they would receive financial compensation for taking part in the interview studies, and they did not pursue the study after finding out that no financial incentive was on offer. It is possible that incentivising participants could have helped to increase numbers and is an option to consider in future research.

Saturation is a qualitative concept but it is poorly defined (Saunders et al. 2018). The concept serves different purposes across the stages of qualitative research and thus, holds different meanings (Saunders et al. 2018). Saunders and colleagues (2018) defined four types of saturation:

- Theoretical saturation – originated from Grounded Theory, it concerns the development of new theoretical categories and is a signal of sampling adequacy.
- Inductive thematic saturation – signifies when no new codes or themes are identified from the data during data analysis.
- A priori thematic saturation – indicates that existing codes or themes are sufficiently represented in the new data.
- Data saturation – when data collection stops because new data is repetitive and offers no new insights above and beyond existing data.

Three types of saturation were relevant to the current research. Data saturation was pertinent to the online group interview study. Recruitment ceased when no new information was forthcoming from participants, indicating data saturation had been achieved. The main messages within the data were being repeated and no novel topics were coming up. At this point, it was decided that conducting further interviews would only reinforce and strengthen existing data and would prove fruitless in terms of identifying anything new beyond what had been discussed within previous group interviews.

Two other types of saturation, inductive and a priori thematic saturation, were applicable to the analyses of qualitative data from the group interviews and the free-text survey responses. Both types were considered at the point of data coding. I used a combination of inductive and deductive approaches to coding, which are described later in this chapter. A priori thematic saturation was achieved when codes that were relevant to the concepts within the analytical frameworks were populated with new data. Inductive thematic saturation was realised part way through the qualitative analyses at the stage when new codes that had been derived earlier on in the analyses had been sufficiently populated and no additional codes were being identified from the data.

It is important to note that decisions around saturation, particularly data saturation, also had to be considered in the context of the wider project and balanced against the timescales that had been specified for the research and recruitment targets.

Sampling

A combination of sampling approaches, including voluntary, purposive and snowball sampling, were employed to recruit adults to two research studies. All are non-probability sampling approaches, meaning study participants were not selected at random from the broader population of people living with skin conditions (Walker 2010). The advantages and disadvantages of these sampling approaches (Bhardwaj 2019; Berndt 2020) are stated below in Table 4.

Table 4: Advantages and disadvantages of sampling approaches used in this research

Sampling approach	Advantages	Disadvantages
Voluntary	Easy, quick and inexpensive to implement. People who choose to participate are more likely to give truthful responses.	Volunteers are unlikely to be representative of the target population, limiting the transferability/ generalisability of findings.
Convenience	Easy, quick and inexpensive to implement.	Risk of sampling error due to poor representativeness.
Snowball	Quick and inexpensive to implement. Useful for recruiting hard-to-reach populations.	Reliance on participants risks low uptake if they do not pass on study information to other potential participants. Risk of sampling bias.
Purposive	Participants are likely to have an appropriate understanding/ experience of the topic, helping to address research aims. Useful for studies seeking to address multiple aims.	Risk of researcher bias. The sample is unlikely to be representative of target population.

People offered to take part in both studies, known as voluntary sampling (Rosenthal 1965). Convenience sampling involves inviting people to take part in a study on the basis that they are easily accessible to those who are conducting the research (Coulson 2015). Snowball sampling is a type of convenience sampling whereby anyone who knows about, or participates in the study, will invite other people they know to take part (Coulson 2015). I relied on the patient organisations who were part of this research, as well as colleagues working in psychodermatology, to share information about the online group interviews and survey with others in their networks. In addition, there was the potential for users of new media platforms to re-share posts about the studies. One example of this is using the re-post function on Instagram. Advertising the survey in the public domain meant that individuals could choose whether to complete the survey and participation was voluntary.

Initially, adults were recruited on a first come first serve basis and were enrolled providing they had completed the registration tasks and were deemed eligible. The goal, however, was to maximise diversity and represent different skin conditions. Therefore, where the number of expressions of interest received exceeded the target number for recruitment, purposive sampling was later employed; I carefully reviewed completed online registration forms before selecting adults to enroll based on their specific demographic characteristics. This meant that not all adults who expressed an interest were able to participate in a group interview. These individuals were informed via email and their permission was sought to keep their contact details on file to contact them about future opportunities related to this research project.

Data collection

All interviews were conducted on an online platform called Zoom, chosen because Cardiff University supports its use for research purposes. Zoom also allows audio and video recordings to be downloaded and saved separately, which was seen as another way to maintain participant confidentiality.

Quantitative data analysis

All quantitative data were imported to IBM SPSS Statistics v27 and descriptive statistics (percentages and frequencies) were calculated to analyse demographic information provided by PPI contributors and research participants and describe the characteristics of these groups. Descriptive statistics were also calculated to determine the number and percentage of respondents who selected each of the response options for the items included in the online survey.

Qualitative data analysis

Qualitative interview and survey data were imported to NVivo 12 Pro. The same thematic approach was employed to analyse qualitative data from the group interview study and the free-text responses to the open ended questions in the online survey following Braun and Clarke's (2022) practical guide for conducting Reflexive Thematic Analysis (TA). TA is a robust and systematic method to coding and identifying themes within data and generating themes in relation to a specific research question (Braun and Clarke 2006; 2014; 2022). It is now referred to as a 'reflexive' method and the role and subjectivity of the researcher is considered integral to knowledge expansion and generation (Braun and Clarke 2019; 2022). TA can be conducted at the semantic or latent level; the former is descriptive and the latter means going beyond the surface of the data to interpret its underlying meaning in the given context (Braun and Clarke 2006; 2022). The six iterative phases of this approach to TA are defined below in Table 5:

Table 5: Braun and Clarke's (2006; 2022) six-step approach to Thematic Analysis

Step		Description
1	Data familiarisation	Data is transcribed, read repeatedly and initial ideas are noted.
2	Initial coding	Preliminary codes are assigned to the data.
3	Identifying themes	Related codes are grouped into potential themes (and sub-themes) with supporting evidence.
4	Reviewing themes	Proposed themes are checked against codes and a thematic map depicting the relationships between the themes is produced.
5	Naming and defining themes	Themes are given a title which captures the essence of the theme and a clear description of themes are developed.

6	Producing the report	Themes are comprehensively and coherently summarised in relation to the objectives and supporting quotes are presented as evidence of each theme.

This approach was selected over other thematic approaches and qualitative data analysis approaches, such as Grounded Theory, because TA offers a flexible approach to data analysis that is not wedded to a particular theory or epistemological paradigm (Braun and Clarke 2014). In addition, TA has been widely used across disciplines, including applied health and psychology research, and is accessible to researchers of all levels (Braun and Clarke 2014). This methodology also supports researchers to analyse data and report findings in a way that can be easily understood by non-academics (Braun and Clarke 2014) and thus, was considered appropriate for the PPI group members, who would also need to understand the results of the interviews to be able to recognise how these data informed the app.

Codes are labels that are assigned to chunks of data which capture the meaning or interpretation of that text (Braun and Clarke 2006). Deductive coding is a top-down approach where an existing framework or code book that is developed a priori are imposed on the data set (Fereday and Muir-Cochrane 2006). Inductive, or open, coding refers to a bottom-up approach whereby codes are identified organically from the data (Fereday and Muir-Cochrane 2006). A combination of deductive and inductive approaches were employed to code the qualitative group interview and survey data, which allowed for a theoretically informed analysis and an opportunity to expand knowledge of existing evidence-based concepts (deductive) whilst also ensuring any novel insights that were relevant to the study aims and objectives were included (inductive).

Fereday and Muir-Cochrane (2006) offer a systematic, six-step approach to combining inductive and deductive approaches to coding and theme development in TA (see Table 6). I followed this hybrid approach, in addition to the Braun and Clarke (2022) methodology, not because the latter was not sophisticated or rigorous enough, as some critics have previously claimed (Braun and Clarke 2014), but rather because Fereday and Muir-Cochrane (2006) provide a worked example of how to conduct a TA using this hybrid approach to coding. This helped to increase my understanding of how to do this successfully, provided a clear process to follow, and, arguably, increased the trustworthiness of the study findings. There was, however, some overlap between the steps involved with these two approaches (see Table 6 below).

Table 6: Overlapping steps involved in hybrid data analysis

Braun and Clarke (2022)	Fereday and Muir-Cochrane (2006)
	Stage 1: Developing code book.
	Stage 2: Testing the reliability of the code.
Phase 1: Data familiarisaton.	Stage 3: Summarising data and identifying initial themes.
Phase 2: Initial coding.	Stage 4: Applying the code book.
Phase 3: Identifying themes.	Stage 5: Connecting the codes and identifying themes.
Phase 4: Reviewing themes. Phase 5: Naming and defining themes.	Stage 6: Corroborating and legitimating coded themes.
Phase 6: Producing the report.	

The following section details how qualitative data were analysed.

Stage 1: Developing the code book.

The code book comprised of concepts from three existing theoretical frameworks that I had used in previous qualitative analyses. This included an analytical framework of the impact of dermatological conditions, which was based on the CSM (Leventhal et al. 1984). I helped to develop this analytical framework for a qualitative concept elicitation study (Pattinson et al. 2022) that was part of a related study in a wider programme of research. From this study five domains of impact that were common across dermatological conditions were identified (Pattinson et al. 2022). However, subsequent field testing found that the financial impacts domain was in itself redundant and the overall number of domains of impact was reduced to four, including life responsibilities (combined with financial impact), physical, psychological and social impacts (Pattinson et al. 2023b). The original analytical framework of impact (Pattinson et al. 2022) was, therefore, adapted to reflect the latest results and included four domains of impact (Pattinson et al. 2023b). The adapted version of the analytical framework formed part of the code book for deductively analysing qualitative data collected from the online group interviews and online survey.

The code book was also informed by the TFA (Sekhon et al. 2017). Concepts of the TFA were included to support the exploration of the perceived acceptability of MiDerm.

The code book also included the COM-B Model (Michie et al. 2011b) and the concepts of capability, opportunity and motivation were coded to understand the barriers and enablers to engaging with the new app.

The concepts from these three frameworks were named, defined and described within the code book (Appendix 4). Open codes were included as the data collection and analysis progressed (Appendix 5).

Stage 2: Testing the reliability of the codes.

The code book was piloted on one transcript to determine the applicability of the codes. I independently applied the code book to the transcript and a colleague (RP) did the same. This collaborative approach to coding not only helped to ascertain the reliability of data coding, but to improve my understanding, and interpret the meaning, of the interview data (Braun and Clarke 2022). We met to discuss the codes and any discrepancies were resolved through team discussion. For example, in instances where the codes differed, we would take it in turns to provide a rationale for the use of a specific code and we would jointly decide whether one or both codes were appropriate, or if there were any other codes that we had missed which might be more suitable. If an agreement could not be reached, the supervisory team were asked to give a final independent opinion. This exercise showed that although different codes had been applied, the codes were usually complimentary rather than contrasting, which, arguably, made for a richer analysis. The code book was then revised where necessary. The process of piloting, discussing and revising the code book was repeated on other transcripts until the frameworks were comprehensive and applicable.

Phase 1: Data familiarisation / Stage 3: Summarising data and identifying initial themes.

In their original guidelines for conducting a TA, Braun and Clarke (2006) explain that transcribing interview audio recordings verbatim is beneficial for data analysis because it helps the researcher to become familiar with the dataset and start to interpret the meaning of it. The audio recordings of the group and individual interviews were transcribed verbatim by an external transcription service called Essential Secretary Ltd and the reasons for this are below.

Whilst it has been argued that verbatim transcription is a fundamental aspect of qualitative data analysis (Halcomb and Davidson 2006), and specific transcription approaches have been developed for some types of qualitative data analysis (e.g., the Jefferson Method for Conversation Analysis), Braun and Clarke advocate that transcription is a helpful, but not necessary, step in TA (Braun and Clarke 2006). Errors in transcription are common irrespective of whether transcription is completed by the researcher or a professional transcriber (Halcomb and Davidson 2006). Verbatim transcription is also a time consuming and resource intensive activity; it typically takes six to seven hours to transcribe a one hour audio recording (Halcomb and Davidson 2006). Halcomb and Davidson (2006), therefore, state that researchers need to balance the benefits of transcription against the time constraints of the research project. Given that I was running the group interview study and an online survey in parallel, time was limited, it was considered more efficient if the interview recordings were professionally transcribed.

Lastly, I conducted all the interviews and completed field notes after each one. Discussing key topics with the participants, and subsequently reflecting on the interviews, all of which helped to expand and deepen my knowledge of the data, facilitating data familiarisation. In addition, I listened to the audio recordings of each interview once and read each transcript twice through, noting my initial impressions of the data. I was confident that, together, these four steps enabled me to get to become familiar with the dataset and start to identify patterns and link key concepts even though I had not transcribed the interviews myself.

I subsequently checked the transcripts for accuracy and any personal data that needed to be anonymised. Transcripts were then imported into NVivo 12 Pro, an established qualitative data management software package (Lumivero 2018). I also uploaded my field notes to NVivo so I could refer to them throughout the analysis.

Phase 2: Initial coding / Stage 4: Applying the code book.

I uploaded the code book to NVivo 12 Pro (Lumivero 2018) to facilitate deductive coding which was applied to all the group interview transcripts and the files containing the comments participants had typed into the chat box on Zoom. I performed inductive coding in parallel so that any relevant information that was separate from the code book was not missed. Coding inductively means to engage with data in a way that gives insight into the meaning of the views and experiences of participants (Braun and Clarke 2022). Latent coding involves moving from the surface meaning to interpreting the underlying meaning of the data and situating it in the context of the individual, other participants and their broader circumstances (Braun and Clarke 2022). Inductive coding, arguably, facilitated data analysis at the latent level by providing a starting point for understanding the meaning of the data and identifying concepts or factors that helped to contextualise and further explain the realities of the participants.

Checking coding reliability is an important step because it provides a gauge of how thoroughly, accurately and consistently the researcher has coded their data and the degree to which the researcher's subjective views and experience influence the coding process (Braun and Clarke 2019). Sections of each transcript were, therefore, independently coded by a colleague (RP or CD) and codes were compared. Involving a colleague experienced in qualitative TA gave me confidence in the quality and precision of the coding and, arguably, made the coding process more rigorous overall. Coding collaboratively also helped to cement my understanding and interpretation of the data (Braun and Clarke 2022). Any coding discrepancies were resolved through discussion, in the same way as outlined above. Any new codes that were identified were included in a separate section of the code book in NVivo so that they could be factored into the analysis. The evolution of codes and development of the codebook throughout the process of qualitative data analysis is recognised as good practice in reflexive TA because it helps researchers to connect and, potentially, collapse, related codes where necessary, and to continually shape and build on their earlier interpretations of the data (Braun and Clarke 2022).

Phase 3: Identifying themes / Stage 5: Connecting the codes and identifying themes.

Themes are overarching concepts comprised of groups of related codes. I searched for patterns in the data and identified and grouped any codes that were related into overarching themes. Participant quotes that were illustrative of a theme were highlighted as evidence of that theme. I regularly articulated potential ideas for themes to my supervisors, who acted as a sounding board and challenged me to justify code groupings and explain the proposed themes and the relationships between them.

Phase 5: Reviewing themes / Stage 6: Corroborating and legitimating coded themes.

Once I had organised themes and sub-themes, my colleagues (CP, CB and RP or CD) independently reviewed the proposed themes and provided feedback. We met to discuss the themes and resolved any issues as a team. Themes and sub-themes were revised where necessary before theme titles and descriptions were agreed.

Phase 6: Producing the report.

I performed a final review of the themes and supporting evidence that were derived from the data. I wrote up the key findings in relation to the study aims and objectives and situated themes in the broader scientific literature. Quotes are presented in support of the findings and the participants' skin condition, country of residence and interview group (G) number are included for context.

Patient and Public Involvement

Behaviour change interventions often do not achieve the intended reach, effectiveness or impact (Byrne 2019). Poor engagement from key stakeholders in the research that underpins behaviour change interventions is one reason for this (Byrne 2019). Stakeholder engagement has been defined as:

> *"the active involvement of public, patients, health professionals, and other decision makers throughout the research process" (Byrne 2019, p. 291)*

Engaging key groups across all stages of research can help to ensure the reach, relevance, appropriateness and impact of the research for the target audience and is, therefore, now considered best practice (Byrne 2019).

Patient and Public Involvement (PPI) refers to the active inclusion of members of society in the development, delivery and evaluation of health services and research (NIHR, 2015). PPI concerns research done *with* or *by* people from the target population, or a range of key stakeholders, and this differs to Patient and Public Engagement whereby lay individuals partake in research studies and research is done *to*, *about* or *for* them (Muller et al. 2019).

The value of PPI in health research is now widely recognised, and its role and prominence are growing steadily (Heague et al. 2022). PPI has facilitated a shift away from research that is entirely researcher-led to a more person-centred approach and the voices and values of patients and members of the public are represented (Muller et al. 2019). The views of the target population should, therefore, be considered across the stages of intervention planning, development, optimisation and evaluation (Muller et al. 2019). It has been recommended to use PPI and qualitative research methods in tandem to increase the quality and diversity of feedback on behaviour change interventions as they are developed, and optimise engagement with them once implemented (Muller et al. 2019).

Involving patients or members of the public in research can also present challenges, potentially that the public lack competence to carry out research activities (Heague et al. 2022). However, while they are not experts in the process of conducting research, they have expertise related to the phenomenon of interest (e.g., health condition, social group) because of their lived experiences of it, which makes them well placed to offer alternative perspectives on research which researchers themselves may be unaware of (Heague et al.

2022). It is the responsibility of researchers to manage their own expectations, and draw on a range of communication methods to ensure mutual engagement and understanding, or offer training for stakeholders, if necessary (Heague et al. 2022). Managing the expectations of PPI contributors can also be difficult and researchers should be clear from the outset about what is realistic and achievable (Heague et al. 2022). Another challenge is the time required to engage a diverse group of lay research partners, including people from underrepresented groups, as well as the effort needed to sustain these relationships once established (Heague et al. 2022). Researchers should allow sufficient time to foster rapport and trust initially to keep PPI contributors engaged long-term. Finally, the boundaries between PPI and qualitative research are sometimes blurred, leading to some researchers prioritising one over the other and missing out on the potential combined benefits (Muller et al. 2019).

On balance, the benefits of PPI in research outweigh the associated challenges and was, therefore, used to develop MiDerm.

Unlike research participants, members of the PPI group were offered a financial incentive, not as a tactic to attract interest and meet recruitment targets, but rather to recognise their valuable contribution of time and experiences to this research. It was agreed that PPI members would not be paid per hour and would instead receive a financial ‘gift’ (local equivalent of 200 euro) that would be paid to them in two equal instalments by our Finance team.

The same process was adopted to transfer the financial gifts to the five patient organisations who agreed to support this research. Each organisation received the local equivalent of 300 euro overall, which was paid in two equal instalments at the end of the second and third year.

The PPI group characteristics are summarised in Appendix 6. However, in 2022, one person with vitiligo withdrew without giving reason. Another member, also with vitiligo, stopped replying to emails after receiving the first instalment of their financial gift. Efforts were made to replace these individuals without success.

PPI contributions. Members of the PPI group contributed to a range of research activities across the project, including:

- Reviewing study materials (e.g., survey items and interview topic guides).
- Taking part in pilot interviews.
- Promoting the three primary research studies, mainly online via new media platforms.
- Attending group meetings.
- Reviewing manuscripts for publication.
- Suggesting potential names for the digital intervention.
- App development and design.

Four PPI meetings were held on Zoom over the three-year project. The meetings focused on:

1. Welcoming the group and introductions.
2. Gathering feedback on study materials.
3. Gathering feedback on study materials.
4. A project update involving the research funder.

The first and fourth meeting involved activities relevant to app development. These activities were interactive and involved using the free version of Mentimeter, an online platform offering an array of features designed to enhance the look of, and engagement with, presentations. I used the ‘word cloud’ feature to gather insights and ideas from members, and a polling feature to gauge the preferred name(s) for the app.

The activities helped build rapport with the group members, and for the members to develop relationships with one another. The results of these activities were carried forward to inform the topic guide for the group interviews. The results from the Mentimeter activities are presented in Appendix 7.

Meetings two and three served the same purpose of gathering feedback on materials for the online survey and group interviews. PPI contributors were invited to review drafts of the survey and interview topic guide to ensure the items and prompts were comprehensive and worded and structured appropriately. Copies of the survey and topic guide were emailed to individuals who agreed to review them. Two online meetings were scheduled on 21/03/2022 to discuss feedback on the survey. Both meetings were hosted on Zoom and were audio recorded. Five people attended a meeting and two people did not attend on the day and gave no reason as to why. One person provided written feedback via email. Feedback on the topic guide and survey is summarised in Appendices 8 and 9, respectively.

The last meeting was hosted in June 2023. Five PPI contributors and three members of staff from the funding organisation (Eucerin, Beiersdorf AG) attended this meeting, along with two other members of the research team (CB and CD). The purpose of this meeting was to:

- Deliver a project update.
- Introduce the funder to the group.
- Gather PPI feedback on the app wireframes and the name MiDerm.
- Determine the preferred logo and colour scheme for the app.

This meeting was also interactive, and used Mentimeter to determine the preferred logo and colour scheme for the app. The results from these Mentimeter activities are presented in Appendix 7. The name MiDerm, the colour scheme and logo of the app were finalised based on the feedback gleaned from this meeting.

PPI contributors supported participant recruitment by sharing the survey details among their networks.

The PPI group were offered the opportunity to contribute to and review the two manuscripts detailed the procedures and findings of these studies, but no one agreed.

Some members of the PPI group supported with app design and content development. These contributions are described in the context of intervention development in Chapter 8.

Research ethics and governance

The health and safety of the people who participated in and contributed to this research was a key priority. This research was, therefore, conducted in accordance with the UK Policy Framework for Health and Care Research (Health Research Authority 2023).

Ethical approval for this research was obatined from the School of Healthcare Sciences Research Ethics Committee (SREC: REC807) in October 2021. The original application covered procedures for the systematic review, establishing the PPI group and the online group interviews and survey studies.

There were several ethical considerations that were accounted for during this research. A PIS and consent form were peprared for each study. The PIS outlined the purpose of the study, potential risks and benefits of participation, participants' rights, and procedures for recruitment as well as data collection, analysis, storage and protection. All participants were encouraged to take time to read these documents before deciding whether to participate and were required to sign and return consent before they were enrolled. This was to ensure all participants were making an informed decision about their role in this research.

All participant data, including consent forms, were electronic. Personal data were kept confidential and anonymised where possible. Participants were reminded of this and were informed that confidentiality would only be compromised should an individual indicate they had or intended to harm themselves or others.

Partipant data were managed and stored in accordance with Cardiff University Records Retention Schedule (2023). Data were stored in separate password-protected folders on One Drive, a secure University online server, for a minimum of 15 years. For example, consent forms were stored in separate folders from interview transcripts and audio recordings. A separate password-protected document was created that contained information that allowed me to match the data files with the participant. The same considerations and procedures were followed for data from PPI contributors and patient organisations who consented to support this research.

The risk of harm to research participants was low, but precautions were taken to ensure their health and safety. Participants were given and reminded of their right to withdraw from the research (up until the point their data were anonymised) at any time without giving reason. The PIS also detailed information about services for participants in the UK to contact should they become distressed as a result of taking part in this research. Participants outside of the UK were advised to contact me and I would liaise with patient organsiations in their country to identify appropriate local services.

Chapter 4: Mixed methods systematic review of psychological interventions in dermatology

Introduction

Chapters one and two reviewed the evidence that skin conditions carry a substantial psychological burden and support for patients is generally lacking or is limited both in terms of availability and quality. Evidence shows that patients may require additional psychological support and justify the development of a new psychological intervention, delivered via digital technology, that aims to support adults to self-manage all aspects of their skin condition(s) effectively. However, little is currently known about the types of psychological interventions that are delivered via digital mediums in dermatology. More specifically, it is unclear whether interventions of this kind are effective or acceptable to the people who use them.

Systematic reviews are a type of evidence syntheses that are commonly used to review, appraise and synthesise existing bodies of empirical evidence against criteria defined *a priori* to comprehensively answer a specific research question(s) (Siddaway et al. 2019). They are considered the gold-standard approach to reviewing research evidence as they follow rigorous and transparent methods that help to minimise bias, facilitate reproducibility and ideally, generate reliable findings that can be used to draw robust conclusions and inform evidence-based decisions on the topic of interest (Siddaway et al. 2019).

To date, no systematic review of digitally delivered psychological interventions in dermatology has been published. Therefore, I conducted a mixed methods systematic review of digital interventions to support the psychological health and well-being of adults living with dermatological conditions.

The review aimed to answer two research questions:

- What digital interventions can support the psychological health and well-being of adults living with skin conditions?
- What are the views and experiences of adults with skin conditions on digital interventions designed to support their psychological health and well-being?

And address the following key objectives:

- Identify psychological interventions for adults with dermatological conditions that are delivered by digital platforms.
- Determine the effectiveness of these interventions for improving psychological (cognitive, emotional and behavioural) outcomes.
- Explore the views and experiences of adults with dermatological conditions who receive or access these interventions.

Our mixed methods systematic review was published in November 2022 as part of a special article collection titled ‘Psychosocial Aspects of Skin Conditions and Diseases’ in Frontiers in Medicine (Hewitt et al. 2022c). The published article is included in Appendix 10. Table 7 lists the additional ‘supplementary’ files that are mentioned in the published systematic review paper. These additional ‘supplementary’ files are all included in their own appendix (see appendices 11-21). The article screening and selection process is presented in an adapted version of the PRISMA 2020 flow diagram (Page et al. 2021) in Figure 9.

Table 7: List of appendices relevant to the mixed methods systematic review

Appendix #	Title	Description
10	Mixed methods systematic review of digital psychological interventions in dermatology	Article published in Frontiers in Medicine
11	Examples of primary and secondary outcomes	A non-exhaustive list of examples of primary and secondary outcomes that were relevant to the systematic review
12	Search strategy for MEDLINE (Ovid)	A list of search terms that was run in the MEDLINE (Ovid) database and other specified databases to identify relevant literature
13	Screening tool	A tool including the eligibility criteria for the systematic review. The tool was developed to support the reviewers to decide which articles to include and exclude
14	Code book	A list of codes that was used for the purpose of a content analysis to capture and synthesise data on study and intervention characteristics and results relating to the main aims of the review
15	Characteristics of studies included in the systematic review	Contains key information about the studies reviewed, including skin condition, country, study design, sampling, recruitment, primary outcomes and follow up period
16	Sample sizes, attrition and participant demographics (gender and mean age) of studies reviewed	A table containing sample sizes, attrition rates and gender and mean age of the participants involved in the studies reviewed

17	Outcome variables and measurement tools reported in the studies reviewed	A list including the outcomes studied, and the measures that were used to assess these, for each study included in the review
18	Critical appraisal of methodological quality of studies reviewed	Results of critical appraisal
19	Rankings of the effectiveness and meaningfulness of evidence reviewed according to the JBI levels of evidence and grades of recommendation working party (2014)	Rankings of effectiveness / meaningfulness of studies reviewed
20	Characteristics of interventions reviewed according to the TIDieR checklist and guide adapted from Hoffman et al. (2014)	Contains key information about the interventions reported by the studies included in the review
21	Results for effectiveness of digital psychological interventions by outcome	States results of intervention effectiveness that were reported in the articles included in the systematic review

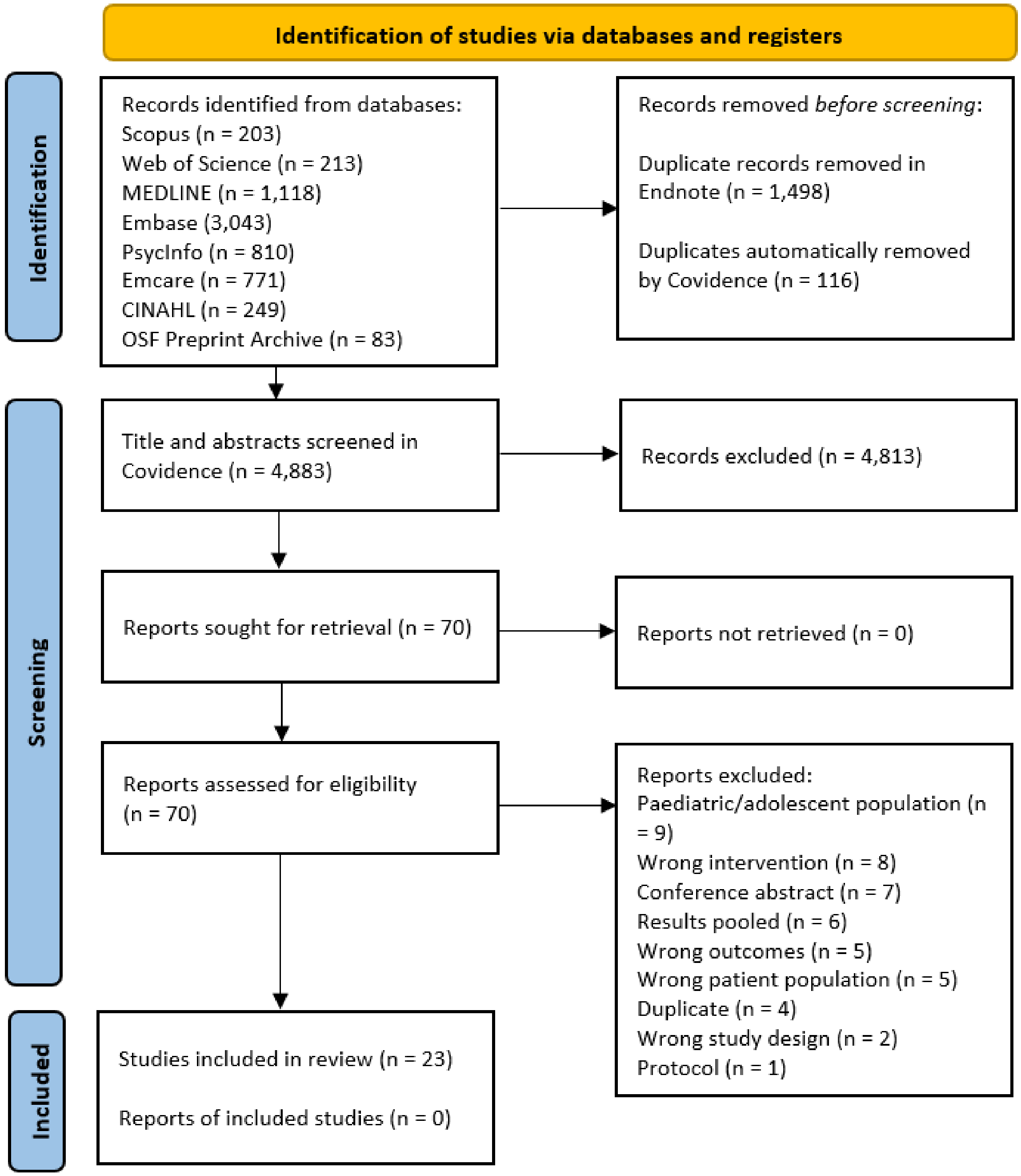

Figure 9: Screening process depicted in the PRISMA 2020 flow diagram (Page et al. 2021).

Overview of mixed methods systematic review

Our review identified a diverse range of existing digital psychological interventions, mainly ones that are delivered via the internet, for some dermatological conditions, mostly psoriasis followed by eczema. It provides preliminary evidence that interventions delivered in this way can positively influence some patient (i.e., personal knowledge of skin conditions and their management, mood, QoL, disease severity in the short to medium term) and clinical (i.e., the therapeutic relationship) outcomes. Digital interventions that focus on improving knowledge, emotional well-being and stress, have support. However, there was substantial heterogeneity and varying quality in the literature and much of the evidence was insufficient and inconsistent. Thus, the conclusions surrounding intervention effectiveness are, at best, tentative. In addition, this review emphasises that whilst interventions of this kind are, to some extent, acceptable to patients, there are clear barriers to their use and input from users was generally lacking or poorly reported.

Current evidence underscored the need for quality and interdisciplinary research to develop and test complex digital psychological interventions targeting a broader range of psychological factors, specifically health behaviours. Developers need to prioritise the patient voice and context and involve the target group across all stages of intervention development to overcome barriers and maximise future use. The findings of this systematic review support the co-development of a new theory-based DBCI with input from adults living with skin conditions.

Identified next steps in the context of this research

This mixed methods systematic review makes clear that further work to design and test digital psychological interventions with input from patients is needed. The field specifically requires more qualitative research to ensure future interventions are feasible, appropriate, meaningful and effective (Jordan et al. 2019) for people with a broad range of common and rare dermatological conditions (Hewitt and Bundy 2021) and to further explore barriers and facilitators to their use and psychological factors (e.g., personal control, acceptance, self-efficacy and knowledge) which might explain the mechanisms of action. Therefore, qualitative research involving adults with skin conditions was a priority for this research.

The systematic review included several studies that focused on treatment behaviours. Whilst treatment adherence and skin protection are important for managing dermatological conditions (Feldman et al. 2017), other modifiable dietary and health behaviours, such as smoking, alcohol consumption, and poor sleep are associated with some, mostly inflammatory, dermatological conditions (Sawada et al. 2021), and increased risk of co-morbidities, including CVD (Marshall et al. 2016; Ingram 2018; Masson et al. 2020). This showed that digital interventions addressing a variety of health behaviours were needed to support a holistic and effective approach to patient self-management. Thus, MiDerm was developed to address psychological processes, specifically health behaviours and behaviour change.

Many of existing psychological interventions in dermatology included an educational component. However, it is recognised that the provision of information alone may not be sufficient for eliciting behaviour change as other psychological factors, including personal capabilities, opportunities and levels of motivation, influence behaviour (Michie et al. 2011b). In dermatology, for example, beliefs about illness and treatments can influence treatment adherence (Feldman et al. 2017). Digital interventions should, therefore, address the psychological processes (beliefs and emotions) which underpin adherence and other related health behaviours in dermatological treatments (Feldman et al. 2017). This finding emphasised that whilst the focus of MiDerm was to promote health behaviour change, the intervention must also account for the factors that influence this.

Whilst intervention development per se was not the focus of this systematic review, it was not always clear from the papers included if or how theoretical frameworks contributed to intervention development. However, it is recommended that DBCIs are informed by theory in order to determine and test mechanisms for change and ensure they meet the needs and preferences of the target group (Michie et al. 2017). The current development, therefore, adopted a theoretical approach.

These findings and considerations informed the development of MiDerm.

Literature that was published since 2022 is discussed in Chapter 9 and summarised in Appendix 22.

Chapter 5: Online group interview study

Introduction

The systematic review chapter highlighted that digital technology offers a useful medium for delivering psychological support to adults with skin conditions. The interventions reviewed were predominantly web-based, educational and targeted specific conditions and treatment-related behaviours. The review showed that digitally delivered interventions can improve some outcomes including knowledge of dermatological conditions and their management, mood, quality of life, the therapeutic relationship and disease severity in the short-term. However, substantial heterogeneity in the literature meant overall conclusions of effectiveness were, at best, tentative.

Since the systematic review was completed, more studies on DBCIs have been published and show promising results for effectiveness, but these are also limited to adults (Gudmundsdóttir et al. 2022) and young people with eczema and their parents and carers (Santer et al. 2022), plus adherence to psoriasis treatment (Cline et al. 2022) or photoprotection behaviours in people with Xeroderma Pigmentosum (XP; Walburn et al. 2023).

There remains a need for new digital interventions in both common and rare skin conditions targeting psychological factors, especially the modifiable health behaviours known to influence skin conditions and associated comorbidities, such as CVD. Current evidence therefore justified the development of the MiDerm app, a novel DBCI for adults with skin conditions.

The findings of the systematic review also suggested that digitally delivered interventions may be acceptable to people living with some dermatological conditions, mainly psoriasis and eczema, who considered them convenient and useful for improving knowledge, personal control and facilitating emotional regulation and acceptance, despite some technical and personal barriers. However, qualitative research involving patients was generally lacking or poorly reported, and it was not always clear if or how patients contributed to intervention development. These findings were consistent with those of a recent scoping review of qualitative methodology in dermatology (Foster et al. 2022), which reported that use of qualitative methods in the development of educational materials was limited – only two studies involving health professionals were identified. Qualitative research should inform new interventions in dermatology (Foster et al. 2022). Furthermore, engaging key stakeholders and understanding the perspective of prospective users is now considered central to developing and evaluating complex interventions, as outlined in the latest MRC guidance (Skivington et al. 2021). Thus, dermatology researchers should prioritise the patient voice when developing new digital interventions to ensure they are relevant for the target group and work as intended (Hewitt and Bundy 2021).

The idea of incorporating the perspective of the people who will use the intervention is the cornerstone of the Person-Based Approach (PBA) to intervention development (Yardley et al. 2015b; Morrison et al. 2018), which was established to facilitate the systematic planning, evaluation and implementation of behavioural interventions designed to support people to self-manage their general health or illnesses effectively. The PBA champions the use of qualitative research to gain a rich understanding of the target population, their context and views on potential behavioural components of an intervention, with a view to defining specific 'guiding principles' (i.e., the objectives and features of the intervention) that steer the iterative development process. Use of the PBA from the outset can help to ensure that new interventions are appropriate, practical and meaningful for the target group, ultimately helping to maximise usage and improve outcomes following implementation. Further discussion of the PBA can be found in Chapter 8.

This chapter qualitatively explores the views, experiences and needs of adults living with skin conditions to determine whether the idea of MiDerm is acceptable to this group and gather information that will inform its content, design and use. The three following objectives met this aim:

1. Understand the impact of skin conditions and how adults self-manage their skin condition(s).
2. Explore what psychological support is currently available to adults with skin conditions beyond standard medical care.
3. Determine the perceived acceptability of the MiDerm app for adults with skin conditions, plus potential barriers and facilitators to use.

The present qualitative study is one of two studies that were conducted in Phase 1 of this project.

Methods

Design

A qualitative study involving synchronous, online, semi-structured, group interviews.

Participants and sampling

English-speaking adults (aged ≥ 18 years) living with a skin condition(s) anywhere in the world and had access to the internet were eligible to participate in this study, part of the first phase of intervention planning.

Sampling

Voluntary, convenience and purposive sampling were employed to recruit participants. The two former approaches are both described in Chapter 3. Purposive sampling is described below as this approach was unique to the group interviews.

People offered to take part (voluntary) and were then invited to join a group interview because they possessed specific demographic characteristics relevant to the study aims and objectives; this is known as purposive sampling (Campbell et al. 2020). Purposive sampling is beneficial because it allows for the selection of individuals who possess characteristics that will most likely enable them to share views, ideas and experiences that are relevant to the research topic (Campbell et al. 2020). It is also useful when time and resources for research are limited (Campbell et al. 2020).

Initially, participants were recruited on a first come first serve basis and were enrolled to the study providing they had completed the online registration form and were deemed eligible. As the study progressed, purposive sampling enabled diversifying the sample to maximise representation of skin conditions and other demographic factors. The use of targeted advertisements supported purposive sampling in that advertisements were directed at people with specific characteristics who were less forthcoming in the earlier stages of recruitment but who it was important to represent within the research. For example, more women than men volunteered to take part in the online group interview study and thus, advertisements targeting males were created to try and increase interest among this group of people.

Materials

Online registration form

I created the online registration form on the Jisc Online Survey platform to gauge the level of interest and streamline the recruitment process. The form included study details, an e-consent form, six demographic questions on age, gender, ethnicity, country of residence, skin condition and patient organisation membership. Contact information (name and email address) was required for interview scheduling. The online format meant people from a range of backgrounds and geographical locations had the opportunity to join the study and was also time, cost and resource saving in comparison to issuing hard copies (Coulson, 2015).

Semi-structured interview topic guide

The guide comprised four sections: (1) the impact of skin conditions; (2) patient self-management; (3) existing types of additional support that are available to patients in addition to standard medical care; and (4) the perceived acceptability of a complex intervention delivered via a smartphone app. Items were developed based on the study aims, extant literature, my clinical and academic expertise and that of my supervisors. Where relevant, concepts from the three theoretical models/frameworks were used to help develop a better understanding the cognitive, emotional, social and contextual factors that might influence behaviours related to the self-management of skin conditions and app use:

- CSM (Leventhal et al. 1984).
- TFA (Sekhon et al. 2017).
- COM-B (Michie et al. 2011b).

Topic guide items and their related theoretical concepts are presented in Appendix 23.

I structured the topic guide in a way that enabled me to cover key questions and facilitate discussion on relevant topics, and promote a positive and convivial interaction with interviewees and between group members (Roberts 2020). Each interview began with broad questions about the impact of skin conditions with specific prompts to focus the discussion and further probe topics raised by participants throughout the interview (Roberts 2020). Items included in the topic guide were structured as open questions to encourage the participants to elaborate, elicit rich responses and avoid one-word answers (Roberts 2020).

Closed questions were asked occasionally as a precursor to an open question or when clarification was needed.

Visual prompts

According to Glegg (2019), visual tools are commonly used within qualitative interviews and serve the five following purposes:

- Effect change (e.g., increasing awareness, capability or confidence in participants).
- Enable communication between the interviewer(s) and interviewee(s).
- Facilitate the relationship between the interviewer(s) and interviewee(s).
- Represent data in a way that is easy for interviewees to understand and digest.
- Enhance the quality and validity of data.

Orr and colleagues (2020) argue that using visual tools can enhance qualitative research in several ways, including:

- Removing the hierarchy and facilitating rapport between the interviewer and interviewee(s).
- Breaking the ice and minimising potential power imbalances between participants.
- Supporting participants with existing health conditions or disabilities to think about and convey information that they may otherwise find difficult to articulate verbally.

I created two visual prompts in Microsoft PowerPoint and utilised these within this study. The first focused on the topic of impact and included seven labels and images depicting common impacts (i.e., physical, psychological, social, financial, daily activities, educational and occupational) that people with skin conditions have previously reported in our groups' work on impact (Pattinson et al. 2022). This visual prompt was introduced to:

- Clearly and simply summarise known impacts of skin conditions (represent data).
- Help make participants feel at ease and build rapport (facilitate the relationship).
- Increase the participants' confidence to discuss potentially sensitive topics and share their personal views and experiences with the group (enable communication).
- Facilitate probing and foster individual reflection and recall, as well as group discussion, on the topic of impact (improve the quality and validity of data).

Coulson (2015) states that group dynamics are an important factor to consider when conducting online group interviews. Coulson explains that early concerns about the online environment not being conducive for participants building relationships with one another were generally unfounded, and the opposite is true and rapport can build quickly in online settings, even in the absence of visual and aural cues (Coulson, 2015). However, people with skin conditions often report feeling embarrassed and anxious in public and social settings because of their skin (APPGS, 2013) and I felt concerned that some participants might lack confidence to share their views and experiences with others in the online setting because of this. Therefore, I presented the first visual prompt at the start of each interview to encourage the participants to discuss openly the ways in which their skin conditions impacted their life and to minimise any potential power imbalances within the groups (Orr et al. 2020).

The second visual prompt displayed potential names for the app which had been suggested by the researcher, the supervisory team and the PPI group. I presented this slide towards the end of the interview to:

- Give participants the chance to offer an opinion on the existing ideas (enhance the quality and validity of data).
- Provide an opportunity for participants to consider and suggest alternative names (enable communication).

In qualitative research, ‘leading’ questions that direct the person responding towards a specific or desirable answer should be avoided (Dicicco-Bloom and Crabtree 2006). It was important that the visual tools prompted discussion among the participants without leading them to certain answers. The content and design of the visual prompts avoided the issue of leading participants in two ways. Firstly, I explained to the participants that although the impacts displayed were found in our research to be common across many skin conditions (Pattinson et al. 2022), they may not necessarily be relevant to everyone (Glegg 2019) and there may be other ways that skin conditions affect people that were not captured on the slide. Also, whilst there was a small risk that the participants might not understand the meaning of the images included in the prompt (Glegg 2019), I resisted explaining the different impacts that were depicted on the slide, allowing the participants to form their own interpretation of the images and words they saw on the screen.

The two visual prompts are presented in Appendices 24 and 25.

Field notes

Reflecting on qualitative interview is considered best practice (Roberts 2020; Braun and Clarke 2022). Focusing on the quality of the interview, the questions asked, their interview style and considering how these learnings can inform and improve subsequent interviews (Roberts 2020; Braun and Clarke 2022) can add value to data collected.

Reflexivity refers to how researchers perceive their personal position influences the qualitative research process and their relationship with participants who are involved (Dodgson 2019; Braun and Clarke 2022). Qualitative research is contextual and subjective, so it is important that researchers are aware of, and acknowledge, how their personal beliefs, assumptions, biases, feelings and experiences might play a role in the research they are conducting, from the inception of research ideas and questions, through to data collection, analysis and reporting (Dodgson 2019; Braun and Clarke 2022). Undertaking reflexive practice can help to increase the credibility of qualitative research and understanding of the findings (Dodgson 2019; Braun and Clarke 2022).

Therefore, a field notes template was developed to help summarise my experience of the group interviews and elicit any thoughts that arose from the interviews (e.g., ideas for codes and themes and potential biases) (Roberts 2020). These reflections informed changes to the topic guide and helped to identify topics to probe further in the remaining interviews (Roberts 2020). The field notes template is included in Appendix 26.

Procedure

Recruitment

Some aspects of the recruitment strategy were common across this research, see Chapter 3. Study advertisements included the Unique Resource Locator (URL) and anyone who believed they met the eligibility criteria could access the link and complete the online registration form. It was only possible to proceed to the demographic questionnaire if the individual selected ‘yes’ responses for all eight questions in the e-consent form.

Participants were offered a choice of interview slots via email and subsequently contacted to confirm the date and time of their group interview and the details of how to join the online meeting platform. The online registration form opened on 23/02/2022 and closed on 30/06/22 following the final group interview.

Recruitment ceased when saturation had been achieved (see Chapter 3 for more information).

Online group interviews

Online group interviews were selected as a method for data collection. In research, the terms ‘group interviews’ and ‘focus groups’ are sometimes used interchangeably to refer to group discussions (Gibbs 2012). At the most basic level, both serve the purpose of hosting an organised discussion to gather multiple perspectives on a research topic, but there are nuances in their definitions and what they entail on a practical level (Gibbs 2012).

Group interviews are used to gather a range of individual opinions on a matter, often in a didactic fashion between the interviewer and interviewees (Gibbs 2012). They follow a question and answer format led by a group moderator (Cox et al. 1976). They provide an opportunity for several people in the same setting to express their personal opinions on a topic (Coulson 2015), and can be used for exploratory purposes, as a pretest for further research, or in conjunction with other research methods to triangulate data (Frey and Fontana 1991). They can support the validation of data gathered from individual interviews, or in real time if participants share the views or experiences during group discussions (Frey and Fontana 1991). The practical advantage of bringing multiple people together at the same time is less costly than conducting individual interviews and participants can prompt each other to delve deeper into a topic, minimising the influence and contribution of the interviewer in the process (Frey and Fontana 1991). However, they do require interviewers to be able to manage group dynamics and there are the issues of social desirability bias, conformity and the possibility of group conflict, which researchers must be mindful of and prepared to deal with (Frey and Fontana 1991). Ultimately, group interviews have great potential to support research in the social and behavioural sciences, but they are often overlooked as a research method (Frey and Fontana 1991).

Focus groups have been adopted within marketing as a method for conducting market research since the 1950's (Cox et al. 1976) and are now widely used across disciplines, including psychology, to conduct qualitative research (Coulson 2015). Frey and Fontana (1991) explain that focus groups are a type of group interview, but what constitutes a focus group has been a topic of debate and many definitions exist (Coulson 2015). Focus groups have been defined as more interactive and open discussions that prioritise the opinion of the group as a whole, as well as those of individuals within the group (Gibbs 2012). Generally speaking, focus groups are recognised as a method for facilitating interaction between members of a group and eliciting their individual and collective views on a topic (Coulson 2015). Coulson (2015) outlines the distinguishing features of focus groups, insinuating that they typically involve participants sharing, debating and negotiating opinions on a topic, meaning the data are a product of these exchanges and likely reflect the group opinion.

Whilst the intention was for participants to share their perspectives and start a conversation around living with a skin condition, the intention was not to enter participants into a discussion where personal views and experiences potentially could become the subject of debate and individuals felt that they had to succumb to or agree with the position of others in the group (Coulson 2015). Ultimately, this led to the decision to run group interviews instead of focus groups in this study.

A semi-structured topic guide was used to direct discussion, including both open and closed questions, as well as prompts and follow-up questions, to understand the topic of interest (Adams 2015; Gill and Baillie 2018). Whilst the group interviews were guided by a topic guide containing a set of pre-specified questions, the semi-structured approach allowed to room to veer away from the topic guide if participants raised a novel point that was relevant to the study aims and objectives, whilst still allowing the interviewer to maintain a degree of control over the conversation (Stuckey 2013). They did not follow a rigid structure whereby the interviewer posed a question and interviewees provided an answer before moving onto the next question, which is consistent with a structured interviewing approach, nor were they completely non-directive or unstructured (Stuckey 2013).

I conducted the group interviews via Zoom (see Chapter 3). Running interviews online offers several benefits, many of which offset the limitations associated with a face-to-face format

(Coulson 2015). Utilising digital technology as a platform for hosting group interviews affords many practical benefits, which stand irrespective of the type of group interview being conducted. These include lower costs and greater convenience, as interviews can be set up to take place at a time and virtual location that works everyone, and an opportunity to reach and engage hard-to-reach populations (Coulson 2015). In addition, the online format allows individuals to get involved and remain anonymous, if they wish to, which can facilitate more open and honest discussions on about sensitive topics (Coulson 2015). Overall, the benefits outweighed the potential disadvantages of attrition and managing challenging group dynamics (Coulson 2015) in this research.

At the beginning of each interview, participants were asked to use the 'raise hand' function in Zoom to respond to a question and were given the option to type additional comments in the chat box, if they wished. I presented the visual prompts to the participants using the 'share screen' function at the appropriate time. The interviews were audio and video recorded. Transcription procedures are detailed in Chapter 3. I completed field notes for each interview.

Data analysis

A qualitative reflexive TA was conducted in accordance with guidance by Braun and Clarke (Braun and Clarke 2022) using a latent TA from an essentialist/realist perspective to reflect the participants' experiences of living with and managing skin conditions and their views and ideas for the new smartphone app (Braun and Clarke 2006). The procedure is described in Chapter 3.

Results

In total, 103 people registered to participate in the present study, although one person did not provide consent and was excluded. Email invitations were sent to 102 people and 61 (59.8%) responded. Two people (3.3%) expressed an interest in participating but did not complete the online registration form and thus, were unable to participate. Four people (6.6%) scheduled an interview but cancelled later. Twelve people (19.7%) scheduled an interview but did not attend.

Overall, 43 people (70.5%) participated in this study. Eight group interviews were completed, with the group sizes ranging from two to seven participants. Most participants identified as female (69.8%), white ethnicity (83.7%), and lived in England, UK (67.4%). The average age was 44.63 (*SD* = 3.02). Most participants had vitiligo (27.9%) followed by psoriasis (25.6%) and were not affiliated with a patient organisation (67.4%). The average number of years lived with a skin condition was 28.02 (*SD* = 15.92). Sample characteristics are presented below in Table 8.

Six themes were derived from the data. The titles of themes and related sub-themes are stated in Table 9. The relationships between these are depicted in a thematic map (Figure 10).

The rest of this section includes detailed summaries of the themes and sub-themes with key supporting quotes. All quotes that were deemed pertinent to each theme are included in Appendix 27.

Table 8: Sample characteristics for online group interview study.

Categorical demographic variable	***N***	**%**
Gender		
Male	13	30.2
Female	30	69.8
Ethnicity		
White	36	83.7
South Asian	2	4.7
Other	5	11.6
New Zealand European/Pacific Islander	1	2.3
White and Southeast Asian	1	2.3
Anglo Caribbean	1	2.3
Mixed heritage	1	2.3
Indian	1	2.3
Skin condition		
Psoriasis	11	25.6
Eczema	4	9.3
Vitiligo	12	27.9
Hidradenitis suppurativa	1	2.3
Pachyonychia congenita	1	2.3
Hyperpigmentation	1	2.3
Ichthyosis	9	20.9
Netherton syndrome	2	4.7
Ichthyosis vulgaris	2	4.7
Llamella ichthyosis	2	4.7
Epidermolytic hyperkeratosis	1	2.3
Type not specified	2	4.7
Multiple skin conditions	4	9.3
Post-hypertrophic cystic acne scarring, hyperpigmentation	1	2.3

Seborrheic dermatitis, psoriasis	1	2.3		
Seborrheic dermatitis, vitiligo, eczema	1	2.3		
Acne, rosacea, hidradenitis	1	2.3		
Country				
England	29	67.4		
Wales	9	20.9		
Scotland	1	2.3		
Ireland	1	2.3		
USA	1	2.3		
Demark	1	2.3		
Sweden	1	2.3		
Patient organisation member				
Yes	14	32.6		
No	29	67.4		
Continuous demographic variables	Mean	*SD*	Minimum	Maximum
Age (years)	44.63	13.02	25	69
Years lived with condition*	28.02	15.92	4	68

Table 9: Themes and sub-themes for online group interview study

#	Theme	Sub-theme(s)
1	Visibility underpinning life course impairment	Cumulative life course impairment (CLCI) and vulnerable patient sub-groups.
2	Seeking control amid uncertainty	Limitations to peoples' understanding of causal factors.
		Regaining control through understanding, self-management and acceptance.
3	Existing support for people with skin conditions	Dismissal by health professionals.
		Issues with treatment and healthcare services.
		Psychological support is beneficial but limited and barriers exist.
		Social support is important but limited.
		Poor awareness and understanding.
		Peer support; a double-edged sword.
4	Patients' attitudes and concerns	App meets need and desire for support.
		Appropriateness.
		Concerns reflecting poor illness and intervention coherence.
5	Patients' ideas for the app	Understanding me.
		Understanding my skin condition.
		Monitoring physical and psychological factors.
		Understanding others.
6	Barriers and facilitators to app use	Personal choice and autonomy.

	Look and feel of the app.

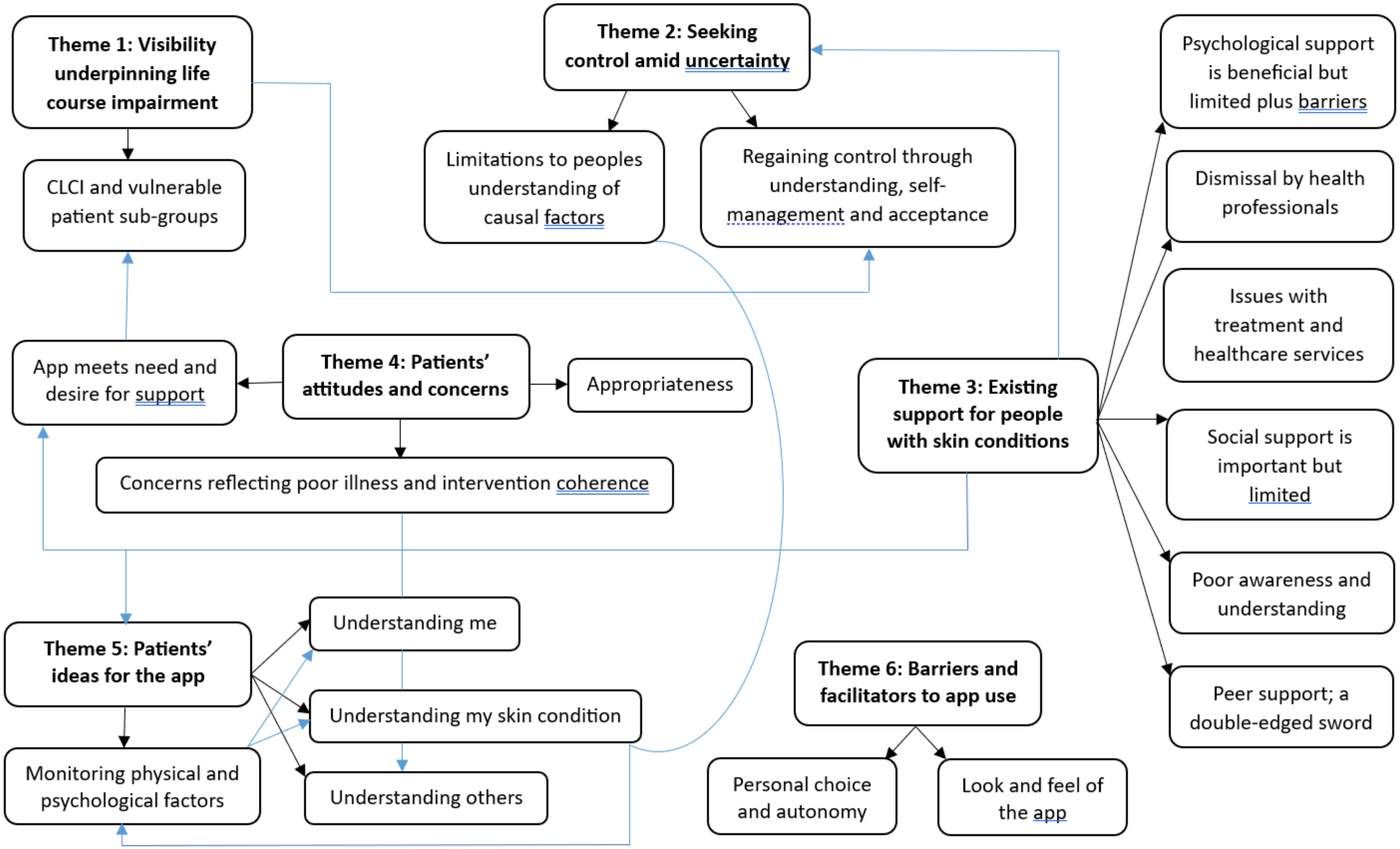

Figure 10: Thematic map

Theme 1: Visibility underpinning life course impairment

This theme provides further evidence for CLCI (see Chapter 1) associated with visible skin conditions. It shows that both common and rare skin conditions presented a range of physical consequences, yet the visible nature of skin conditions was a significant issue that influenced patients' personal beliefs, emotions and health and social behaviours, ultimately preventing individuals from leading rich and meaningful lives. It also draws attention to specific sub-groups of patients, including children and young people, females and adults with late condition onset, who may be particularly vulnerable and need additional support to adapt to having a skin condition(s).

Participants reported a range of physical symptoms and some (i.e., pain, dryness and itch) were experienced across some skin conditions (i.e., psoriasis, eczema, ichthyosis) and caused considerable discomfort. Conditions that included vitiligo and hyperpigmentation presented different symptoms, including discoloration and sensitivity, which was painful at times. Fatigue and comorbidities (i.e., migraines and inflammatory joint disease) were evident and one participant with Ichthyosis reported complications during pregnancy, demonstrating the effect on general health. Symptoms could impair mobility and disturb sleep, which impacted daily activities, personal choices and increased the psychological burden.

> *"It was just like the um, affect it had around my legs and the back of my knees, and then um, because I'm quite into fitness as well, so that had a bit impact, and I had to stop exercising for about five months, completely, um, because my skin was so bad. And then again, when you stop doing the things that you're used to doing, it takes a toll on your mental health." (G1, Eczema, Wales)*

Visible skin signs (e.g., plaques, sports, pigmentation and scarring) had a substantial impact on psychological and social functioning and health behaviours. The presence of a visible skin condition can reinforce difference to others, which affects mood, self-esteem, body image and challenge personal identity (Thompson et al. 2002; Bundy et al. 2014; Ablett and Thompson 2016).

> *"Having a skin condition is visual - you can feel like an anomaly sometimes" (G4, Epidermolytic Hyperkeratosis, Wales)*

These feelings of difference can result in low mood, mental health conditions and hopelessness.

> *"So, I was so depressed, and my skin was the reason why I was depressed […] Like hopelessness, like hopelessness about my future, was like the biggest one. Like constantly knocking myself down and [...] like just feeling hopeless about life." (G3, Lamellar Ichthyosis, USA)*

Strong emotional reactions to skin conditions, including self-disgust (Schienle and Wabnegger 2022) and depression (Clarke et al. 2020) are common. Some participants describe how changes in appearance challenged their self-identity and self-image, with a few describing their visible symptoms in strong terms such as *"disgusting" (G7, Ichthyosis, England)* or *"repulsive" (G8, Vitiligo, England)*.

Some of the findings reflect what is already known about the social impact of skin conditions (see Chapter 1). Most participants were self-conscious of their visible symptoms, which was detrimental to self-esteem and self-confidence. Social anxiety was pronounced; many felt embarrassed by their skin condition and worried about future social interactions, especially those involving romantic partners, and the perceptions of others. The perception of being different resulting from the visible nature of symptoms evoked feelings of loneliness. Some participants reported hypervigilance, they were concerned or paranoid that other people were focusing on their skin and described a cognitive dissonance between feeling pressured to discuss their condition with others and wanting to avoid the conversation.

> *"Er, but it's just more of a … um, a visual thing for me. I think I'm treating it quite well and being treated quite well. Um, but it's more of a social thing, it's just a bit embarrassing, more than anything actually, for me." (G1, Psoriasis, England)*

> *"Um, it leaves weird ... a weird sort of atmosphere for you, where you've got this thing between you and other people, where perhaps they're not mentioning it. You know about it, they know about it, but it's something in the room that's [...] it's something that you feel like you should be dealing with, but at the same time you don't really want to deal with." (G7, Vitiligo, England)*

Chapter 1 discussed the widespread and persisting public stigma surrounding visible skin conditions and related factors, including social standards for appearance and poor awareness of skin conditions and their impact. The participants' perceptions and feelings were influenced by their broader social context, including societal standards for appearance and attractiveness and how others reacted to visible skin conditions. Stares and comments from people without skin conditions were common. It was reported that healthcare professionals occasionally used derogatory descriptors, which likely contributed to the persisting stigma surrounding skin conditions. These perceived social ideals and encounters further eroded self-esteem and could elicit catastrophising thoughts relating to fulfilling preferred gender roles and finding romantic/intimate relationships, particularly in younger people.

"I think society and the media, expects us all to be this perfect air brushed beings, but we're not […] I honestly believed I would never have a relationship. Well, every boyfriend, whenever it broke up, I blamed my skin and I never, ever thought I would settle down, marry and have kids. […] So, um, yeah it's a lot of societal pressure and um, but the psychological impact is massive, absolutely." (G4, Psoriasis, England)

How individuals thought and felt influenced how they behaved in response to their skin condition(s). Many participants described types of avoidant coping and seemed to limit their activities to accommodate their skin condition, which increased isolation and enhanced feelings of loneliness. Feelings of insecurity drove individuals to withdraw socially and disengage from preferred and especially public activities, such as swimming and going to the gym. This is concerning because of the well-established link between physical inactivity and increased risk of long-term conditions, such as cardiovascular disease (Lee et al. 2012), which are also associated with some skin conditions (Bulger et al. 2021).

"Yeah, talking about the mental thing is about becoming more and more isolated from people. […] I climbed Mont Blanc – I used to go climbing all the time. I rarely leave this house, other than to go to work. […] I go and see my mum and dad once a week, and once in a blue moon I will go and see somebody else. But other than that, this is, this is where I am." (G7, Vitiligo, England)

A few participants who continued to pursue activities they enjoyed remarked how these were beneficial for quashing inaccurate perceptions, improving self-confidence and sociality, and instilling a sense of normality, further emphasising the importance of encouraging patients to engage in health-protective behaviours.

> *"Dancing, yeah. Er, so that is a way for me to feel normal. I can dance quite close with people. Now, no-one ... Perhaps not the right word, but I don't get any comments and people seem to like me for me, and not for my skin. Er, so that was kind of a self ... er, a self-confidence boost." (G3, Netherton Syndrome, Sweden)*

People often make choices about their clothing and styling to cover, conceal or camouflage their skin condition and fit in within society (Pattinson et al. 2022). Some participants reported trying to avoid seeing themselves and attracting the attention of others. Choice of clothing and products were limited, and these were chosen carefully and selectively to reduce checking behaviours and visibility. One participant with psoriasis welcomed the introduction of face masks during the SARS-CoV-2 pandemic for this reason.

> *"… so I knew I had to go to work […] but I would come home and like close the doors and I didn't want to see anybody and when it was like really hot, long sleeved tops on, long trousers, everything was covered and the only mirror I have in the house was the mirror for my face, that was it, I didn't want to see the rest of me." (G8, Vitiligo, England)*

The presence of a skin condition can also influence major life decisions (Pattinson et al. 2022). The same was found in the present study. Some participants reported choosing not to pursue their preferred career and taking alternative career paths because of their skin.

> *"Um, I actually chose a job which was fully remote working, um because I felt like I couldn't cope with going into an office." (G5, Psoriasis, England)*

Sub-theme 1.1: CLCI and vulnerable patient sub-groups

Adapting to having a skin condition can be challenging due to the substantial impact that they can have on every aspect of life (Rumsey 2018). The rate and degree of adjustment varies and is influenced by factors such as attachment styles (Krasuska et al. 2018), personality traits (e.g., optimism versus pessimism and resilience), and personal perceptions and societal ideals of appearance (Rumsey 2018). A scoping review by Zhang et al. (2019) found the following factors influenced adjustment:

- Demographic – age, sex, education level, ethnicity, marital status, family history, BMI, sleep quality, smoking history, physical activity levels, topical treatment use.
- Psychological – anxiety, depression, suicidal ideation, body image, self-esteem and stigma.
- Social – social support and interaction, sexual intimacy, economic burden
- Physical – disease activity, severity, duration and symptoms.

In the current study, the degree of the psychological impact of visible skin conditions seemed to change across the lifespan and vary with condition duration. Many participants had lived with their condition for several years and reported that the psychological impact was greatest during childhood and adolescence and lessened over time into adulthood as they developed skills and qualities through occupational and leisure pursuits, which helped them to shift their outlook and successfully adjust to life with a skin condition(s). Some of these participants believed the impact of skin conditions may be greater for adults who develop their condition later in life and have not fully adjusted, suggesting this may be a sub-group of patients who might need additional support. A few participants with late condition onset agreed with this, although others indicated that the self-assurance that comes through life experience and maintaining long-term social connections, can help to buffer the psychological impact.

"Yeah, so I've had my skin condition for 20 years, give or take, and I would say now it doesn't affect me whatsoever. […] But going out, because I used to work abroad, and I'm a scuba dive instructor, I used to have to wear swimwear and I became very confident in myself, by my job." (G1, Vitiligo, England)

"… I'd sort of call it a late developer of psoriasis, I've only had in in the last five years. Um, being nearly 55, um, I sort of don't worry about things in some ways, maybe, that others have done, if they've been living with the condition for a longer period of time. I don't mind it, um, I'm sort of old enough and ugly enough for it not to affect me." (G1, Psoriasis, England)

Both childhood and adolescence are critical transitional periods in human development due to the co-occurrence of various physical, neurocognitive, psychological, social and contextual changes, which subsequently influence general functioning during adulthood (Shaffer and Kipp 2014). Participants stated several reasons why having a skin condition was more challenging as a child or young person, which reflect these key life changes. For example, a couple of participants reported that they, as children, lacked the cognitive ability and confidence needed to explain their skin condition to others and struggled with social interactions with people who did not recognise or understand skin conditions, including health professionals.

> *"And I did end up going to the doctors at one point, about feeling down […] It would always be just like oh, it's hormone related, I'm a teenager, I'm a child, you know, it would never actually be maybe my skin condition is the reason that feel the way I do. And I feel like there's that lack of support there, especially as a teenager, as a child […] it's different as an adult, because in a way, you can talk for yourself, whereas I was very reliant on my parents, to help me when I was younger." (G1, Vitiligo, England)*

One participant described the challenge of having to deal with the onset of their skin condition whilst their body was physically developing and they were beginning to explore new relationships and their sexuality. Several participants described their younger years as being a time of seeking social validation and acceptance yet having a visible skin condition was, to some extent, a barrier to social development, as they differentiated individuals from their peers and prevented them from doing things that were typical of their age group, such as experimenting with their appearance and leisure activities. A few participants also reported being bullied and excluded by their peers in school because of their skin and attributed the behaviours of others to poor awareness of skin conditions (see sub-theme 3.5). These experiences had negative repercussions for psychological health and well-being and influenced how individuals thought and felt about themselves. This was often compounded by the pressure some individuals previously felt to meet perceived social standards. Some participants reported they used to believe their skin condition would prevent them from fulfilling their preferred gender roles and meeting societal ideals for appearance and attractiveness and romantic relationships set by society.

> *"… when my vitiligo came about, when I, when I was sort of, say like sort of 10, 11, 12 […] when as a young girl, you're starting to notice your body and things changing and happening and boys at school and all the rest of it." (G6, Vitiligo, England)*

> *"Like growing up, I got made fun of. There isn't a day that I didn't get made fun of, that I didn't get stared at or felt different." (G3, Lamellar Ichthyosis, USA)*

Worthy of note is that almost all the supporting quotes presented under this sub-theme came from female participants, suggesting that younger females may be especially vulnerable to cumulative life course impairment resulting from the presence of a visible skin condition(s). Women, especially those of younger age (Campbell et al. 2021), are more vulnerable to experiencing poor mental health, including common mood and anxiety disorders, than men (Seedat et al. 2009). In addition, poorer mental health and overall quality of life are recognised in people living with long-term health conditions (Megari 2013). It is, therefore, plausible that the burden of skin conditions and resulting CLCI may be more profound for females than males, especially those of younger age.

Theme 1 summary

Noticeable changes in appearance caused by skin conditions can have profound psychological, social and daily consequences for the people who live with them. These impacts, and wider social factors, can compound one another over time, resulting in poor QoL, which broadens support for CLCI across a range of skin conditions. It seems supporting people to engage in activities that benefit health and well-being, and challenge self-limiting beliefs and emotions, is imperative to them realising their full potential and generally living well with their skin condition. In addition, this theme demonstrates that having a skin condition can compound the physical, cognitive, emotional and social challenges associated with childhood, adolescence and even early adulthood. Younger people, especially females, may need support to successfully navigate these key developmental phases and social situations whilst they are adjusting to life with a skin condition(s). Adults who develop a skin condition later in life may also benefit from additional support as they learn to adjust, but opinions were mixed. More research is needed to better understand these potentially vulnerable patient sub-groups.

Theme 2: Seeking control amid uncertainty

According to the CSM, the perceived cause and controllability of illness are two key cognitive representations of illness which can inform emotional and behavioural responses to illness (Leventhal et al. 1984). This theme shows there was a great deal of uncertainty surrounding the cause and factors affecting skin conditions. Participants reported a loss of personal control and increased distress. They sought to regain a sense of control by self-management and improved understanding and acceptance of skin conditions were critical to individuals achieving this.

Sub-theme 2.1: Limitations to peoples understanding of causal factors

Beliefs about the cause of illness are also central to the CSM (Leventhal et al. 1984). However, people with skin conditions have previously expressed uncertainty about causal factors and triggers of their condition (Ghio et al. 2020; Ip et al. 2021a). Some people are unaware of the role lifestyle factors (Trettin et al. 2021b), nor are they informed about their condition and want more information to aid understanding (De Vere Hunt et al. 2021). There were clear gaps in the participants' knowledge of the causal factors of skin conditions, which had a knock-on-effect on personal thoughts and emotions, and played a part in individuals taking a trial-and-error approach to condition management. In addition, this limited understanding had repercussions for some major life decisions facing patients and their families.

While some acknowledged genetics as a causal factor, referring to family histories or genetic testing, most seemed unsure of the full meaning of 'genetic' factors.

> *"I feel like there's been a lot of ways of putting a plaster on it, why we can give you this cream, that cream, try this and that, but up until this day, I don't know what the root cause is." (G1, Eczema, Wales)*

The uncertainty detected was discussed as having implications for partners and families of people living with a skin condition. Several participants reported concerns about their children inheriting the same skin condition and how this influenced the major decision to have a family and could fuel anxiety even after having children.

"Agree - it was a strong consideration when deciding whether to have children. Putting them through the same thing." (G2, Psoriasis, England)

Episodic conditions, such as eczema, follow a cyclical timeline with repeated flare ups, which can be triggered by changes in their environment (e.g., weather), geographic location, hormones, lifestyle behaviours and stress (Ghio et al. 2020). Triggers are difficult to predict, causing uncertainty (Ghio et al. 2020) and diminished personal control (Pattinson et al. 2022).

Participants with psoriasis, ichthyosis and eczema, experienced skin flares, which they attributed to a range of triggers that became apparent over time. These included injury to the skin and biological, environmental and psychological factors. Hormonal changes during menstruation, pregnancy, the menopause and use of hormonal methods of contraception were thought to influence condition progression. Environmental factors, including seasonal changes and exposure to certain materials and chemicals in household, cosmetic and hair products (e.g., detergents, soaps and make-up) were highlighted. Chlorinated and salt water, for example, reportedly worsened and improved physical symptoms, respectively. In addition, stress was considered both a causal and triggering factor and the bi-directional relationship between mood and the skin was reported. Health behaviours, such as alcohol consumption and inadequate sleep and diet, were also perceived to exacerbate symptoms.

"So, it [hyperpigmentation] developed then, once I'd had the Mirena coil. […] they didn't tell me it would make it worse and within a year, it spread all over." (G6, Hyperpigmentation, Wales)

"First of all, you know, looking at what makes it worse, or aggravates it. For me, those examples would be sort of stress, which could be through work. It could be late nights; it could be having too much to drink. You know, and also windy weather sort of dries it out. […] I live with anxiety and certainly the two things completely go hand in hand." (G6, Eczema, England)

Participants reported that flare ups were highly unpredictable and this, combined with the knowledge that skin conditions were incurable, gave rise to uncertainty around the long-term progression of most, if not all, of the skin conditions reported. Individuals subsequently experienced a loss of personal control over those processes and felt anxious about the future. This also posed challenges to daily living and self-efficacy for self-management.

> *"But the progression and the pathway might take me in a different direction at some point, who knows where it all leads? […] It's got a mind of its own (laughs), sometimes I think I'm in a great place, and I wake up the next morning and it's just kicked off, and I think, what … I just can't explain it." (G1, Psoriasis, England)*

Sub-theme 2.2: Regaining control through understanding, self-management and acceptance

Participants described how the uncertain and unpredictable nature of skin conditions influenced their approaches to self-management. Individuals sought to better understand how to manage their skin condition(s) and implement changes. Gathering and applying new knowledge through self-management practises were both useful tasks in that they helped individuals regain some control over their lives. Acceptance was also part of this and was another way in which the participants claimed back control.

The participants discussed what the term 'self-management' meant to them and overall, there appeared to be two main sides to this concept: 1) treating and protecting the skin, and 2) maintaining mental health.

> *"Um, for me, like two different things that have just been on my brain. I'm ... I love to work out; I'm a big fitness guru. Um, so getting in like my thirty minutes of working out or yoga and eating all the proper things that make me feel good, like inside of my body – and I also do feel like I help my skin somewhat. So, that's one. And then two is, managing my skin. […] Um, if I didn't do those things (bathing and ear irrigation), if I didn't take care of my skin […] then I just ... I, I hurt. Like my skin doesn't feel great." (G3, Lamellar Ichthyosis, USA)*

Participants were aware of the need to look after their health and reported performing health-protective behaviours, mostly physical activity and exercise, and engaging in well-being enhancing activities, such as meditation. Such activities were seen to be beneficial for the skin but also health and well-being more generally. These activities reportedly increased self-confidence and personal abilities to cope with stressors, including major health threats (Hewitt et al. 2022b). Known barriers to performing physical activity need to be addressed to support people with skin conditions to become more active and help reduce their CVD risk (Auker et al. 2020).

> *"I've recently started trying to get healthier - not just because of the psoriasis but also the co-morbidities linked (e.g. heart disease / diabetes). So I now want to make sure my BMI is healthy range etc. Also I find going to exercise classes and getting back out there is helping my confidence grow again" (G5, Psoriasis, England)*

Both healthcare professionals and participants appeared to prioritise the management of physical symptoms. While self-management centred around regaining a sense of personal control; it seemed that by controlling the skin and possible triggers, individuals felt better in themselves and could live life as they wanted.

> *"Being able to keep my condition at bay so that it doesn't interfere with other aspects of my life." (G8, Eczema, England)*

Personal perceptions of control are based on different aspects of skin conditions (e.g., symptoms, the need for treatment and life impact) and levels of control vary between individuals (Howells et al. 2019). It is, therefore, important to understand what represents, and is an acceptable level of, control for the individual.

Evidence shows that people access the internet for support with their skin condition (Kanji 2019) and treatments (Greenwell et al. 2021) and consider online resources to be useful for self-management when access to healthcare is limited (Steele et al. 2021).

Our participants wanted more understanding of their skin conditions in order to achieve better control.

> *"There is no control, but more awareness and understanding would help." (G5, Psoriasis, England)*

Trial-and-error approaches to self-management are common (Johnston et al. 2018; Teasdale et al. 2021). Our participants reported that approaches to self-management were mostly *"trial and error" (G7, Ichthyosis Vulgaris & Psoriasis, England)* and some continued to seek a fix despite knowing their skin condition was incurable, suggesting that this knowledge alone was not enough to deter them from searching. The desire for control and, for some, desperation, seemingly drove some participants to try treatments and implement lifestyle changes despite a lack of evidence and without expert guidance. Some participants, for example, attempted strict juicing and elimination diets to identify possible dietary triggers, usually with little success. This seemed to reduce self-efficacy for self-management and further diminish feelings of personal control.

Elimination diets can be effective for long-term term conditions, traditionally Irritable Bowel Syndrome (Altobelli et al. 2017; Gibson 2017a) and some symptoms of IBD, when implemented with professional support (Gibson 2017b). However, they are not currently recommended for the management of skin conditions, raising questions around patient health and safety in the context of self-management. In psoriasis, for example, few studies have investigated time restricted eating and the Mediterranean diet is not currently recommended due to low-quality evidence, only hypocaloric and gluten-free diets can be recommended for people who are overweight and gluten intolerant, respectively (Zanesco et al. 2022).

> *"I don't know how to manage it at all. Like I just bounce back from cream to cream, from infection to infection. Um, tried every shampoo going, tried ... I took my list with me to the dermatologist today, of all the different steroid tablets, steroid creams, foams, the lot. I just ... Yeah, I don't feel confident that I'm managing it at all […] I don't really have any control over it. It's not diet-based. I've tried to cut out diets…" (G2, Psoriasis, England)*

Skin conditions carry a substantial treatment burden and many patients spend time and effort adhering to, and planning around, treatments (Bundy et al. 2014). Participants reported developing routines that they deemed necessary for controlling their skin as they became more familiar with their condition over time. These routines were all consuming and tiring, as they required substantial time, effort and planning, and impacted daily life, especially work and leisure time. Adherence was considered essential to preventing symptoms from worsening and maintaining well-being. This further increased the pressure, and overall burden, on individuals.

> *"Er, just if I don't take care of myself, I don't feel good. I'm not, I'm not presentable outside, more or less. Er, for me, I need to do this every day. It can't wait, like until the next day. It needs to be done every day, because it's ... My body runs like a twenty-four-hour watch. So, if I bath at ten in the morning one day and four in the morning the next day ... The four in the*

> *morning, it's not happening. It's been too short a time, so the skin hasn't loosened up enough." (G3, Netherton Syndrome, Sweden)*

Adaptation and acceptance are important concepts in skin conditions (Ghio et al. 2020). Adaptation has been defined as a process whereby individuals or groups make a conscious choice to integrate physical, psychological and social aspects of their life (Roy 2011). To accept a health condition means for a person to acknowledge that they are unwell and that they have to deal with the consequences of their illness (Zalewska et al. 2007). Although, coming to terms with an incurable condition can be challenging. The degree of acceptance has been associated with psychological distress, treatment adherence (Zalewska et al. 2007), gender and life satisfaction (Kowalewska et al. 2020).

In addition to increasing understanding, participants acknowledged that coming to terms with having a long-term skin condition(s) was necessary for living well with it and interrupting the CLCI (see Theme 1).

> *"… there's almost like this thing of accepting that you've got a chronic condition that you're never going to cure." (G7, Psoriasis, Wales)*

A few participants explained that they had changed their perspective, and other people's opinions, about their skin condition. Shifting their outlook helped them to feel more in control of their skin condition and this significantly and positively altered the impact of it on their life. However, acceptance did not come instantaneously or easily; acceptance was described as a process that occurred over a long period of time and was part of the journey of adjusting to and learning how to successfully manage their skin condition(s). It was clear that some participants had not yet reached this point but were striving for this.

> *"… I had to accept because I know that otherwise it ends up in a spiraling level of lack of confidence and low self-esteem and it is something that obviously I have to live with every single waking hour of my life so, as I said, it's just one of those things that over time […] it's just something I've had to readjust my own thinking around, around how I perceive myself, erm, and, and building that confidence […] because otherwise it was consuming every single part of my life in terms of what I wore, er, social anxiety around meeting new people, you know, every single aspect of, of my life, it was touching on, and as I said I needed to take back that control." (G8, Vitiligo, England)*

Theme 2 summary

Patients should be better educated and supported professionally to accept and adapt to their skin condition(s) and health professionals involved in the management of skin conditions need to routinely measure and work with patients' beliefs about their health and management to effectively support peoples' emotional needs and promote health-protective behaviours. Patients may need support to identify ways of maintaining a sense of control amid the uncertainties of living with a skin condition(s). Increasing understanding was important to these participants, yet evidence-based information is required to ensure the individual coping styles and self-management strategies are effective, safe and contribute positively to well-being. Finally, this theme suggests that whilst knowing skin conditions are incurable, accepting this is another matter.

Theme 3: Existing support for people with skin conditions

This theme discusses the different types of support that are currently available to people with skin conditions, including standard medical care and psychological, social and peer support, and it explores associated issues and barriers. Findings have implications for education and training, the structure of health services and the broader support network for patients.

Sub-theme 3.1: Dismissal by healthcare professionals

Clinicians 'personal models' (see Chapter 2) can influence their approach to management and engagement with patients during consultations (Hewitt et al. 2022a). Many participants explained that healthcare professionals involved in the management of skin conditions often prioritised the treatment of physical symptoms. Nearly all reported that dermatology specialist staff and general practitioners especially, referred to and managed skin conditions as localised, visible skin complaints and did not recognise or understand the broader impact on patients, which affected how healthcare professionals communicated and behaved with them during consultations.

> *"I think GPs and all medical professionals are amazing, but more recognition for, for skin conditions. I think it's sometimes passed off as just 'Oh, it's, it's aesthetic'. But you know, it has a very physical and mental impact on a lot of people's lives." (G6, Psoriasis, England)*

Most participants recognised that their skin condition was incurable and needed long-term self-management. This information was often communicated by healthcare professionals, although how this news was communicated could have a profound psychological impact on patients that seemed to go unrecognised. Individuals were informed their condition was incurable and nothing could be done to help them, which left them feeling dismissed, distressed, hopeless and forgotten. This echoes previous findings that skin conditions are misunderstood, trivialised and dismissed by others, including health professionals (Bundy et al. 2014; Johnston et al. 2018; Ra et al. 2021; Teasdale et al. 2021).

Several participants described clinical encounters that reinforced the dismissive attitude of some healthcare professionals These scenarios highlight that people with skin conditions are sometimes made to feel like they are not a priority despite the substantial burden they face. They suggest that health professionals working in dermatology settings might benefit from additional specialised training to communicate potentially life-changing information to patients in a more sensitive manner.

"…it was the hardest thing hearing it [diagnosis] from dermatologists, like there's nothing we can do, and that was it, it was like just having a door close in your face, like there's no hope." (G1, Vitiligo, England)

"You know, my son, who's got really bad, horrendous acne on his back ... He's twenty […] He's had to go to the GP, and they've said: 'We're not ... We're only seeing emergencies at the moment. So, that's not ... We don't need to see you.' He needs, he needs medication for it." (G7, Ichthyosis Vulgaris & Psoriasis, England)

"Er, when I went to the GP and he gave me some, like, steroid cream, he spent most of his time telling me how expensive it was for him to give me that. […] That's the level of interest he had in the condition." (G7, Vitiligo, England)

Shared decision-making can improve the quality of patient care and is preferred by both patients and many healthcare professionals in dermatology (Larsen et al. 2019; Morrison et al. 2021). However, health professionals do not always engage in shared decision-making due to their beliefs about the condition they are treating and their patients (Hewitt et al. 2022a).

The present study reflects existing findings. Some participants recognised the value of collaboration and shared decision-making and wanted to work in partnership with healthcare professionals to manage their conditions effectively. Most participants reported that healthcare professionals rarely engaged them in decisions about their care and some reportedly adopted a paternalistic approach, evidencing a power imbalance. The responsibility to raise concerns and manage skin conditions was sometimes transferred to patients who were often not prepared for this role, evidenced by the time and effort they spent searching the internet for guidance on management (see sub-theme 2.2).

> *"I think quite often the appointments feel quite rushed […] I'm quite excited to have seen someone and that there's a solution, um, and it's quite often provided to me as this is what you have to do, rather than, these are some options." (G5, Eczema, Wales)*

Collectively, conversations of this kind, along with repeated treatment failures, led to a lack of trust in and disengagement from the healthcare system, and individuals self-managing their skin condition as best as they could without support.

> *"I self-manage my condition completely, which is, which is because no-one else can really do anything about it." (G7, PC, Wales)*

Sub-theme 3.2: Issues with treatment and healthcare services

Inequities in treatments and healthcare systems were apparent and these posed challenges to self-management and further increased the physical and psychological burden on patients.

The availability and choice of effective standard medical treatments was limited, especially for rarer skin conditions, and seemed to vary by country. Participants reported they had tried several treatment options with little success. Some were aware of alternative treatment options but could not access these or were unsure if these treatments were available locally. Those that were available were often discontinued with conflicting or no explanation, leaving patients with no management strategy. Thus, individuals had to go to great lengths to obtain their preferred treatments, although it was unclear whether these were recommended or evidence based. Many resorted to using skin care products that could be purchased over the counter, although these were sometimes costly and difficult to access and were often ineffective or discontinued. This collection of findings echoes those of previous research in this area (Johnston et al. 2018; Ip et al. 2020; Pattinson et al. 2022).

> *"… I had quite a big course of the light therapy […] the Specialist said, "We're gonna stop it on the NHS now, but you can come and have your ninety seconds privately um and I'll carry on treating you that way." So, I was kind of, again, you know, a little bit left in limbo…" (G5, Vitiligo, Wales)*

> *"We haven't physically gone to America, but we're buying things [medication] from the States now, because you can't buy it over here.." (G7, Ichthyosis Vulgaris & Psoriasis, England)*

Access to, and availability of, free medical care were also major issues. Some participants explained that they had difficulty accessing services due to their geographical location and spent a substantial amount of time and energy travelling distances to access healthcare services.

> *"I live in a very rural area, and in the last few years it's been very difficult to get dermatologist consultants, so um, I've certainly felt I've had to be a bit more proactive, and ask the GP um, for a bit of advice or to review the meds I'm on. […] I was being reviewed every sort of six months, but that hasn't been possible, because of the limited number of um, dermatologists in the area I live…" (G1, Eczema, Wales)*

The UK has had shortages of specialist dermatology staff for over a decade (Eedy et al. 2009). Participants reported poor access to timely care and long waiting times to see a dermatologist, clearly staffing levels do not currently match patient demand. Often it was a case of waiting a year or more to see a dermatologist or pay for private care although in some countries it was standard practice to pay for medical care and treatments. These issues were compounded by the SARS-CoV-2 pandemic, which forced some people to work even harder to obtain the care they needed.

> *"Erm, but I guess in the context of it being incredibly difficult to see an NHS dermatologist currently, erm, I've had to pay to go privately, so I think there is more of a burden on people to kind of work out what they want to do and seek help for themselves." (G8, Multiple skin conditions, England)*

> *"…with the effects the pandemic and things, you know, waiting times have just gone through the roof. They were bad enough before." (G7, Psoriasis, Wales)*

However, not all participants reported negative experiences during the SARS-CoV-2 pandemic. Similarly, Steele et al. (2021) found most people with eczema reported having more time to apply emollients and bathe during the pandemic and could still book GP appointments.

The participants in the present study were also dissatisfied with current models of patient care, in particular the stepped approach, which was perceived as lengthy and arduous and seemed to feed the trial-and-error mentality and method surrounding the management of skin conditions. Individuals commented on a reactive versus preventative approach and explained how this could work against patients depending on the state of their skin at the time of their appointment. Ultimately, current approaches to patient care largely concerned physical aspects and medical treatments, not the whole person. They left patients needing to prove they were worthy of more advanced treatments, which was difficult and exhausting for individuals to navigate.

> *"You know, it's eighteen months' wait to see a dermatologist, and then on the days you go and see a dermatologist, your skins looks really good and they're like: 'Well, sorry. You know, you're only ... I'm only seeing what I'm being presented with at the time.' So, then you've got to go back to square one again. It's only on the day that actually if I go in and my skin's bad, that they might consider seeing me again." (G7, Ichthyosis Vulgaris & Psoriasis, England)*

Sub-theme 3.3: Psychological support is beneficial but limited and barriers exist

Chapter 2 discusses the lack of specialist psychology and psychodermatology services in the UK. This research emphasises that little has changed in the way of increasing psychology provision within dermatology.

These participants reported that the psychological impact of skin conditions was profound and explained that this aspect of their condition affected them the most, supporting previous findings (Pattinson et al. 2022). However, access to psychological support was limited and requests for psychological support were often overlooked.

"It's alright dealing with it um, physically dealing with it, applying moisturiser, but it's the mental side of it, that, that's worse than anything I think. You can sort of learn to live with it to a degree, but it's just the psychological side of it, you get no help with that at all." (G4, Ichthyosis Vulgaris, England)

Qualitative research in dermatology is generally lacking (Foster et al. 2022; Pascual et al. 2023) and existing evidence on psychodermatology is mainly based on the opinions and experiences of dermatology experts and a limited number of cross-sectional and observational studies (Bewley 2017). Little is known about the experiences of people who access psychodermatology services or other forms of psychological support, despite patient experiences being the main focus in existing qualitative studies in dermatology (Pascual et al. 2023). This study aimed to address this gap in the literature, albeit challenging given that few people had previously received any form of psychological support.

Nine participants reported previously accessing some form of psychological support but did not specify the type of therapist they saw. No one specifically mentioned psychodermatology services. Therapeutic approaches reported included mainly Cognitive Behavioural Therapy and counselling, but psychotherapy and hypnotherapy also.

Experiences of psychological support were mostly positive and several cognitive, emotional and behavioural benefits were noted. In terms of cognitive functioning, patients reported feeling heard, experienced a change in perspective, and gaining skills to deal with negative thoughts. Emotional benefits included an improved ability to recognise, discuss and regulate difficult emotions (e.g., anger and sadness) and increased self-confidence, particularly in social situations. Individuals learned a range of practical tips, including breathing and distraction techniques, which helped them to cope effectively, especially with social anxiety. These techniques seemed to instill a positive sense of well-being both in the short and longer term. One participant also reported that their psoriasis cleared following hypnotherapy. A few participants reported seeking psychological support, but not in relation to their condition, and one participant said they found it helpful discussing the burden of their skin condition with their therapist who validated their feelings of frustration.

"… my skin had made me feel very down and very depressed, and at the time the CBT was helpful, within its limitations. […] I did learn some really good distraction techniques that

> *were useful for grounding myself and very grounding in the moment […] I still use them, like you know, 20 years on. […] regulating my own emotions, so that I'm not reacting back out with anger, I'm not reacting back out feeling sad or, you know, even bursting into tears, which I had done on previous occasions as a child." (G1, Post-Hypertrophic Acne Scarring & Hyperpigmentation, England)*

Participants reported that the psychological impact of their skin condition(s) affected them the most, but also described these aspects as the most challenging to manage. Individuals reported struggling to maintain their mental health and well-being and wanted more support.

> *"… it impacts almost every domain of life, emotional, mental, physical, professional, sexual, social. Um, there isn't an area that it doesn't impact on. […] that's one aspect of living with a skin condition, that I've always struggled with. And from speaking with others who've the same condition as me, that has always been a struggle…" (G1, HS, Ireland)*

However, some barriers to psychological support were identified. At the patient level, inaccurate perceptions of skin conditions may be a barrier to some seeking psychological support. Several participants referred to skin conditions as cosmetic or visual issues, rather than complex long-term conditions. This suggests patients may not understand, be attuned to, or may have normalised the degree to which their skin condition impacts them, although this could not be deciphered from the data. Often healthcare professionals described skin conditions in the same way, indicating poor medical awareness of the broader impact of skin conditions. These findings reinforce previous research on clinicians' personal models of psoriasis (Chisholm et al. 2016; Hewitt et al. 2022a) and highlights the need to address both clinicians' and patients' personal models of skin conditions to improve understanding and influence a whole person approach to clinical and self-management.

> *"…it's more of a cosmetic thing, I would say. […] I can't remember the last time I went to a dermatologist, but the last time I did go, they pretty much said to me, it's a cosmetic issue, there's nothing we can do." (G1, Vitiligo, England)*

In addition, it seems that some patients may misunderstand what psychological support entails and who it is intended for. One participant, for example, believed that psychological support was exclusive for people in society who are of higher socioeconomic status and they also discussed the stigma around seeking psychological support, both of which may stop people from seeking appropriate support.

> *"… we live in this world now where everybody who's famous and everything, they've all got about five psychologists that look after them and do alright. But I think for regular people, it kind of seems ... Certainly for me, it just ... It doesn't, it doesn't seem like that's something that I would be doing. […] I know this'll probably sound quite silly now, but I kind of feel like I'm not, I'm not mental. So, so, I don't ... Like I don't know what it's going to do for me, but at the same time a lot of what I go through is mental stuff." (G7, Vitiligo, England)*

The strategies that individuals employed to cope with their skin condition(s) also appeared to be a barrier to them accessing psychological support. One participant, for example, explained that they came from a family who did not engage in discussions about personal issues, including emotional well-being, and they had learned to avoid unpleasant emotions, demonstrating avoidance coping:

> *"… I'm a bit of a ... kind of an ostrich. […] Er, I come from a family where we don't talk about things. Er, so it's never been a question, to talk about how I feel, or if I have a problem, or ... So, I haven't really talked about it that hard, frankly." (G3, Netherton Syndrome, Sweden)*

Upward and downward social comparisons are cognitive strategies that people employ to evaluate their own traits, characteristics, attitudes and circumstances against those of others in society, mainly their peer group (Taylor et al. 1990). Upward comparisons involve viewing oneself relative to other people who they consider to be in a better position (Taylor et al. 1990). Downward comparisons occur when one assesses themself against others who they perceive to be in a less desirable situation (Taylor et al. 1990). The role of social comparison has been recognised in the experience of and adjustment to stressful life events (Taylor et al. 1990), such as illness.

Many participants reported using downward social comparisons as a way of coming to terms with their skin condition(s). They compared themselves to people living with other long-term conditions, such as cancer, which they perceived as more serious. Individuals often said they felt fortunate to have a skin condition, which were commonly defined as visual or cosmetic issues. Whilst, overall, this seemed to be a helpful coping strategy that supported personal adjustment, the use of downward social comparisons is also problematic because it suggests that patients either downplay the burden of skin conditions, or do not recognise the extent of the impact on their lives, and this seemed to be a barrier to some seeking appropriate support. Participation in this study seemed to help some individuals to realise impact and legitimise the need for psychological support.

> *"And I'm lucky, really, I suppose [...] Jada Pinkett has got alopecia, which is an autoimmune condition. […] Would I swap it? No, I wouldn't swap it. So, you know, in the scheme of visible differences and skin conditions, it doesn't cause me any pain or discomfort." (G2, Vitiligo, England)*

> *"… you don't necessarily look for psychological support. […] but part of me thought: 'Oh, I've only got a skin condition.' You know, you're dealing with people with cancer, with motor neurone – blah, blah, blah – you know, and it's almost sort of something where you can just go quick ... you know, easily and find something and think: 'Well, actually, yeah, you do deserve to have a bit of psychological support,' even if it's online or something." (G7, Psoriasis, Wales)*

At least four participants in this study had sought psychological support privately and discussed the cost implications of this. While psychological support may be available to some in the UK and few on the NHS, the cost of psychological support, and healthcare more generally, may be a barrier for many in other parts of the world, as noted by one participant. Two participants stated the benefits of psychotherapy and counseling outweighed the financial costs that they and their families paid to attend these services.

> *"I felt at the time it was rather expensive, but it was one of the best investments I ever made. The return on this investment paid for itself many, many times." (G1, Hidradenitis Suppurativa, Ireland)*

Psychological support was not readily available to most individuals and is a likely reason why patients do not actively seek psychological support, yet most attributed this to differences in the expertise of staff and resource available across dermatology services. One participant with psoriasis reported that they sometimes used a DLQI app and regularly completed the DLQI (Finlay and Khan 1994) during hospital visits, which they discussed with their nurse or doctor. Another participant living with ichthyosis in the USA explained that their doctor recognised that they were distressed as a child and recommended they find a counselling service. However, most healthcare professionals did not discuss the psychological impact of skin conditions, let alone recommend or offer psychological support to patients. Participants attributed this to poor awareness of impact and insufficient medical training, as well as broader issues with the general approach to and structure of healthcare, all of which are discussed within Theme 3. A few participants perceived there to be a lack of psychological support for people with skin conditions and attributed this to the majority of clinicians working from a biomedical, rather than a biopsychosocial, model of health (Picardi and Pasquini 2007). This view is consistent with the findings of a recent qualitative study involving people with psoriasis and health professional involved in psoriasis management (Trettin et al. 2021b).

Participants also recognised the dualism between physical and mental healthcare and saw this divide as a potential reason why psychological support was rarely offered or available. This seemed to influence perspectives of self-management.

> *"I've never been offered any sort of assistance with my mental health or like the medical model, of disability is so rampant in the hospital, and it's never really looked at, err, from a psychological perspective…" (G4, Epidermolytic Hyperkeratosis, Wales)*

Sub-theme 3.4: Social support is important but limited

Social support from friends, family and partners can influence how people adapt to life with a skin condition, support positive well-being (Zhang et al. 2019) and buffer depressive symptoms (Wojtyna et al. 2017).

Having a solid support network was important for living well with a skin condition and generally made coping feel easier. Friends and family supported participants in various ways, including physically, psychologically and financially. The participants valued close relationships with friends and family because they felt known and understood. Individuals felt comfortable to lean on these groups for help with applying creams and everyday tasks, if necessary. Some were grateful to their loved ones for providing a safe and trusted space to talk about the challenges of having a skin condition(s) and for the time spent together, which helped to buffer stress.

> *"… it's easier to cope with it when you're confident and you have a good support network around you, family […] But when you're isolated, it's very hard to deal with, it magnifies it*

and you can't get your head in the right space to deal with something that's probably quite simple, because it's overwhelming I think." (G4, Vitiligo, England)

However, there were perceived limitations to the level of support that people without skin conditions could provide. Several participants described situations where friends and relatives made unhelpful comments and offered unsolicited advice. This led to the opinion that people without skin conditions could not truly understand the reality of living with and managing skin conditions. As with healthcare professionals, the reactions of others were linked to a lack of awareness and understanding of skin conditions, which is explained in detail in the next sub-theme. Thus, even though patients may report having social support, not all relationships are helpful.

"… and then of course, you have all the, very well-meaning friends who go 'Oh have you tired E45?' Yeah, no, just no." (G6, Eczema, England)

Sub-theme 3.5: Poor awareness and understanding

Poor awareness of skin conditions and their impact among the public and the medical community may be responsible for widespread lack of support for patients. Furthermore, some people with skin conditions may not fully understand their skin condition and underestimate the impact of their condition and the commonalities with other skin conditions.

Chapter 2 refers to issues with current medical curricula, including poor coverage of dermatology and particularly psychodermatology. The present theme reiterates that the current level of training is not sufficient for practice and health professionals require more education to provide adequate care for people with dermatological conditions.

Participants believed that skin conditions and their impact were poorly understood by health professionals, including GPs, pharmacists and dermatologists, as well as counsellors and therapists. This seemed especially true for rare skin conditions, which were often not recognised let alone understood. This was evident from the personal experiences described by participants and how health professionals working in a variety of health settings reportedly interacted with and treated them (see sub-theme 3.1). For example, several participants reported that health professionals referred to skin conditions as visual or cosmetic issues and provided inaccurate diagnoses. Poor awareness and understanding may explain why some health professionals transferred the responsibility of management to patients.

> *"I was told by a number of doctors 'I don't know what it is' you know, go home, you know, don't worry about it. It's nothing. And then I went to the Pharmacies. They didn't know, they didn't even tell me to wear sun-cream or, you know, or anything." (G6, Hyperpigmentation, Wales)*

The lack of awareness and understanding of skin conditions among the general public extended across countries and cultures, echoing the results of a previous survey which found poor social awareness of psoriasis, including a lack of knowledge and misconceptions of psoriasis (Özer and Yıldırım 2020).

Many participants attributed negative social interactions with people in society to poor awareness and myths surrounding skin conditions (i.e., they are contagious). Some, but not all, explained that their friends and family members viewed their skin condition as trivial or mistook them for other health conditions, such as cancer and leprosy. Participants described uncomfortable experiences of being stared at and receiving comments about their skin, which fueled feelings of self-consciousness, insecurity, social anxiety, low self-esteem and frustration. Some reported traumatic experiences of bullying and social exclusion during childhood, mirroring existing findings in people with acne, psoriasis and eczema (Magin et al. 2008). These negative social encounters seemed to reinforce negative self-perceptions, contributed to isolation, and encouraged covering behaviours.

> *"… I've had situations where people have come up and they've rubbed my skin to see if it's like, you know, it's coming off, or it's contagious or I've been burnt and obviously it isn't any of those, it is the vitiligo…" (G8, Vitiligo, England)*

However, it was acknowledged that people often have good intentions, or are unfamiliar with and are curious about skin conditions, but do not realise the impact their words and actions can have. Two participants explained that conversing friends about their skin conditions reinforced that skin conditions are generally misunderstood and their impact underestimated.

"… they say, oh no, what's wrong, what have you done to yourself? And all of a sudden you feel like you did when you were ten years old and you're different from everybody else […] it's meant with kindness, it's not malicious at all, but it's those sorts of enquiries and things, just makes you feel a lot worse about yourself." (G5, Psoriasis, England)

The general lack awareness of skin conditions seemed to drive patients to seek information for themselves online and from people with similar experiences. There was a sense that little was being done to improve understanding of skin conditions and a few expressed gratitude for our study. Participants often saw themselves as the expert as a result and made it their job to educate themselves, their peers, health professionals and others about the consequences of having a skin condition(s), which was rewarding for the individual. There were calls for more medical research, public campaigns and resources to increase awareness and improve the management of skin conditions and ultimately, ease the burden on patients.

"Um, it's not so much to do with self-management. It's more to do with perceptions of other people, and there's very little publicity, as far as I'm aware, about skin conditions [..] because if people were more aware, then people probably wouldn't start at you, and you wouldn't feel so self-conscious." (G2, Vitiligo, England)

Previous research by our group also found that people did not fully understand their skin conditions, with much of the uncertainty centring around causes and timeline, including symptom variability and the prognosis (Pattinson et al. 2022). In addition, the links between psoriasis, lifestyle factors and the risk of developing comorbidities are poorly understood by some patients (Trettin et al. 2021b). Children may lack understanding because their diagnosis and information about their condition is communicated to the parent or carer instead and doctors assume patients understand because they have had a skin condition for years (De Vere Hunt et al. 2021).

Some participants reported that they were unsure what triggered their skin condition while others were clear that stress triggered their condition. Others were confident that poor sleep and excessive alcohol consumption were triggers, but some struggled to pinpoint exact triggers, especially those related to diet.

> *"…I've had this [psoriasis] since I was seven, but I've only just realised that psoriasis has got a connection to people having heart attacks and problems with the heart – and it's like: 'How has no-one ever told me?'…" (G1, Psoriasis, England)*

Whilst some participants believed that having lived experience of a skin condition made them expert in their own condition, not all felt so, and many felt unprepared to manage their condition. Participants lacked awareness of the different approaches to management, and subsequently spent long hours searching for information online on how to best manage their skin condition. One participant did not realise that there was an existing organisation dedicated to his skin condition, which suggests others may be unaware of the informational support available from patient organisations.

> *"About five years ago, I got a melanoma and I had to go to hospital, and it was only then that I read ... I got time to read the boards there in the, you know, dermatology-sort-of-clinic and found out that there was an ichthyosis support group […] But I'd gone sort of, you know, fifty-five years, you know, managing it with one type of cream, with nobody sort of saying: 'Well, you know, 1) there's an ichthyosis support group, or 2) there are different things to try.' You know, I now feel a little bit, you know, forgotten and sort of ... You know, you know, I've had to manage it myself, when possibly there's been out there, all those years, some other avenues I could have explored to help me manage it better than what I've been doing." (G2, Ichthyosis, England)*

There was a sense that a few participants were unaware of the way in which their skin condition impacted them, for example:

> *"…I agree with [name]. Psychological aspect catches you unawares at times." (G4, Vitiligo, England)*

Only one participant understood that some impacts are common across skin and other health conditions. This person believed that connecting with others who have encountered similar experiences and consequences because of having a long-term skin, or other health, condition could be beneficial because people can learn from and support one another.

> *"… there is something to be said about mixing with people who've got ... where their condition has got a similar impact, rather than you've got the same condition. […] I think*

> *what he [participant] is going through, other people with other sort of conditions, particularly people who have facial psoriasis and things like that, would be getting, you know, exactly the same sort of effect on their life as well. [...] Can we possibly learn and support each other with other conditions?" (G7, Psoriasis, Wales)*

This echoes qualitative research (Iliffe and Thompson 2019), which found that peer support via a Facebook support group helped to normalise experiences of alopecia and improve self-acceptance, social connection and self-confidence in group members.

Education on the common impacts of skin conditions could benefit some adults and the study by Iliffe and Thompson (2019) emphasises some psychological benefits of doing this. The MiDerm app could serve as a platform to disseminate information to increase understanding and awareness of skin conditions, and their impact, among people with whom they live.

Sub-theme 3.6: Peer support; a double-edged sword

The participants viewed peer support as a form of informational and emotional support. Several participants believed having a skin condition set them apart from others and such beliefs perpetuated strong feelings of loneliness and social isolation (see Theme 1). Many wanted to feel understood, although it was clear that this desire was not being satisfied, as people without skin conditions, including friends and family and medical professionals, did not understand or empathise with participants (see Sub-theme 3.5). The internet and social media enabled individuals to access information about their condition(s) and connect with and share experiences with similar others. Patient-to-patient communication, whether that be through an established organisation or online, was perceived important for coping, giving individuals hope for the future and confidence to self-manage.

> *"I, I would say social media, so, these Facebook groups and stuff like that is a key source of support, in, in particular the vitiligo society […] I don't know how you would know anything or speak to anybody if, if, that didn't exist, if I'm quite honest." (G4, Vitiligo, Scotland)*

Several participants were either members or leaders of existing organisations or groups representing people with their skin condition. Some were unaware that dedicated support groups existed. Patient organisations appeared to be vital sources of informational, psychological and social support for patients. Participants reported learning about their condition and management from the information and patient stories that were available on organisation websites.

> *"I would highly recommend contacting every single group, every group that is relevant to your, to your condition […] Because not only do you pick up some really good hints and tips but you may find some really great, great partnerships or friendships or just get some, get some really good knowledge and experience from people in, in the same boat as you." (G6, Vitiligo, England)*

Many of the same advantages were reported for online peer support groups on social media platforms, such as Facebook and Instagram. These connections sometimes developed into lasting friendships. Online groups offered a space and almost immediate access to advice and guidance that existing sources of support (i.e., health professionals) did not offer. They provided an insight into how others managed different aspects of their skin condition(s), including the choice and efficacy of treatments, which was especially helpful in between medical appointments. These advantages are also reported by Iliffe and Thompson (2019).

> *"… I found two accounts on Instagram, which is an app I use all the time. And they share their story and they share how they're getting on and the treatments they're going through. And that's probably the best thing ever for my mental health and has been, in terms of living with a skin condition. And we've reached out and we chat online and we say 'Oh, you know, having a really bad day' or 'It's flared up this week' or you know, 'Really itchy' […] just having someone there that knows how you feel. Really key." (G6, Psoriasis, England)*

However, unlike the previous study, participants in the present study also reported several disadvantages of online peer support groups. Poor regulation was an issue, as trolling and selling occurred and individual members could dominate the group or offload their personal problems, all of which could negatively affect other members, lowering mood and morale and increasing hypervigilance towards symptoms. There was also the issue of individuals feeling overwhelmed by the amount of information they were exposed to. It was noted that online groups rarely, if ever, have input from people who were qualified to offer specialist advice on the management of skin conditions and thus, the information available was often not evidence-based or safe for patients. This is consistent with previous qualitative research involving people with vitiligo, who shared concerns about the credibility of condition-related information online (Teasdale et al. 2018). This is also problematic because it suggests that some patients, who are desperate for new insights, may be willing to forego reliable information if they believe it could improve their skin condition. Implementing appropriate safeguards (e.g., restricted access, group moderation) was deemed important to ensure online peer support groups are safe, beneficial and do not add to the psychological burden of skin conditions.

> *"When I went onto some Support Groups on like Facebook and that. And they tell you like different things and they don't tell you that, or if you take like 20% like, Tretinoin for example, you're going to, you're going to be all scaly. And then obviously when that happened, I just thought 'Oh my God' I didn't realise it's because I had to have a small percent first of all, you know. So, yeah, just need to be aware, it just needs to be monitored, the people only share factual information and information that can't, wouldn't make somebody do it to burn their face and things like that, or skin, or anything." (G6, Hyperpigmentation, Wales)*

Theme 3 summary

Psychological support for people with skin conditions was lacking and patients often had to battle to obtain the care and support they needed and this came at a financial cost, but had clear and lasting cognitive, emotional and behavioural benefits. Participants conveyed both a need and desire for increased provision of dedicated psychological support. However, barriers to psychological support were identified. In addition, this theme shows that skin conditions and their impacts were misunderstood; poor awareness seemed to underpin most of the issues and barriers described. More education on all aspects of skin conditions is needed at the societal, service and patient level to influence how people are treated (both medically and more generally). Further research on health professionals' and patients' personal models of skin conditions could help to alter inaccurate perceptions of, and approaches to managing, skin conditions. Lastly, participants valued peer support because it normalised their experiences, mitigated isolation and provided opportunities for learning about their condition and management. Patient organisations appeared to be an important and largely underrecognised and underutilised part of the wider support system for people with skin conditions. Health providers and services, professional dermatology organisations and researchers should work collaboratively with the leaders of these organisations to improve the types, quality and safety of support that is available to patients.

Theme 4: Patients' attitudes and concerns

This theme provides evidence for the acceptability of a novel smartphone application (app) offering psychological support for adults living with skin conditions. It highlights specific sub-groups of patients who may benefit most from this app and indicates that altering the personal beliefs patients hold about skin conditions could alleviate concerns about the appropriateness and suitability of the app.

Sub-theme 4.1: App meets need and desire for support

The systematic review indicated that qualitative evaluations of existing digital interventions were limited (Hewitt et al. 2022c). Participants were asked about the perceived acceptability of MiDerm and were largely supportive of this idea.

Nearly all the participants reported that the psychological impact of their skin condition(s) affected them the most and was most challenging to deal with, especially in the absence of professional, specialist and dedicated psychological support. Some participants believed the psychological consequences of skin conditions were often overlooked. These findings reaffirmed existing findings on impact (Chapter 1) and inadequate support for patients (Chapter 2). Most viewed the proposed app as a deserved and novel form of support that would go some way to meeting this unmet need:

"Yeah it [MiDerm], it's nice actually, cos like, yeah, we don't really have anything like this, I never really thought of it before. […] it's very hard to get people to, to recognise that this [the impact of skin conditions] is a thing..." (G4, Vitiligo, Scotland)

"We deserve an App dedicated to us." (G4, Psoriasis, England)

The burden associated with the practical management of skin conditions was discussed. Participants reported that they spent a considerable amount of time and effort managing their skin (e.g., bathing and applying creams or treatments) and planning their life around their condition, which is an established finding (Pattinson et al. 2022).

Many participants in the present study sought information online to better understand their condition(s) and find cost-effective strategies for self-management. Information available online often came from unregulated and condition-specific online support groups, questioning whether these sources were reliable. These information-seeking activities were time consuming and effortful. No one website provided the factual information required and individuals had to search multiple sources for appropriate advice and guidance on managing all aspects of their skin condition(s):

> *"It's that there isn't like a one-stop shop for people with skin conditions generally. […] You just drive around the internet, trying to find something that's going to fix this problem, when you can't fix it. It's just ... You've just got to manage it." (G7, Ichthyosis Vulgaris & Psoriasis, England)*

This supports earlier findings that despite the questionable credibility of information that is freely available online, people with skin conditions now commonly look online for guidance on self-management (Kanji 2019) because they are not given opportunities to ask questions during consultations and health professionals sometimes offer conflicting advice (De Vere Hunt et al. 2021; Greenwell et al. 2021; Teasdale et al. 2021).

Recall bias indicates that people with lived experience of a health condition or event (aka cases) are more likely than people with no health condition (aka controls) to search for explanations and situate past events in the context of their health conditions (Schmier and Halpern 2004). Recall bias is an issue in cross-sectional and case-control studies, which rely on participants providing retrospective, and potentially inaccurate, accounts (Schmier and Halpern 2004).

Several participants in the present study reported that they struggled to recall details of their condition and treatment history over time and during consultations, which were often weeks, if not months apart. Participants believed the app could offer a convenient space to store information about skin conditions and their management that could help to alleviate the physical and cognitive burden associated with searching for information online, as well as the challenge of retrospectively recalling their medical history. Thus, the proposed app could help to improve the accuracy of information that patients self-report and mitigate the risk of recall bias.

> *"That it's all in one place, would be useful, because you just don't have that at the moment. […] when you're given a new cream, like you search back twenty years: 'Oh, I think I had that when I was fifteen or whatever.' You know, to have it all in an app and all the information up to date, current, easily accessible, would be ideal I think." (G2, Psoriasis, England)*

Many participants expressed scepticism towards the quality and accuracy of the resources available online. Similar concerns have been expressed by people with vitiligo (Teasdale et al. 2018), eczema (Teasdale et al. 2021) and acne (Ip et al. 2021a). These concerns are valid given that advice on acne on YouTube and Instagram is often inaccurate and inconsistent with NICE guidelines for acne treatment (Borba et al. 2020; Ward and Rojek 2022).

Participants were conscious of misinformation online and expressed a strong desire for evidence-based information on skin conditions and their management from reputable sources, including qualified experts from universities, patient and health organisations and the NHS. This reflects previous findings that despite the concerns of some doctors that googling condition-specific information could cause patients unnecessary fears and concerns, the opposite may be true as some people with eczema have reported that they are conscious of the credibility and accuracy of the information they read online and actively seek out reliable information from credible sources, such as the NHS (De Vere Hunt et al. 2021)

Pharmaceutical companies were not considered a credible source because they were seen to be financially motivated. In addition, some participants were conscious of the exploitation of desperate individuals by predatory marketing that they claimed would improve, or even cure, skin conditions with no scientific backing. Participants believed MiDerm could satisfy this desire and would offer a legitimate digital platform that patients could trust, rely on and feel safe using.

"… there's so much misinformation online, none of the information, or very little information that we're getting online or digitally, is regulated in any form. Now how do I know that if I go onto a site, unless I'm familiar with it, am I getting solid information here, is it evidence-based information, or is it just some idiot who's watched a YouTube video and is a self-appointed expert? You know, let people who have the education, training, experience, impart, reputable information, that's where I go, but not everyone does. There are lot of cynical people in life, who are trying to take the hard-earned money from your pocket, and are offering cures for conditions that are currently incurable. And we're all constantly being inundated with nonsense messages along those lines. Not all people will have the wherewithal to wade through this and filter it effectively." (G1, Hidradenitis Suppurativa, Ireland)

This reflect previous qualitative findings, which emphasised that input and endorsement from respected organisations, including health providers and government agencies, but not commercial companies, could facilitate use of an mHealth app for skin cancer screening among the Dutch general population (Sangers et al. 2021).

Sub-theme 4.2: Appropriateness

The consensus was generally supportive of the idea of MiDerm, although the app was perceived to be more appropriate for certain groups of patients than others.

Some participants explained that adapting to life with a skin condition took time and described the adjustment as a process or journey. They believed MiDerm would be most useful for adults who had recently developed a skin condition who were starting out on their journey of adjustment; a time when the psychological impact was perceived to be greatest and individuals were least prepared to cope effectively with their skin condition(s) on top of the existing demands of their daily lives, such as work and raising a family. This contrasted with adults who had lived, and come to terms, with their skin condition(s) over several years:

> *"I personally wouldn't find it particularly helpful […] I've lived with it for a really long time and I've talked about it til the cows come home to other people who have it, and its, you know, it is what it is. […] if I developed psoriasis now, at this point in my life, then actually, I probably would find that level of support and community quite helpful, because, you know, it is completely new to you." (G5, Psoriasis, England)*

We cannot assume everyone has adapted to living with a skin condition and some struggle to adapt irrespective of the duration of their condition.

MiDerm was also considered to be an ideal intervention for children, adolescents and young adults. These groups were perceived to be especially vulnerable and in need of additional support because of the physical, psychological and social changes that they naturally experience during these earlier and critical life stages, which were made worse by the presence of a skin condition (see sub-theme 1.1).

> *"It would be a fantastic concept, this is an under researched area for skin conditions. And has the potential to be a valuable source for younger people (teenagers)." (G4, Epidermolytic Hyperkeratosis, Wales)*

The participants believed an intervention of this kind could, to some extent, help to facilitate continuity of care for patients from childhood through to adulthood.

> *"So important to focus on the younger age and develop the support as people get older." (G4, Psoriasis, England)*

A few participants believed the app could potentially help younger people to form positive habits relating to self-management from the outset, including health-protective behaviours and treatment adherence in particular:

> *"So, I don't know what it will look like, but you know things like creaming? Like if you've got to cream more, looking after the skin, I think that would be really good, purely because I think the more you get into something, the more it becomes a behaviour and you get more used to it. Especially with children with skin conditions, they don't like creaming, they don't like doing self-care as such, but if you do something in the app... I don't know, they track it and it gets better, that might really help." (G7, Lamellar Ichthyosis, Wales)*

These findings are both helpful given that continuity of care is valued by patients, but generally lacking across primary or secondary care services (Nelson et al. 2013), and the needed for new approaches to support treatment adherence (Hewitt et al. 2022c).

The use of digital technologies is now commonplace and these are now integral to global strategies aiming to improve population health and health and social services (WHO 2021). Several participants looked favourably on the idea of MiDerm given that the use of smartphones and apps is now a social norm, although it was acknowledged that not everyone is receptive to this and some are unable, or choose not, to utilise digital technologies. Younger generations were seen to be more adept in using digital technology and this was another reason why the proposed intervention was deemed most suitable for younger people with skin conditions.

> *"I think it is a good idea. It is how many people are used to engaging with others now. It won't be for everyone but will be for many." (G6, Eczema, England)*

Sub-theme 4.3: Concerns reflecting poor illness and intervention coherence

Whilst the general attitude towards MiDerm was positive overall, indicating perceived acceptability, the participants also had some concerns.

Participants commented on the range of existing apps that are designed to support people's general health and well-being. They questioned how the MiDerm app would differ from these and expressed concerns about the market being overcrowded and competitive and how the focus on skin conditions might not be sufficient to set the app apart from others and emphasises the need to ensure the purpose of the app is clear to prospective users:

> *"I think there are already a plethora of Apps out there, that look at trying to improve mental health and physical health um, so, my question would probably be, what's your different, what would be the differentiator of this App, to any one of those other Apps? Apart from the fact that it might focus in a little bit more on, on skin conditions, etc., which wouldn't, wouldn't be a bad thing. Um, more information is always better, but yeah, we, we would need to have some kind of differentiator to be effective." (G5, Psoriasis, England)*

Our group's research provides evidence for common physical, psychological, social, financial and daily impacts across skin conditions (Pattinson et al. 2022). However, only two participants in the present study acknowledged this, and it seemed one of these individuals only realised this through taking part in the group interview.

> *"…although we all have different conditions, there was a lot of commonality and there's a lot of common ground…" (G1, Hidradenitis Suppurativa, Ireland)*

Some expressed concerns relating to individual differences, which gave rise to questions about the scope and suitability of an app for people living with a range of skin conditions. Most believed that the physical manifestations, life impact and the way in which people manage and cope with skin conditions differs from person to person and this led to doubts as to whether a generic app for skin conditions would be comprehensive enough to cover the nuances of each skin condition.

> *"I would just express a wariness, or concern, about that. Sort of, you know, a skin for... a cream for ichthyosis may not be the same as a cream for something else, or somebody's experience, you know, who's got eczema, may not be relevant for somebody that's got ichthyosis, etc." (G2, Ichthyosis, England)*

Different people will require different levels of psychological support to live well with a skin condition and the app may not be appropriate for everyone as each person has a personal level of need. Signposting users to other forms of psychological support was regarded as a potentially helpful solution to this:

> *"Great in principle, it depends on the content and how tailored it is to different skin conditions. Also wonder how suitable it would be for people with more substantial mental health problems e.g. major depression linked to their skin condition vs those with milder symptoms." (G8, Multiple skin conditions, England)*

These findings suggest that it may be necessary to raise awareness of the common impacts of skin conditions among the people who live with them as well as the medical community and public. This was a useful finding given that MiDerm was intended for adults with a range of common and rare skin conditions and aimed to support adults to deal with psychological consequences that are recognised across skin conditions.

The concerns voiced by these participants seemed to stem from the discussion about MiDerm, which, at the time of these interviews, did not exist. Many expressed uncertainties about the app and struggled to envisage what the app might offer in terms of psychological support, and some asked the interviewer for clarification. Whilst most participants reported they had little to no prior or experience of psychological support, this arguably alludes to the idea that some people do not understand what psychological support entails and thus, what kinds of support the MiDerm app could provide.

> *"…That's what I was just trying to get my head around in terms of, of what it specifically intended to target, or if it's about a direction to resources around help or so forth or if there's a chat function for example [laughs], if you do want to talk to someone. […] it's a good idea in principle because if people have an out-, not an outlet but an app which they can use and they've got a, er, knowledge, [sighs] should I say a knowledge forum that's actually full of credible information is super important…" (G8, Vitiligo, England)*

Theme 4 summary

A new smartphone app providing psychological support may be an acceptable adjunct to standard medical care for adults, potentially children and young people with skin conditions. It seems the app could help to fill a persisting gap in dermatology service provision and offer a novel, convenient and credible source of support for people, especially for those who are adapting to life with a skin condition. This theme also offers some useful insight into the participants' illness beliefs and what they understand about skin conditions and their impact and management. Some adults lack a coherent understanding of skin conditions, particularly their impact beyond the physical manifestations, and what psychological support involves, and explains the concerns expressed by participants. Collectively, this theme indicates that some people might benefit from education on the impact of skin conditions and how specialist psychological support could help them to self-manage effectively. The provision of information alone via digital interventions may not be sufficient to evoke behaviour change; increasing awareness could go some way to helping people to adapt to life with a skin condition, but this remains to be tested.

Theme 5: Patients' ideas for the app

Despite low expectations of support, there was a clear desire for an app that increases people's awareness of the physical, psychological, social and environmental factors associated with their skin condition(s) and improves their personal capability to formulate problems and identify and implement solutions to improve self-management.

Self-Determination Theory (SDT), a socio-cognitive theory of human motivation (Deci and Ryan 1985) was a helpful framework in this context. The term 'self-determination' refers to one's personal ability to manage themselves, make decisions confidently and think independently (Deci 1971). SDT argues that human behaviour is predominantly driven by three psychological needs, which, when satisfied, positively influence psychological health and well-being:

- Competence – the feeling that one possesses appropriate knowledge and skills.
- Autonomy – a sense of independence.
- Relatedness – as sense of attachment and belonging that is achieved through close and supportive relationships.

Generally, ideas for MiDerm centred around helping people to better understand themselves (competence) and how similar others cope (relatedness) to support them to become a specialist in managing their own skin condition (autonomy).

“It’s just the fact that the App is dedicated, for people like us […] a massive part of that will be mental health, but also like, there is also the physical things that you go through, which is like, making sure that you’re physically comfortable, and being put in touch with people, helps. Your three pillars, you’ve got the physical aspect, the social aspect and the mental health aspect.” (G4, Vitiligo, Scotland)

Sub-theme 5.1: Understanding me

The COM-B Model stipulates that better understanding of a health problem can improve capability and increase motivation for behaviour change (Michie et al. 2011b). Most participants demonstrated understanding from the active coping strategies that they reported, mainly seeking information. The motivation and behaviours reported by participants were indicative of the SDT concepts of competence and autonomy.

The participants level of self-awareness of psychological impact varied across the sample. MiDerm was perceived as a platform for helping individuals to recognise and address the psychological impact of skin conditions.

“Not focused, but more into the subject regarding self-awareness of skin conditions. What the problems might be causing how you feel, the way you feel” (G3, Netherton Syndrome, Sweden)

Feelings of frustration and embarrassment were common and a few participants said they were disgusted or repulsed by the visible appearance of their skin condition, echoing existing evidence of feelings of anger (Hughes and Hunter 2022), shame (Sampogna et al. 2012) and disgust (Schienle and Wabnegger 2022) in patients.

Some participants, however, were clearly striving for self-acceptance and wanted to be less self-critical and more accepting of their skin condition(s).

“I would love to get to a place where I can just accept it and me. That’s my ultimate goal and I think that comes with time.” (G6, Psoriasis, England)

A few participants said it was important to support people to shift their thinking away from their physical appearance and others explained that they found it helpful to think about their positive traits and qualities. They suggested incorporating compassion-based approaches into the app and including content that prompts users to focus on body functionality and their personal strengths.

> *"… but I think there has been a shift now to kind of more neutrality because I personally think it's quite hard to tell people, you, you should feel beautiful with your skin condition. I think for some people that's really difficult but perhaps it's more realistic to be accepting and just to be neutral about it. […] other people might be, erm, interested, this idea of like your body's a tool, it does stuff for you, it's not, it's not an aesthetic object, erm, which I think is quite an interesting, erm, concept." (G8, Multiple skin conditions, England)*

Some participants recognised the substantial emotional burden of skin conditions and believed it was important to help individuals to identify, process and regulate their emotions effectively. This was important given that alexithymia – the inability to recognise and label emotional responses to a scenario – is common in people with psoriasis (Panasiti et al. 2020). Participants considered MiDerm could be a safe place for people to explore and normalise their thoughts and feelings related to their skin condition(s).

> *"… release you know, strong feelings that get generated in our kind of reaction to our own bodies, but how we think others are reacting, erm, and, erm, especially disgust, it's not something we talk about very much, erm, and in itself it feels quite shameful so I think, erm, I just feel like maybe kind of stuff that we wouldn't normally kind of want to talk about. I think an app would be a really good safe space to, to kind of explore some of those difficult feelings maybe, and then kind of normalise them, erm, and then maybe if there were some kind of strategies, erm, yeah…" (G8, Multiple skin conditions, England)*

Participants wanted the app to provide practical tips that would enable them to label emotions appropriately and control their emotional reactions, especially in social situations where they felt self-conscious and were hyperaware of other people's reactions to them. Relaxation techniques, such as mindfulness, breathing and gratitude, were discussed, although opinions on mindfulness were mixed.

"In terms of psychological things, you could have exercises relating to breathing, meditation, challenging thoughts, increasing confidence with showing your condition, dealing with negative reactions from others etc. Like a toolkit." (G8, Eczema, England)

Existing evidence shows the promise of mindfulness-based interventions for reducing psychological distress, stress and disease severity and improving acceptance and QoL in dermatology patients (Bartholomew et al. 2022; Meneo et al. 2022) (Russell et al. 2019). However, criticisms of mindfulness-based programmes include the length and repetitiveness of meditation sessions (Russell et al. 2019), as well as a lack of personal choice and clarity around their purpose (Fordham et al. 2015). These criticisms may explain why some participants expressed negative attitudes towards mindfulness interventions. Tailoring mindfulness interventions to suit individual preferences and learning styles might increase acceptability (Fordham et al. 2015).

Sub-theme 5.2: Understanding my skin condition

Some people with psoriasis do not understand the links between their skin condition, lifestyle factors and related comorbidities (Trettin et al 2021b). Participants reported that bridging the gaps in patients' knowledge of these factors and the relationships between them would provide a useful steer for self-management and would be a means to re-gaining a sense of personal control. It was thought that the provision of evidence-based information could also improve knowledge and increase personal intentions for change. They conveyed a strong willingness to learn about the interplay between cognitive, emotional and behavioural factors and the skin and believed MiDerm could be a useful platform for delivering such information.

"Control is a very important thing, it's one of the aspects I struggled with a lot […] educating myself about my condition has been empowering, and it's given me back some sense of control." (G1, Hidradenitis Suppurativa, Ireland)

Providing people with the facts was viewed as to a way to alleviate concerns, dispel common myths about skin conditions and the factors that influence them and help people to identify enjoyable activities that are suitable for their skin condition(s).

"I've heard, people are not wanting to do it [physical activity] because they're fearful of like not sweating. So, like ... I don't know. Again, factual ... Like you can still like be active and

> *move your body. You just have to be mindful of like how hot you're getting." (G3, Lamellar Ichthyosis, USA)*

However, most participants understood the importance of living a healthy lifestyle and were aiming for this. Some had felt frustrated and patronised by health professionals who imparted generic health and lifestyle advice with no explanation as to why this was beneficial specifically to their skin condition(s). Participants also wanted practical tips on coping and management, and guidance on how to implement these successfully.

> *"I think yeah in terms of leading a, a healthier lifestyle, I think that's something that we, everyone is striving for […] they [doctors] always say oh yeah, you should reduce your stress. And you're like, that's not helpful, because all that does is increase your stress, trying to reduce your stress, it's not something you can actively choose, not to be stressed. Um, so, um, that's probably the, the least helpful advice, um, you know, maybe some coping mechanisms would be better." (G5, Psoriasis, England)*

Similar findings have been reported in psoriasis (Trettin et al. 2021b) and Keyworth and colleagues (2016) found that primary care practitioners gave individualised, or a combination of generic and individualised, CVD risk information to people with psoriasis during consultations, but mainly used informational or instructional statements. It is, therefore, important that health professionals consider *how* they communicate information about lifestyle to patients. The present findings emphasise the need to establish what people already know, and do, regarding lifestyle, and avoid telling them what to do.

Other aspects of skin conditions that participants wanted to be more informed about via the app include comorbidities and effective treatments to improve understanding of their condition(s) and personal control and influence over decisions relating to the management of their condition(s). They suggested signposting users to other, evidence-based resources on these topics.

> *"… it should have maybe a button or a link that takes you to the actual certified factual information of what the condition is and what, what all of the treatments, the certified treatments that you have and percentages […] So, if it's to do with, you know, psoriasis then it needs to have links to a page that actually is from a medical profession about psoriasis […] I think it would really be helpful." (G6, Hyperpigmentation, Wales)*

Beliefs about the cause of an illness is a key dimension of the CSM (Leventhal et al. 1984). Some participants demonstrated an awareness of possible causes and triggers of skin conditions, but there was also a great deal of uncertainty around the meaning of the genetic influence and whether skin conditions were automatically inherited. Similarly, research shows that people with acne are more likely to attribute acne to diet and hygiene than genetics (and stress) (Ip et al. 2021a).

Skin conditions, such as psoriasis, and their associated comorbidities and treatments can affect fertility, pregnancy, childbirth and breastfeeding (Olejárová et al. 2022). Family planning should, therefore, be a consideration in their management to help alleviate patients concerns about effective symptom control and their children inheriting the same condition (Olejárová et al. 2022). European dermatology guidelines for psoriasis advocate for more open discussions around patients' aspirations to have a family (Nast et al. 2021).

Male and female participants in the current sample reported concerns about starting a family because of their skin condition. Those who had children were anxious or fearful of their children inheriting the same skin condition.

> *"I'm terrified of my daughter getting it, like how, how she would react. [...] I would like to know if it could affect my daughter. So, it's that unknown." (G4, Vitiligo, Scotland)*

Some participants wanted information and support around family planning to help alleviate common concerns and allow patients and their partners to make informed decisions.

> *"If you put something like that on the App, cos people are genuinely worried about having kids and passing it on to their generation, um, I'm sure, whether it could pick it up, I don't know but it is quite a serious thing, cos you could sort of stop your child from having, you know, what you, what you've been through." (G4, Ichthyosis Vulgaris, England)*

Some female participants referred to the unpredictable nature of their skin condition(s) during key reproductive stages, including pregnancy and the menopause, but also in relation to using certain types of hormonal contraceptives. There was much uncertainty regarding female reproductive health, specifically the link between the endocrine system and the skin. Health professionals, as well as patients, reportedly lacked this knowledge.

> *"I have a lot of uncertainty about the future, with my condition, because I know yes, it's a cosmetic thing, but my future children, will they have vitiligo, when? I know people have been pregnant, and they've actually had their pigment come back, so it's little things like that, I have quite a bit of uncertainty." (G1, Vitiligo, England)*

These beliefs and feelings expressed by participants validate the cause and timeline dimensions of the CSM and provide some validation of the usefulness of this model in understanding people's conceptualisations of skin conditions.

One participant explained that there was little information available on ichthyosis and pregnancy and that other women had contacted her for advice and guidance on what to expect during pregnancy.

> *"I've answered a lot of questions about pregnancy and ichthyosis […] I was just learning as I went […] Like as I'm getting older, like wanting to know, like if my skin ... What to expect of my skin, if it's better or worse as I get older? What do older women find more helpful? […] Um, like I've had people reach out about the whole genetics thing, asking me like if ... You know, did we go through genetics before we ... genetic counselling before we had babies? Um, and we did. So, I can, you know, point them in the right direction, where to go for that. Um, and then I've had a few women that have ichthyosis, that have reached out, wanting to know like if their skin changes at all while they're pregnant." (G3, Lamellar Ichthyosis, USA)*

There is currently no standard clinical guidelines or evidence-based recommendations for dermatologists to follow during consultations with female patients of reproductive age (Olejárová et al. 2022). These findings suggests that the provision of standardised, evidence-based information and guidance specific to female reproductive health and skin conditions is needed for patients and clinicians.

However, it was noted that that providing too much information could increase the cognitive burden on users and could lead to people disengaging from the app.

> *"Thinking about content, this, this... If I click here, I get this information. Click here, I get... I go to this. It's, it's, it's now a zillion different options that... That it is difficult to handle." (G3, Netherton Syndrome, Sweden)*

Sub-theme 5.3: Monitoring physical and psychological factors

As well as the provision of educational material and practical advice, there was a clear appetite for an app with a tracking function and there were several perceived benefits to this. Participants believed this would help them to connect the dots between the physical symptoms they experience and other environmental and psychological factors. This reflects the views of people with RA who reported use of a self-monitoring app improved their 'grip' on their condition (Seppen et al. 2020).

Many participants believed that monitoring their mood, health behaviours and physical symptoms, and environmental factors (e.g., the weather) would improve their understanding of triggers relevant to their condition(s) and enable them to recognise new patterns, which they could address through self-management.

> *"… And I guess that's probably one of the things with the app: you can recognise when you have flare-up. What did you mostly eat? Was it late nights? Was it alcohol? Was it spicy food? All these things that people say that it could be connected to. Or is it just the fact that, I don't know, it's part of that time of the month? You know, so it's like finding patterns, when you can understand maybe why you're where you're at." (G2, Psoriasis, England)*

Participants thought this would not only improve self-awareness and understanding but increase motivation and direct personal goals for health behaviour change, as well as reinforce and support the maintenance of current health behaviours that have a positive impact.

> *"I started like a calorie-counting app and I'm finding that's working really good for me. […] I think it'd be really good to reinforce that behaviour as well, I think. It's making me focus on ... So, it's giving me a goal. […] I think, you know, if there's an app that will help you achieve your goal in something – for example, like I say, about skincare – then you know, seeing your skin improve will be the achievement. So, that's, that's just giving me a sense of achievement at the end of it then." (G7, Lamellar Ichthyosis, Wales)*

Whilst there is no certainty that these positive perceptions will translate into action when MiDerm becomes available, it is encouraging to see that people at high risk of melanoma who tested a smartphone app for skin self-monitoring reported performing regular skin checks irrespective of whether they continued to engage with the app or not (Habgood et al. 2021).

Other reported benefits included easing the physical and psychological burden. Some participants explained the challenge of having to remember information relating to their medical and treatment history in between and during consultations, which could be months apart. An app with an inbuilt tracking feature, possibly in the form of a calendar or diary, was viewed as a way of reducing the cognitive load on users. This is an important finding given that people with psoriasis perform significantly worse on neuropsychological tests and experience greater cognitive dysfunction (information processing and retention) than healthy controls, independent of disease severity and depression scores (Marek-Józefowicz et al. 2017).

> *"Yeah, um, and I'm just agreeing with earlier comments about the ability to note what you've tried and the outcomes. It can be really hard to remember, and even when you're seeing a dermatologist and they've got all the information I front of them, they may not necessarily have comments about what has or hasn't worked, and it may not be your own view of what has and hasn't worked. […] If you can't get an appointment for ages, and then you're there, you've got ten minutes. You can't remember your questions; you can't remember your history. Um, yeah, that could be helpful." (G2, Psoriasis, England)*

MiDerm was also considered a potential convenient and useful tool for dermatology consultations that could enable patients to collate their personal information in one place, rather than having to use multiple health apps, and recall information more easily, potentially saving time during consultations. I discuss the implications of this related to recall bias under Sub-theme 4.1. The app was something participants felt they could share with health professionals to make them more aware of the broader impact of skin conditions, facilitate meaningful discussions and shared decision-making.

> *"I suppose another utility of that which wouldn't necessarily be for like self-management would be that you could potentially take that to your dermatologist or GP, erm, if you've got quite a systematic way of like looking at links between those things, it could be useful in that respect as well." (G8, Eczema, England)*

Several participants reported using health-tracking apps, demonstrating acceptability, but also recalled disadvantages to tracking over time. These mainly related to the emotional burden for users, including low motivation, an increased sense of pressure and heightened healthy anxiety.

> *"I know there's quite a lot of, erm, research and things around like fitness apps and sometimes they're actually kind of encouraging like unhealthy behaviours or people becoming quite obsessed or, erm, if people susceptible to eating exercise disorders that can be problematic, so I don't think I have an answer that I think trying to make it useful but not trying to make it into one of those things where people feel like they have to be leading a certain lifestyle or doing a certain thing."*
>
> *(G8, Eczema, England)*

This point should not be overlooked given that health and well-being apps that require tracking lots of information, and frequently prompt tracking, can increase the cognitive load on users (Szinay et al. 2021) and symptom hypervigilance is common in adults who feel self-conscious and embarrassed about their skin (Bundy et al. 2014; Pattinson et al. 2022).

Sub-theme 5.4: Understanding others

Social support, belonging to a social group or being cared for by others, including friends, family members and people in the community (Cohen and Syme 1985) can be categorised as:

- Emotional – showing care, understand and compassion either verbally or non-verbally.
- Informational – exchange of knowledge or experience to improve understanding.
- Financial – offering or giving monetary aid.
- Tangible – practical or physical assistance (Vaux 1988).

Peer support is a form of social support and, in the context of health, involves the exchange of knowledge and experiences between people living with a specific long-term condition (i.e., skin condition) to facilitate adjustment and self-management and to help one another to cope well with their condition in general (Dennis 2003). Peer support is recognised as a person-centred strategy for health improvement that can help to improve patient care quality and health outcomes (Dennis 2003).

Dermatology support groups, particularly those on the internet, appear to be a valuable source of informational, social and emotional support for people living with skin conditions (Thorneloe 2019). However, qualitative research exploring personal experiences of online communities is currently limited and it seems patients and clinicians have different opinions on their use, with clinicians expressing more reservations about inaccurate, misleading and conflicting advice (Thorneloe 2019).

Almost all the participants emphasised the value of peer support and seemed to consider it to be a form of psychological support in its own right. Many reported they were already part of patient communities on social media or through membership of a patient organisation but they emphasised the importance and need for more, better regulated support from people living with a skin condition(s) (see sub-theme 3.6). Participants believed MiDerm should offer some form of peer support and facilitate communication between users, either synchronously or asynchronously. The majority wanted to interact with people who have the same skin condition as them.

> *"Support from other people with your condition is essential" (G6, Lamellar Ichthyosis, England).*

Potential advantages of an app offering peer support were discussed and provide evidence for the perceived effectiveness of MiDerm. Some participants believed that having access to MiDerm would help individuals to increase their social networks and reduce social isolation. This was supported by the experiences of a few participants, who explained they had developed new and lasting friendships with peers on social media, evidencing the positive impact that access to digital platforms can have on sociality.

> *"I've even like become friends with people through like the Facebook groups, like where we ... One of my close friends lives in Canada, but we Zoom and stuff like that from here, from time to time. But yeah, friends that I've made through the community groups." (G3, Lamellar Ichthyosis, USA)*

MiDerm was also viewed as a platform for providing emotional support, which many participants were missing. MiDerm was perceived as a space where adults could share their thoughts, feelings and experiences with people who could relate to, and empathise with, what they were going through. It was thought this would help to combat feelings of loneliness, provide comfort and normalise the challenges associated with having a skin condition(s).

> *"it's about knowing people that have, are living with the same condition […] It really touches home, because you think 'Oh my God, yeah, that, that lady or that guy has just written about something that, that's exactly how I felt, and that's exactly how, and it just makes you feel like you're not the only one with this, you know, and there are millions of people out there, across the world, that are in exactly the same boat as you." (G6, Vitiligo, England)*

MiDerm could be a useful source of informational support. Most participants explained that they struggled to obtain advice and guidance for condition management from existing sources of support (i.e., health professionals). They saw the new app as a valuable opportunity to learn from their peers and understand how others approach self-management. Several participants, who were part of existing online support groups, said the app would provide timely insights and inspiration into new management and coping strategies that would enable them to deal with all aspects of their skin condition(s) effectively, especially in the interim period between medical appointments.

> *"I'm often my own doctor, which is why I tend to rely a lot on the Ichthyosis Support Group. For example, I'll put in a post on there and say, right, this is happening to me now, is this new? Is this something that comes with age? Um, have either of you dealt with it? And straightaway, you know, I'll get um, universal comments from people err, offering support and help and what sort of treatments they've used. […] and something my Dermatologist couldn't answer, someone from Arizona in the US has been able to answer for me. It's just things like that really, the sort of collective experiences online, can help you get the support that you need." (G4, Epidermolytic Hyperkeratosis, Wales)*

Social support is not always positive and can be a source of concern if inaccurate or unhelpful information is being shared (White and Dorman 2001). The participants recalled several disadvantages of existing online peer support groups based on their previous experiences (Sub-theme 3.6). The provision of patient stories in the app was suggested as an alternative and acceptable form of peer support that could provide insight into coping and managing skin conditions and give people hope for the future, whilst offsetting the challenges associated with online patient forums or groups. However, this highlights the need for expert input to validate information and neutralise concerns in a professional and supportive manner.

> *"Hear, hear to hearing inspirational stories from others. Patients listen to other patients more than anyone else." (G1, HS, Ireland)*

In addition to the provision of peer support via the app, some participants noted that virtual interactions often lack empathy and wanted face-to-face contact with other people living with the same condition.

> *"I just had a quick thought, I know this is about like an app, and everything is online, but maybe through this app, having like a face to face group, so whether there could be an option like, on this app, to have … you know, like changing the settings, so that people living close by, so if their postcodes meet, whether they could have like a workshop somewhere, like in a local community centre, where you can see people face to face. Because sometimes we can be so harsh over the screens, and then when you meet people face to face, and you physically see them, it kind of breaks down those barriers, and we become less harsh as well, because there's more empathy towards another human being." (G1, Eczema, Wales)*

This supports the findings of our group's previous work, which showed that remote consultations were useful in psoriasis management during the SARS-CoV-2 pandemic but were limited by the absence of non-verbal cues and emotions (Hewitt et al. 2022e).

For some participants, the opportunity to meet other people with lived experience of skin conditions in person was considered a greater priority than the proposed app.

> *"My entire life, I've never met anybody other than my sister that has the same condition. Wouldn't it be great to meet other people who have the similar condition? You could sit down and say 'Look, this is my problem'. You know, how do you deal with this? And the sort of thing like an app you're talking about is great but it would be nice to meet people you know, like this." (G6, Lamellar Ichthyosis, England)*

Participants questioned whether the app could facilitate in person or synchronous virtual meetings between users in local areas or collate local data. Although this demonstrates poor coherence of the proposed app, these ideas show that there is a demand for face-to-face peer support, which could inform future research ideas for increasing social support for adults with skin conditions.

> *"I think the first time I spoke to someone err, was in my thirties, who had vitiligo, I'd never seen anyone with vitiligo, so, it, it did a lot to boost my confidence, that this person, who had it much worse than I did, was coping, and it, it, you know. So, I think meeting face to face or even in a Zoom condition like this, would be very good, but I don't know how that would work with the App, could you organise it to do it, I don't know?" (G4, Vitiligo, England)*

Theme 5 summary

Three components were considered important parts of a new app designed to support the psychological health of adults with skin conditions. These components mainly related to increasing personal capability (knowledge and skills) for self-management and included: education, practical psychological techniques and peer support. The provision of information on the causes and triggers associated with skin conditions, and a feature that enables individuals to record and monitor these factors, were perceived as ways to increase self-awareness and personal control, and direct goals for self-management. Peer support was considered integral to the app development because it can be a source of both informational and emotional support that could facilitate self-management and coping. Lastly, the app was perceived as a potential space where individuals could process the thoughts and feelings around their condition(s) and learn therapeutic techniques to help regulate these as they arise during daily life. These components mirrored the key psychological needs of competence, autonomy and relatedness which SDT posits are important for human functioning, growth and well-being (Deci and Ryan 2012).

Theme 6: Barriers and facilitators to app use

Several potential barriers and facilitators to accessing and engaging with MiDerm were discussed. These were closely linked to the content, design and functionality of the app.

Perceived barriers and facilitators were mapped against the components of the COM-B Model (Chapter 3). They are presented in Appendix 28 and described below. Some of the potential barriers were applicable to two aspects of the COM-B model and this is made explicit in the text where relevant.

Capability

There was evidence that aspects of both physical and psychological capability need to be addressed to increase the usability of MiDerm.

Physical capability

Some participants recalled using apps that required them to manually enter data or information, but not being able to do so because their skin was sensitive or painful, or limited their dexterity. These apps were described as time consuming and effortful, highlighting the psychological burden on users. Participants suggested MiDerm prompt users with questions and basic response options (e.g., yes/no answers) for them to select, or numeric rating scales to indicate how they are feeling. These question types were considered less cognitively and physically demanding, more time saving and thus, more appropriate.

> *"… I wouldn't want the app to be too much effort. I don't want to document things, just maybe click when I feel the need." (G2, Vitiligo, England)*

Psychological capability

There were several perceived barriers related to the psychological capability of users. Participants thought some adults may be reluctant to use MiDerm because they hold inaccurate beliefs about mental health and employ unhelpful strategies for coping with emotions that they had learned during childhood from familial norms. Whilst this relates to personal beliefs and behaviours, they appeared to be socially constructed beliefs and arguably, related to social opportunity also. Further research is needed for ideas on how to overcome these cognitive and behavioural barriers.

> *"… I'm a bit of a ... kind of an ostrich. […] I come from a family where we don't talk about things. Er, so it's never been a question, to talk about how I feel, or if I have a problem…." (G3, Netherton Syndrome, Sweden)*

Internationally, there is a persisting public stigma around seeking professional support for mental and psychological health (Vogel et al. 2017). Some people internalise the public stigma associated with seeking psychological services, which can lead to self-stigma and subsequently influence the attitudes and help seeking behaviour of individuals (Vogel et al. 2017).

A few participants believed that self-stigma may prevent some adults with skin conditions accessing appropriate support via the app. No suggestions were made as to how to overcome this.

> *“yeah but do people think that they go to mental support because they’re going mad or something like that? And there’s still a bit of a stigma, a stigma in my mind, certainly. But there may be a stigma in people’s mind. It’s a skin condition at the end of the day. Yes, it does affect you mentally.” (G6, Lamellar Ichthyosis, England)*

A few participants expressed scepticism towards corporate organisations. Participants were wary of pharmaceutical companies, who were perceived to be more motivated by sales and economic gain than the welfare of patients. This suggests a lack of trust in the people, or organisation, who fund new digital interventions may be a barrier to their use. It relates to the finding under sub-theme 3.6 referring to the questionable quality of freely available information on online patient support groups. Together, these findings show that there is an absence of safe and quality guidance on self-management from credible sources who adults with skin conditions trust. Participants proposed endorsement from charitable organisations that represent people living with skin conditions to overcome these concerns about the role of industry.

> *“[Moderator]: [participant] said ‘no links to big pharma’, [participant] do you want to say a bit more?” “[Participant]: Only that, erm, you know, I think being suspicious of anyone who you think is trying to sell you medications [laughs]. Erm, you know, I think it’s important the developers have integrity, erm, and you feel like they genuinely have like patients best interests at heart and, so I think it would be good if the skin charities were kind of able to endorse the content and say, you know, this is a trustworthy source […] I think would give confidence.” (G8, Multiple skin conditions, England)*

Similar findings have been reported elsewhere; Sangers et al. (2021) found that mobile app developers with a commercial motive were perceived as unreliable in contrast to GPs, dermatologists and government regulating bodies whose endorsement was viewed as a sign of quality and safety assurance .

MiDerm was funded by an industry partner and thus further research is needed to deepen our understanding of these concerns and identify other ways to alleviate them.

Several participants believed that some people, particularly older adults, may lack the skills to use digital technology compared to younger people who were generally perceived to be more proficient in the use of technology.

> *"Well, I was just going to say that I think of myself as being quite computer literate, but then I look at my grandchildren and I don't ... I'm nowhere in their league. […] you mustn't always make the assumption that everybody that has a skin condition is young and has grown up using their thumbs for technology, if you like." (G2, Vitiligo, England)*

This quote highlights self-efficacy; the confidence that one has in their own ability to perform a behaviour successfully (Bandura 1977). Self-efficacy is one of the key concepts of the TFA (Sekhon et al. 2017). The systematic review showed that digital psychological interventions have the potential to increase self-efficacy (Hewitt et al. 2022c). One of the studies reviewed showed that self-efficacy (and knowledge) moderated the relationship between use of a digital intervention for adults with melanoma and performance of sun protection behaviours advocated within the intervention (Manne et al. 2021). It seems some adults may not be proficient in the use of technology and others may lack confidence to engage with digital platforms. Thus, self-efficacy should be considered throughout the app development process.

The participants emphasised the importance of developing an app that is user-friendly and simple to navigate so that it is suitable for everyone, irrespective of their skill or confidence levels. Similarly, Sangers et al. (2021) found that a complex and distracting interface may be a barrier to users, particularly those of an older age, quickly and successfully navigating a skin cancer screening app. Participants believed MiDerm should resemble existing apps (e.g., NOCD) that they had used and suggested a simple interface comprised of distinct sections for different topics to ensure ease of use.

> *"Different icons/squares to click on with different sections (e.g., forum, tracker, information etc.)" (G8, Eczema, England)*

Providing prospective users with instructions for using the new app could help to increase their confidence and skills, although this suggestion did not come from the participants.

Participants thought that developing an app in English only would prevent people who are not proficient in the English language from engaging with the app. Translating the content into other common languages was considered important for reaching people with skin conditions whose first language is not English.

> *"The easiest answer is translation […] It needs to be accessible in a lot of languages, not perhaps only the standard English, Swedish ... Sorry, Spanish, French. The biggest – Chinese, perhaps. I don't know. […] It needs to get more accessible in more languages, I think." (G3, Netherton Syndrome, Sweden)*

The term 'health literacy' refers to how well people understand information that relates to their health, well-being and services (Gursul 2022). Health information often involves complex or technical terminology and numbers, which people have difficulty interpreting (Gursul 2022). Health literacy is a public health issue because it can influence the extent to which people manage their health (e.g., taking medicines as prescribed), engage in health services and patient health outcomes, including morbidity and mortality (Gursul 2022).

Low health literacy is a common problem in the UK; it is estimated that 7.1 million adults read at, or below, the level of an average a 9-year-old and four in ten adults have difficulty understanding health information, which rises to six in ten where health information includes numbers and statistics (Gursul 2022). Poor health literacy is common in people who are socially disadvantaged and marginalised groups are less likely to understand health content (Gursul 2022). The SARS-CoV-2 pandemic emphasised social disparities in health literacy (Gursul 2022). Making health information comprehensible could help to improve health outcomes and the following recommendations have been proposed as to how to communicate health information so that people with all literacy levels understand (Gursul 2022):

- Use simple, balanced language – avoid jargon, clarify who the information is for, make it relevant to the target audience, provide a balanced picture of the evidence and mention the quality of the evidence.
- Find the focus – ensure key health messages are clear and are framed appropriately.
- Online information needs to be relevant – health information needs to be relevant to the individual, group or population you want to reach.

- Consider suitable ways of communicating with groups who may face additional barriers (e.g., language, low literacy, living with existing health conditions or disabilities).

Participants emphasised the importance of writing the app content in lay language and avoiding using jargon so that the health information included can be understood by all who use the app, irrespective of the literacy level. Including visual content was suggested to make information easier to understand.

> *"Easy navigation, so, you've got an easy drop down menu, you can find things quickly, there's not lots of jargon and that way, people who aren't as text savvy as perhaps we are online, um, can still navigate, it shouldn't exclude people who are less text savvy, yeah." (G4, Psoriasis, England)*

The issues language translation and terminology should be addressed to ensure adults can access the app irrespective of the language they speak and their literacy level. It is important to determine the level at which health information is best processed and understood to reduce the cognitive burden on prospective users of MiDerm.

Opportunity

Social opportunity

Poor awareness of the app was perceived as a potential barrier that could influence the number of people who access MiDerm when it becomes available, highlighting the importance of effective marketing. Getting trusted and credible sources, mainly patient organisations, to endorse and promote the app was suggested to increase awareness of it among the target group, as was advertising the app in GP surgeries and making MiDerm available on prescription and via the app store.

> *"I think going direct to the Organisations/Societies and ask them to put the App on their site(s) and recommending members to download it. Also, Doctor surgeries advertising it and all Groups associated with skin conditions." (G6, Vitiligo, England)*

Physical opportunity

High cost was perceived to be a potential barrier reducing opportunity for wider reach to the population in the present study. Previously low or no cost of use was a perceived facilitator to engagement with a skin cancer screening app (Sangers et al. 2021).

Social prescribing, or community referral, is the ability of health professionals to prescribe non-clinical services, or alternative activities, to help give people more control over their health and well-being; it is a key strategy for personalising care outlined in the NHS Long Term Plan (NHS England 2019). Participants discussed making MiDerm available on prescription to improve access for people on lower incomes. A few participants said they would be happy to pay a low subscription fee if they perceived the app useful.

Several participants expressed concerns about safety online, especially when using social media platforms (sub-theme 3.6), which was also related to psychological capability. Introducing a small subscription fee was proposed to deter people with ulterior motives from accessing MiDerm and make prospective users feel more safe and secure when using the app.

> *"Having a small cost would deter those that aren't kind of genuine, but then equally you don't want to exclude people from being able to access it on a financial basis […] I think about the term 'Social prescribing' you know, a doctor could prescribe it almost as a support tool for those that couldn't necessarily access it." (G6, Psoriasis, England)*

However, most participants believed the app should be free to access to allow all adults an equal opportunity irrespective of income and especially considering the extra expenses that people regularly incur due to having a skin condition.

> *"I think with people accessing it, because even if it was quite cheap to buy, if people have got limited income or are spending money on quite a lot of other things helps, then I think it [no cost] would open it up to more people." (G1, Psoriasis, Wales)*

'Digital divide' is a phrase that describes inequities in the availability, accessibility, affordability and usability of digital technology, as well as the capability to use it. We know certain groups within society, including people of lower socio-economic status and literacy level, colour, older age and female gender typically have more difficulty accessing and using digital technology (White and Dorman 2001). The digital divide contributes to existing health and social inequalities and increases the likelihood of poorer health outcomes in already vulnerable groups (Reddy et al. 2022). It was also amplified by the SARS-CoV-2 pandemic (Local Government Association 2021).

Participants recognised that having limited or no access to a smartphone or the internet were physical barriers that could prevent people from accessing psychological support delivered via an app. Building a web-based app that works on different digital devices (e.g., a computer) and producing downloadable content for people to use offline were ideas for improving accessibility.

"… you have to take into account, not everybody has a Smart Phone and an App and it can be difficult. […] We need to work on a variety of devices as well, so, a lot, a lot of the time, some of these Apps are designed in a way that, that you, you don't need a new phone […], you want it to be able to work on, anything, so, your development costs would be a lot higher to test it." (G4, Vitiligo, Scotland)

Motivation

Reflective motivation

Speaking from prior experience, several participants explained that accessing and continually engaging with apps is a personal choice that depends on how one feels, physically and psychologically, from day-to-day. This seemed especially true for apps with a tracking feature, which participants struggled to adhere to over time because of the regular and consistent input these apps require. Low reflective motivation was, therefore, perceived to be a potential barrier to maintaining continued use. It highlights the importance of considering strategies for behaviour maintenance, as well as initial behaviour change.

"I always start off really well with these tracking Apps and I am like the perfect student for the first three days and then I just am really bad at them…" (G5, Psoriasis, England)

This corresponds with previous findings that people living with RA consider respondent fatigue a possible barrier to using disease self-monitoring apps (Seppen et al. 2020), and motivation for using self-care apps tends to decrease once users identify personal triggers (Anderson et al. 2016). Motivational dips were also cited as a barrier to regular engagement with a complex, personalised behaviour change intervention for people with XP, particularly during winter months when the perceived importance of performing photoprotection behaviours was lower (Walburn et al. 2023).

Various ways of maintaining motivation and engagement over time were discussed. One participant explained that their motivation would depend on the effectiveness of the app, specifically whether they observed any physical improvements in their skin after a period of using it.

> *"So, all the facets that we've talked about, whether it's educational, social, psychological, diet, or whatever, all of those would come in and if I saw that by participating in what the App had to offer, led to my skin, being better and me being able to help it to be better, absolutely, that would keep me in, keep me in, I'd be thinking, I've things to do (chuckling)." (G5, Psoriasis, England)*

More generally, the participants suggested incorporating the perspectives of the target audience into the development of the app from the outset to ensure the content of the app is relevant to the target population. One participant, who came from a research background, suggested cognitive interviewing as a method for capturing ideas and feedback from adults living with skin conditions. This shows some participants valued a PBA to intervention development (Yardley et al. 2015b) and is evidence of ethicality, a key concept of the TFA (Sekhon et al. 2017).

> *"I guess people who might use the app at the end, so people like us, erm, maybe doing like think aloud interviews or something like that, where someone tries to walk through it and then goes, oh, I don't understand where this is or, oh this is really hard to use or that kind of thing, I think is really important because even if it's got really good information on it, if people find it really inaccessible or clunky then they probably won't use it." (G8, Eczema, England)*

Other ideas for sustaining motivation included regularly updating the app's content and providing users with progress updates, praise and virtual rewards in real time when using the app.

> *"I think it depends what the main purpose of the App is gonna be, if it's tracking, I think having kind of rewards and goals […] if you log seven days in a row, you might have a smiley*

> *face or something […] there's a recognition of what you're putting in. If it's an information App, um, then obviously, just making sure that the, the content is regularly updated, um, so that there's a reason for people to go in, um, um, or if, even if the content is not updated regularly, um, it's at least reviewed regularly." (G4, Psoriasis, England)*

Sub-theme 6.1: Personal choice and autonomy

There was a clear desire for an app that individuals can use flexibly to suit their preferences and circumstances. Respecting the autonomy of users was seemingly important for sustaining app use in the longer term. Examples of this related to the privacy settings and specific functions of MiDerm, including push notifications.

As mentioned above, willingness to engage with the app was dependent on a range of individual factors, including fluctuating levels of motivation and mood. Because of this, the participants believed it was important that there was no expectation of, or pressure on, users regarding the frequency or duration of app use. Participants wanted the app to be flexible in the sense that users are given autonomy to decide how often, and for how long, they use the app for.

> *"Um, so, it would be good if the App just, you could go in and out of it […] if you think, yeah, I've kind of conquered it for a few months and then you kind of have to go back with your tail behind your legs and be like, oh it's come back again. Um, so, just that kind of, you may not be getting people using it, day in, day out, constantly, but it would be nice, if there's, if it's easy for people to take a break from it and then step back in." (G5, Psoriasis, England)*

Message framing should be considered when communicating health information because how health messages are worded can influence people's intentions for performing a behaviour (Rothman et al. 2006; Gallagher and Updegraff 2011). *Gain*-framed messages convey the benefits of performing a behaviour and can increase intentions for performing health-protective behaviours, such as keeping active (Rothman et al. 2006; Gallagher and Updegraff 2011). An example of a gain-framed message related to sleep would be "Consistently sleeping for 7-8 hours per night can reduce the risk of several serious health conditions". *Loss*-framed messages emphasise the risks or consequences of not acting and may be more suitable for encouraging health-detection behaviours, including attending health screening appointments (Rothman et al. 2006; Gallagher and Updegraff 2011). An example of a loss-framed message on sleep would be “Consistently sleeping less than 7 hours per night can increase the risk of several serious health conditions”. However, evidence for the different types of framing is somewhat inconsistent depending on the context in which they are used, the target group or behaviour, and outcomes of interest, for example, whether the focus is on influencing behavioural attitudes or intentions or behaviour change (Gallagher and Updegraff 2011).

Keyworth and colleagues (2018) found significant effects of messaging framing on behavioural intentions for alcohol reduction in people with psoriasis, but not physical activity or diet. Loss-framed messages were found to be more effective for communicating CVD risk reduction information whereas gain-framed messages were more effective for conveying information on reducing physical symptoms of psoriasis (Keyworth et al. 2018). Condition-specific health messages should be framed appropriately depending on the health behaviour and and the proximity of the potential risk (Keyworth et al. 2018).

Participants in the present study discussed the use of push notifications to support long-term motivation and engagement and emphasised the importance of message framing. Some participants looked favourably on using push notifications that include upbeat and encouraging messages, such as quotes or tips for coping. Messages of this nature were viewed as a source of daily hope and positivity that could act as nudges to performing health-protective behaviours.

> *“A simple thing that I found very effective in the group I do, is to post an upbeat message every day, a nice, simple quote. […] Just something positive, simple, something to hope for, I think. […] You know, things can get better, things can improve. Moods change, feelings change, etc., etc., today’s a bad day, but tomorrow may be a good day, that type of thing.” (G1, HS, Ireland)*

Participants explained that receiving regular push notifications had been a source of frustration and pressure for them in the past and could adversely effect mood and motivation, particularly if the messages they included were instructional or negatively framed.

> *“I, I personally think that too many prompts and too many reminders could, could perhaps have negative connotations, because if you’re already beating yourself up because, you*

> *know, you perhaps think you've done something that aggravated your skin condition because you're […] it could have a negative downside, make you feel worse." (G2, Vitiligo, England)*

This reflects a previous finding that reminders for tracking could cause users harm by reminding them of the behaviour they are trying to reduce (Szinay et al. 2021).

How messages within push notifications are worded could also be a deterrent to long-term app use.

> *"Personally I hate them […] It's like you're being told off, because it's like oh yeah, it's a reminder that you haven't done it, it's like then it turns into a chore." (G1, Vitiligo, England)*

> *"I think generally the notifications are really annoying […] often the problem with notifications is that they, they come too often, so people finish up, er, blocking them or, or uninstalling the app that sends them or whatever." (G8, Multiple skin conditions, Denmark)*

Ensuring messages are worded appropriately for the target audience was suggested to reduce the psychological burden on users and maintain engagement with the app.

> *"So it's a reminder that the app's there, but also it is that little bit of hope, rather than being annoying that you haven't done this today, or oh yeah, like pick up your phone, go on the app, it's still there, but without being in your face." (G1, Vitiligo, England)*

As was allowing individuals to choose the frequency and time of delivery of push notifications.

> *"Yeah, it's just reminders that you get on your phone, that the user can control when, what time of day might be best to update, not that I always do these things, but you know, if it's, if you've got something popping up at a regular time, every day, then you might be more inclined to, to update something." (G5, Psoriasis, England)*

Sangers and colleagues (2021) showed that concerns about privacy and data sharing may be barriers to people using mHealth apps for skin cancer screening. These concerns relate to the psychological capability of users. Interestingly, when the participants in the present study were asked how they would feel about inputting personal data (e.g., medical information, geographical location) into the new app, most said this would not be an issue providing protocols for data protection are followed (i.e., General Data Protection Regulations [GDPR]), that those responsible for data handling are trustworthy, and there is transparency around how and why their data will be used.

“Fine as long as proper data protocols, clear use and not vehicle for data mining or selling.” (G2, Psoriasis, England)

One participant believed people are often fearful of inputting personal information into apps or online but tend to overlook or discount this when they come to use these digital mediums, suggesting these concerns do not necessarily translate into generalisable behaviour.

“Everyone just downloads things and clicks accept on anything. Everyone says like: ‘Oh, I’m terrified about my data being stolen.’ Then as soon as they’ve got an app or something and it needs accepting to use it, they just accept it and off they go. So, I’d be surprised if anyone actually cared about that – but maybe they do?” (G7, Vitiligo, England)

Giving people the choice to register anonymously with a username was suggested to help overcome potential concerns about privacy and confidentiality. Allowing users to remain anonymous was also viewed as a potential research opportunity for data collection.

“I mean, they could make some sort of username that has nothing to do with their personal information. […] Like I’m an open book, so I can put ... I could put my name, if I wanted to do that. So, that way, like you’re covering people that want to build the community, and then people that would rather remain, remain anonymous.” (G3, Lamellar Ichthyosis, USA)

Sub-theme 6.2: Look and feel of the app

Potential designs of the new app were discussed, and this aspect of intervention development was considered important for two main reasons: inclusivity and creating a positive user experience overall.

Participants recognised that people often present with more than one skin or health condition. They wanted the app to account for this and acknowledge the complexity of people’s situations instead of asking them to specify one condition. This point relates to the physical capability of prospective users.

"Able to use it if you have multiple skin conditions ie not made to pick one main one in order to use the app." (G8, Multiple skin conditions, England)

Participants also recognised that prospective users may have other health complications, or comorbidities associated with skin conditions, which may be physical barriers to them using the app. They emphasised the need to consider people's physical health status. It was recognised that some people living with skin conditions, such as Netherton Syndrome, may have impaired vision or hearing, which could reduce their physical capability to engage with the app. To increase accessibility, participants stated that the colour scheme needs to be carefully considered and audio descriptions should accompany written material and on-screen captions should appear with any audio or video content.

Captions, audio, visual, use of colour." (G5, Psoriasis, England)

The design of the app was also deemed important for creating a positive user experience. The points below were not relevant to the COM-B model and were classified as 'other' potential barriers to using MiDerm.

A couple of participants described apps or websites that they had used in the past that they felt resembled a 'clinical' environment. They conveyed that the way in which these platforms were designed influenced how they felt and their overall experience of their use.

"During Covid, I was one of the First Responders and the app was just so clinical and clunky and not very easy to use. And just something that's really simple, it's got some nice graphics, etc. You know, it just, it doesn't look like your GP's website basically, which are notoriously not easy to use. But yeah, I think just a bit more friendly, a bit more welcoming. Something that is aesthetically pleasing, that you would want to go and look at as opposed to going onto an app and going 'Oh, okay right, it's just words, it's just text, that kind of thing'." (G6, Psoriasis, England)

Participants wanted the app to make them feel welcome, part of a community and calm. Some were aware that colours can signify different qualities and emotions; they believed the people responsible for designing the app need to give careful consideration to its colour scheme and brand identity more generally to ensure these align with the purpose of the app.

“I’ve been reading recently about the psychology of colours and a lot of health authorities use blue and green scrubs etc., etc., it inspires confidence and intelligence, etc., etc., there’s a lot to sort of psychology of colour.” (G1, Hidradenitis Suppurativa, Ireland)

The consensus was that light colours, mainly shades of blue or green, were most appropriate for the new app. These colours were used within existing apps in the health, well-being and fitness space that participants reported using previously. The new app was likened to these apps; participants believed they shared the common goal of supporting healthy living, and thus, they envisaged the new app would look, and potentially function, in a similar way. Some participants recommended looking to existing health and fitness brands (e.g., PureGym) for inspiration for the design of the new app.

“… but I do think that the idea of sort of looking at what some of the gyms do may not be a bad idea. […] It’s all about, you know, let’s, let’s be positive and let’s talk about food and let’s talk about this and that. and you know, like pictures of people living their full life, which is what I suppose we’re wanting to, to do here.” (G6, Eczema, England)

Theme 6 summary

Whilst a smartphone app offering psychological support may be appropriate for some adults with skin conditions, there are several factors that could limit or prevent use. Many studies, including the present one, have shown that skin conditions carry a substantial burden. It is essential that digital interventions, including the proposed app, help to reduce, rather than increase, the burden on patients. This theme highlights that intervention developers cannot make assumptions about people’s level of confidence, knowledge, skills or physical ability to use digital technology; it needs to be tested. It shows the value of the COM-B Model (Michie et al. 2011b) in identifying a range of factors at the individual and society level that influence behaviour, information that developers can carry forward to ensure interventions are suitable and practical for the target audience. The data presents a range of ways in which the design and functionality of the new app could help to minimise the physical, psychological and financial burden on potential users and be inclusive of groups of patients who are at greater risk of marginalisation due to having more complex health needs or poor access to technology. Ultimately, intervention developers need to engage key stakeholders, including patients, throughout the development process to ensure the new digital product is easy to understand and use. The app should allow some degree of flexibility and offer users a choice over the functionality of certain features to maximise usability and engagement in the immediate and longer term.

Discussion

We confirmed that visible skin conditions can have a substantial impact and alter the life course of the people who live with them. Participants reported several issues with the current provision of medical care, including how medical professionals interact with them during consultations. Individuals often relied on patient organisations as a trusted source of informational, emotional and peer support, necessary for coping effectively with a skin condition. Online support groups were another avenue of support, although participants were skeptical of the motives of some people using these platforms, questioned the quality, safety and credibility of information available, and reported that their use could adversely affect psychological well-being. Despite reports of the psychological impact being most difficult to self-manage, most participants had not received any form of psychological support from healthcare sources. Those who had reported lasting benefits to their self-confidence and capability to address negative thoughts and emotions, especially during social situations, but specialist and dedicated psychological support from qualified health professionals with experience in managing skin conditions was mostly missing.

The idea of a new complex intervention delivered via a smartphone app was acceptable to these participants, although the intervention was perceived to be more beneficial for certain groups, and it is important to convey how psychological support could potentially help individuals to live well in their own skin. Participants desired an app that could be used flexibly, offered evidence-based information and tips for addressing the psychological aspects of skin conditions, and included peer support. The main ideas for the reflect the core elements of SDT (Deci and Ryan 1985); participants wanted opportunities to relate to and learn from similar others and have greater autonomy over their skin condition by becoming more competent in managing all aspects of it. Education on skin conditions, potential triggers and approaches to management, as well as supporting people to accept their skin condition, were viewed as important for increasing personal control and intentions for, and enacting, health behaviour change. Participants believed a new app could help to improve communication between patients and health professionals. Participants discussed several barriers that could potentially affect engagement with the app and suggested how the content, functionality and design of the app could help to overcome these barriers.

What this study adds

Themes one to three covered the topics of impact, existing support and the pursuit of control amid uncertainty, and these data demonstrate the need for additional support for adults with skin conditions and justify the development of MiDerm. The findings reinforce those of our previous research on the impact of dermatological conditions; impact can be both point in time and cumulative and different types of impact are akin to common and rare skin conditions, although the psychological and social aspects carry the greatest burden for patients (Pattinson et al. 2022).

Some of the findings reflect those of a recent systematic review, which concluded that younger age, female gender and late condition onset are some potential risk factors for CLCI (Von Stülpnagel et al. 2021). The present study shows that children and young people, adults with late condition onset and women may be more vulnerable to CLCI because they do not have sufficient knowledge, skills or confidence, and they are not professionally supported, to successfully adapt to having a skin condition. This partly aligns with research involving adults with visible differences, who recognised that personal levels of psychological need vary and individuals with recently acquired visible differences are likely to have a higher level of need (Zucchelli et al. 2021). Similar results have also been reported in the XP population; a complex behaviour change intervention targeting photoprotection behaviours was considered more appropriate for people who are newly diagnosed with XP because they require more reassurance and guidance on XP and its management during that early stage (Walburn et al. 2023). It seems these three groups, and particularly adults who have recently acquired their skin condition, may be in greater need of psychological support via an app.

Participants, especially those who had lived with their condition for years, emphasised the role of self-acceptance in effective self-management. Being able to accept oneself and their condition was perceived as a way for individuals to regain some control over their condition and live better with it. A qualitative online interview study investigating the benefits of a private peer support group on Facebook for people with alopecia found that group membership fostered feelings of connection and belonging among individuals, who subsequently felt compelled to meet similar others and give back to the alopecia community (Iliffe and Thompson 2019). In addition, being part of a group reportedly facilitated self-acceptance and individuals gained more courage to attend social events and live life as they wanted (Iliffe and Thompson 2019). These present and past data suggest that supporting people to be more accepting could lead to improvements in psychological and social functioning. This has implications for MiDerm and it is important to consider how the app could support users to accept themselves as they are.

Our findings reiterated that current provision of care mainly follows a biomedical model (Trettin et al. 2021b) and specialist and dedicated psychological support for people with skin conditions is still widely lacking (Massoud et al. 2021). Generally, participants wanted to work collaboratively with health professionals to make informed decisions on the management of their skin condition(s) (Larsen et al. 2019). However, most health professionals reportedly missed opportunities to address the psychological impact and discuss health behaviour change (Nelson et al. 2016) and only offered generic lifestyle advice during consultations (Trettin et al. 2021b). The development of a new digital psychological intervention, with a specific focus on support for behaviour change, for adults with skin conditions was, therefore, warranted.

It is understood that most people receive little, if any, support to manage the psychological impact of skin conditions (APPGS, 2020). Little is currently known about the views and experiences of people who have received psychological support in relation to their skin condition. The results of a survey of 544 people living with a diagnosed skin condition indicated that only 18% received psychological support. In terms of psychological interventions, counselling and CBT were most reported followed by antidepressant medications and habit reversal and mindfulness, but waiting times for mental health services were lengthy and support tended to be generic rather than specialist and dedicated to dermatological conditions (APPGS 2020).

This study contributes to existing literature and offers some insight into the advantages and disadvantages of psychological support from the patient perspective. Participants desired specialist support from health professionals with expertise in psychology and dermatology but suggested some people may be less receptive to receiving psychological support because they might not fully understand the psychological impact of their skin condition, or what psychological support involves and how it could help them. This relates to the findings of an earlier survey, which found that many people do not actively seek help in connection to their psychological health and well-being due to poor awareness of existing types of psychological support, as well as low availability of appropriate services and a lack of mental health diagnoses and signposting by health professionals in dermatology (APPGS, 2020). Only 14% of people who participated in the survey were aware that the NHS offers a limited number of psychological services for people with skin conditions (APPGS, 2020).

Similar issues have been identified in the context of other long-term health conditions, including chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (Sykes 2002). The question as to whether CFS should be classified as a physical or mental health condition has been a subject of debate, as has this distinction been the subject of major criticism (Sykes 2002). The cause of CFS is currently unknown and people experiencing CFS report a range of physical and psychological symptoms, many of which are medically unexplained, which further complicates the challenge of identifying causation (Sykes 2002). Nowadays, a combination of pharmacological and psychological approaches is recommended for managing CFS that are tailored to individual presentation (Noor et al. 2021). However, medical misattributions, common misconceptions and public stigma around mental illnesses (Sykes 2002), and the presence of physical symptoms only, has meant that some people with CFS reject psychological explanations and approaches to managing CFS (Hareide et al. 2011).

Collectively, present and past findings suggest it may be necessary to make adults more aware of the psychological consequences of skin conditions, as well as psychological support that is available to them and the benefits that have been reported by patients. It is important that the purpose of future psychological interventions, including MiDerm, is clear to the people who will receive them.

In addition, this study highlights the pros and cons of additional types of support that are available to people with skin conditions other than standard medical care. Peer support was of high importance to these participants. Patient organisations played a crucial role in supporting self-management and the use of online support groups, particularly on social media, was relatively common (Szepietowski et al. 2018; Kanji 2019), although these platforms need to be better moderated and regulated to protect the physical and psychological health and general safety of users (Petukhova et al. 2020). Featuring patient stories within an app was considered a useful form of peer support that could offer some of the same benefits (e.g., learning ways of coping and managing) as a Facebook support group for people with alopecia (Iliffe and Thompson 2019), whilst offsetting many of the issues that participants in the present study had experienced with online peer support.

Despite evidence that health behaviours implicated in future health risk of CVD (Sawada et al. 2021; Hu et al. 2022), few studies have sought to explore the types of support that patients need to effectively reduce health risk behaviours. People with psoriasis have previously reported that they do not understand the link between psoriasis, lifestyle and risk of developing comorbidities (Trettin et al. 2021b), indicating a clear knowledge gap. Parents and carers of children with eczema have reported that their knowledge of eczema triggers and treatments is limited, as are their skills needed to manage and co-manage their child's eczema (Sivyer et al. 2022). The current study suggests this knowledge and skill gap may be a barrier to behaviour change. Participants wanted to better understand their condition and approaches to management. They believed the provision of evidence-based information linking psychological factors and environmental triggers to the skin, as well as self-monitoring via the app, could motivate people to make necessary lifestyle changes. Recent evidence shows that digital psychological interventions can increase condition-specific knowledge in adults with skin conditions (Hewitt et al. 2022c) and young people with eczema (Greenwell et al. 2022).

Education alone may be a necessary, but not sufficient, condition for behaviour change and it is now widely recognised that digital interventions should be based on established theories and techniques for behaviour change (Michie et al. 2017). A recent qualitative study evaluated the retrospective acceptability of a complex, personalised and multi-modal intervention for changing photoprotection behaviours in people with XP (Walburn et al. 2023). Increases in photoprotection behaviours, such as applying sunscreen, were reported by participants who attributed changes in their behaviour to greater awareness, increased motivation and self-confidence, goal setting, and the formation of habits, which supported the maintenance of newly adopted behaviours (Walburn et al. 2023). This suggest that the provision of education can, in part, have a positive influence on health behaviours. Featuring educational material within the MiDerm app was deemed appropriate by participants in the current study, but it is important to determine the mechanisms for change including whether any acquisition of knowledge resulting from the new app impacts health, and particularly lifestyle, behaviours.

Furthermore, whilst health tracking devices can increase personal awareness of behavioural patterns and motivation for health behaviour change in people with long-term health conditions (Birkhoff and Smeltzer 2017), the use of digital devices to track health behaviours has been found to increase health anxiety in people with health conditions, such as atrial fibrillation (Rosman et al. 2020), and participants in the present study suggested the law of diminishing returns may apply to digitally tracking health behaviours over time. An app that allows users to monitor their physical and psychological symptoms and triggers may be desirable, developers must ensure that the inclusion of a tracking feature does not increase the physical or psychological burden on users.

The current findings collectively alluded to the idea that apps are more than just a platform for disseminating condition-specific education. They indicate that an app which facilitates interactivity may help adults to retain or regain a degree of personal control, as the data individuals input belongs to them, and the individuals can use their data to increase their personal capability for self-management beyond what could be achieved through the provision of information alone. Whilst this claim needs to be validated through further research, it is important at this stage to consider the people who use the app as more than just passive recipients of information and to develop the app in a way that meets more than information needs alone.

Finally, this study used the COM-B model (Michie et al. 2011b) to identify potential barriers to engagement and how the content, functionality and design of the app could facilitate initial and sustained use. Ensuring content is relevant to the needs of the target audience (Zucchelli et al. 2021; Walburn et al. 2023) and up-to-date was considered important (Teasdale et al. 2018). It was recognised that the physical symptoms and comorbidities, including pain and impaired vision (respectively), associated with some skin conditions might impede people’s ability to engage with the app and thus, ensuring ease of use was an important consideration (Sangers et al. 2021; Zucchelli et al. 2021).

Text messages can act as useful reminders that can help reinforce new habits, including skin protection behaviours, such as applying sunscreen (Walburn et al. 2023). Participants in this study expressed mixed views about the use of push notifications to encourage people to engage with the app. How messages within push notifications are framed was perceived to influence whether people choose to continue using the app. Participants advised against instructional, generic and patronising language and advocated for messages (e.g., quotes) that help to remind and inspire people to use the app and improve psychological well-being. This highlights the importance of messaging framing to ensure push notifications serving as prompts for behaviour change are appropriate and encourage, rather than deter, use of the new intervention. It seems positive, gain-framed messages may be more likely to encourage use of the app overtime.

The ability to use the app flexibly was also a priority (Zucchelli et al. 2021). The participants wanted freedom to decide when they use the app and choose the settings for some features (e.g., frequency of push notifications) so the app meets the personal preferences of the user.

Strengths and limitations

One of the main strengths of this study is that it builds on our systematic review (Hewitt et al. 2022c) and followed the PBA, a systematic and evidence-based approach to intervention development that champions the use of qualitative methods (Yardley et al. 2015b; Morrison et al. 2018). It provides a practical example of how dermatology researchers can utilise qualitative research to inform the development (or adaptation) of interventions for patients, as well as how to systematically combine inductive and deductive coding to ensure comprehensiveness when analysing qualitative data. In addition, the interview topic guide and analysis were underpinned by multiple established psychological theories. This enabled a detailed exploration of how, for example, drivers of behaviour (capability, opportunity and motivation) might influence user engagement; information that will inform app development and ultimately, reduce barriers to its use.

It is increasingly recognised that research should be conducted with, not just about or for, people living with skin conditions and the role of PPI should be intertwined throughout the research process rather than tokenistic (Heague et al. 2022). PPI offers many benefits, including, but not limited to, helping to address the priorities of the target population and bringing together different perspectives, experiences and expertise, which can enhance the research (Heague et al. 2022). However, integrating PPI within research is not without its challenges, including contributors perceptions of the level of knowledge and skills required, a lack of guidance and training on PPI for researchers and inadequate representation of the target population (Heague et al. 2022). People with lived experience of skin conditions made a substantial contribution to this study, which I considered another major strength. Specifically, six PPI members representing four skin conditions (eczema, rosacea, psoriasis and X-linked ichthyosis) inputted to the development of the interview topic guide, which helped to ensure questions were relevant and appropriate for participants.

This study was conducted online and there are advantages and disadvantages to using this as a medium for qualitative research. Hosting the group interviews on the platform Zoom increased the global reach of this study and provided an opportunity for people from different backgrounds and countries, including the US, Sweden and Denmark, to participate (Coulson 2015). However, given that nearly all the participants were from the UK and the majority reported having vitiligo or psoriasis, the findings should be extrapolated with caution as there are likely to be other geographical, economic, social, cultural and individual factors that influence engagement with digital technology globally (Cullen 2003; Dimaggio et al. 2004; Wenz and Keusch 2023), which were not addressed here.

Advertising the study on new media platforms provided a free and efficient method of recruitment (Coulson 2015). It also alerted several other patient organisations in different countries to this research and facilitated professional relationships with the leaders of these organisations who I may not otherwise have met (Coulson 2015). Although, several suspicious requests for participation were received, suggesting there were loopholes in the online recruitment process. This issue was unforeseen but appears to be increasingly common in online research (Pozzar et al. 2020). Secure methods of validating the identity of potential participants are needed to safeguard researchers and participants and the integrity of online dermatology research (Hewitt et al. 2022d).

In addition, several people originally expressed an interest in taking part in a group interview but did not reply to further email correspondence. Whilst it is possible that these individuals had lost interest and ignored the emails, it is common for emails of this kind to be seen as ‘junk’ mail and either deleted by the individual or blocked by the email server (Coulson 2015). These are plausible explanations for the lack of responses I received from potential participants.

Finally, the use of non-probability sampling methods may have introduced bias to this study. People who choose to take part in online psychological research may be more motivated to share their opinions than others given that they have spent time and effort accessing, reading and responding to the study information (Coulson 2015). These individuals are unlikely to be representative of the wider population of interest. It is, therefore, reasonable to assume that the adults with skin conditions who volunteered to participate in this study may differ somewhat from others in this population. Thus, the transferability of the present findings is limited and caution should be exercised when considering the findings in the context of other adults living with skin conditions in different settings.

Identified next steps in the context of this research

This study and a study by Sangers et al. (2021) remarked on the importance of ensuring that intervention developers are credible. Individuals are exposed to an abundance of information online in relation to skin conditions and their management, but it is often unclear whether the information available is evidence-based and comes from a trustworthy source. Participants expressed concerns about apps funded by industry partners; pharmaceutical companies were seen to be motivated by sales and finances rather than the needs of people with skin conditions and this was regarded as a potential barrier to app use. It is important to deepen our understanding of these concerns and find solutions to encourage engagement with apps that are developed or funded by industry.

Despite the high prevalence of acne worldwide (Heng and Chew 2020), recruiting people with acne proved challenging and few participated in this study. Recruiting through patient organisations highlighted that there is a widespread lack of support for people with acne globally. According to The International Alliance of Dermatology Patient Organisations (aka Global Skin), Acne Action is currently the only registered non-profit organisation that represents people living with acne in Canada. It is important to capture the views and experiences of people with acne to ensure the app has at least some relevance for this group. However, this is indicative of a wider issue of recruiting people with acne to research and new approaches are first needed to reach and engage this population.

Other suggestions for future research identified from this study are covered in Chapter 7.

Practical implications

These findings provide clear evidence for the invaluable, but currently undervalued, role of patient organisations in supporting people to manage and generally live well with skin conditions. However, unlike other skin conditions, this type of support is currently not widely available to people with acne. Funding is needed to establish dedicated organisations for people with this common skin condition. More generally, it is important that researchers, medical professionals and policy makers recognise patient organisations as a key contributor to the wider support network for people with skin conditions.

Medical care for people with skin conditions is often sub-optimal and many people take on the responsibility of managing their own condition but are unprepared for this (APPGS, 2003; 2013; 2020). Patient support groups, including those online, are growing in popularity, although it seems people with lower HRQoL may be more likely to access these groups (Butt et al. 2020). They can be useful for people with skin conditions because they usually offer advice and guidance on self-management and help to normalise the impact of skin conditions, which can positively influence the psychological health and well-being of some users (Iliffe and Thompson 2019). They offer people opportunities for learning about their condition and management, as well as psychological and social support (Idriss et al. 2009).

Many of these participants reported using online peer support groups and the benefits of doing so. They also discussed the disadvantages of seeking support online. The participants main concerns centered around the provision of information that is not evidence-based, as well as the poor regulation and censoring of available content, on public groups and those on social media which they believed could cause physical and psychological harm to users. This is supported by the results of a recent study which analysed the content of posts in a closed Facebook support group for people with keratinocyte carcinoma, which found that many posts detailed medical advice, but claims were usually unsupported or misinformed (Petukhova et al. 2020). The consensus called for tighter moderation and increased resourcing, including input from qualified health professionals, to ensure the health and safety of people accessing online support groups.

Health professionals in dermatology may benefit from further clinical communication skills training to address the psychological impact and improve how they convey potentially life changing diagnoses to patients. Health professionals have reported breaking bad news to be a highly pressurised, distressing and isolating experience and training and supervision are needed to support practitioners (Francis and Robertson 2023). A recent study found that using simulation for training dermatology residents to diagnose melanoma resulted in a perceived improvement in communication skills and ability to manage stress and control personal reactions (Dietrich et al. 2021). Training works but well controlled patient outcome studies are needed to quantify the impact.

There is a clear need for specialist training to enable health professionals to confidently address the psychological impact of skin conditions and provide tailored support to patients to change health risk behaviours (Keyworth et al. 2014; Nelson et al. 2014; Keyworth et al. 2016; Nelson et al. 2016; APPGS, 2020). Many dermatology staff are receptive to receiving further training (Trettin et al. 2021b) to improve their knowledge, skills and confidence to provide behaviour change support (Keyworth et al. 2020). The PsoWell™ training programme (Chisholm et al. 2017; Hewitt et al. 2021) supports the development of consultation skills that are needed to facilitate behaviour change and effective shared decision-making, which our participants wanted. Health professionals have benefitted from this training (Chisholm et al. 2017; Hewitt et al. 2021) and it is possible that patients could too. The development of the PsoWell™ approach is ongoing and more funding is needed to continue to develop, evaluate and implement PsoWell™ for key stakeholders in dermatology.

It seems some people currently lack understanding or hold inaccurate beliefs about what psychological support is, who it is for and its appropriateness. Increasing awareness among patients of what psychological support entails and how it could benefit them, either through the new app or otherwise, could help to reduce the persisting stigma around seeking psychological support and increase the likelihood that people with skin conditions make the most of a new app that is intended to support their psychological well-being through behaviour change in order to live well with a skin condition.

Reflexivity

There are several ways in which my own knowledge, views and experiences could have impacted this research. Given that this study formed part of a PhD to develop a new complex digital psychological intervention for adults with skin conditions, there may be a bias in reporting findings that support the aims of this research project. The interview topic guide covered a range of health behaviours, but the discussions that took place in the group interviews may have focused more on physical activity and dietary behaviours than other health behaviours due to a personal interest in these topics. My interest in women's health may have also influenced how certain data were analysed and the conclusions that were drawn about women being potentially more vulnerable than other people with skin conditions. Conversely, my personal views, experience and passion for these health behaviours could have influenced the study in a positive way as we were able to have in-depth discussions on these topics and notice nuances and patterns in the data.

Attempts were made to offset these biases, including the supervisory team verifying conclusions and checking the strength of the language used to report the findings. Peer review of presentations and publications on this work were also built into the research.

In addition, I previously completed introductory and intermediate training courses in MI and have since coached other health professionals in this as both a style of communication and structure for leading consultations with patients (Hewitt et al. 2021). MI forms the basis of my clinical and academic work and my expertise likely had a positive influence on how I conducted the group interviews.

Chapter summary

Most adults are not prepared to self-manage the impact of skin conditions, especially the psychological consequences, and appropriate support from professional and credible sources is lacking. Psychological support is needed and can benefit people with skin conditions, but barriers to its access exist. Dedicated services delivered by health professionals with expertise in psychology and dermatology are needed. This study provides evidence for the *perceived* acceptability of a new psychological intervention delivered via a smartphone app as an additional form of support for people with skin conditions but not as a replacement for expert support. The next step is to develop a DBCI in line with the needs and ideas of those who participated.

Chapter 6: Online survey

Introduction

The previous chapter provided insights into the many challenges associated with having a skin condition. It identifies gaps in existing patient support and how the MiDerm app could help to fill some of these gaps and promote better self-management. We plan global reach with the proposed app, therefore, it is important to gather a wider perspective of adults living with skin conditions to ensure contextual and cultural factors that could potentially affect its use are accounted for.

In addition to the use of qualitative research methods, Yardley et al. (2015a) encourage a mixed methods approach to support intervention planning and specifically recommend conducting observational and questionnaire studies to establish people's attitudes and preferences and potential barriers and facilitators to intervention use.

An online survey allowed us to gain insight into the needs of adults living with skin conditions in different countries to inform the development and implementation of MiDerm. This chapter reports on the survey which was run concurrently with the online group interview study.

The survey study aimed to:

- Investigate the impact of skin conditions and their management.
- Identify types of support that are currently available to adults in addition to standard medical care.
- Investigate coping and health behaviours in adults living with skin conditions.
- Determine the perceived acceptability of MiDerm and any additional support that adults with skin conditions require from it.

Materials

An online web-based survey (Appendix 29) was developed for the purpose of this study.

A survey is a research method that concerns the process of distributing a questionnaire to a specific group of people and collecting and analysing the data from it to answer a specific question(s) (Fowler 2013). Survey differ from questionnaires, which include a set of questions on a particular topic (Malhotra 2006).

Online surveys are being used increasingly within health sciences because they can increase the reach of research, are easily accessible to people who use the internet regularly and can be targeted at specific demographic characteristics (Coulson 2015). They are a useful vehicle for investigating sensitive topics as they offer people an opportunity to express their views and experiences anonymously (Coulson 2015). Online surveys are also time and cost saving compared to traditional survey methods, as they can be shared widely with the click of a button, mitigating printing and postage costs (Coulson 2015).

However, online surveys are not without their challenges. They are unlikely to be representative of the target population, given that not everyone can access, or uses, the internet, and rely on self-selection making them prone to sampling bias (Coulson 2015). There is also a risk with online surveys that they will be completed by people who do not meet the eligibility criteria, that one person could submit multiple responses and skew the data, or that people in the target population may not complete the survey due to concerns about data privacy, or because email invitations are blocked, or automatically directed to junk folders, by mail servers (Coulson 2015). On balance, online surveys are a cost-effective and efficient means of collecting data if researchers implement appropriate strategies to offset the associated challenges and risks (Coulson 2015).

The survey was comprised of five sections, as detailed below.

Section 1 – Demographic information

The first section aimed to gather information on specific demographic variables (i.e., age, gender, ethnicity, country of residence, education, skin condition, and years lived with a skin condition) to describe the survey sample.

Section 2 – The impact of skin conditions

Items were based on the analytical framework used in other work from our group (Pattinson et al. 2022). This was based on the CSM (Leventhal et al. 1984) described in Chapter 3. Survey items addressed the perceived controllability and timeline of skin conditions and common domains of impact (Pattinson et al. 2022; Pattinson et al. 2023b).

Section 3 – Self-management and coping

This section included the Brief Coping Orientation to Problems Experienced (COPE) Inventory; a self-report questionnaire consisting of 28 items (14 sub-scales, each with two items) designed to assess the frequency of cognitive, emotional, and behavioural coping strategies that can be adopted in response to a stressor (Carver 1997). The presence of a skin condition was considered a stressor in the present study. The Brief COPE (Carver 1997) is well-validated and has been used to measure coping in a variety of health contexts (García et al. 2018). Early studies investigating the psychometric properties of the Brief COPE provide evidence for the internal reliability (Carver 1997) and convergent and discriminant validity (Carver et al. 1989) of the measure. It originally specified three categories of coping:

- Problem-focused.
- Emotion-focused.
- Dysfunctional coping.

The three categories and the associated constructs are listed in Appendix 30.

Meyer (2001) reduced the original categories of coping to two categories: adaptive and maladaptive coping, see Appendix 31.

The Brief COPE does not cover all health behaviours relevant to the management of skin conditions. Research has shown several health behaviours can influence skin conditions (Ko et al. 2019; Sawada et al. 2021; Hu et al. 2022; Loman and Schuttelaar 2022), including:

- Smoking.
- Sleep.
- Physical activity.
- Diet.
- Treatment adherence.

Our wider group's work has shown that many people hide their skin condition and take part in voluntary or advocacy activities as ways of coping with their skin condition (Pattinson et al. 2022). Therefore, additional items were included to investigate specific health behaviours in the survey sample (see Appendix 32).

Section 4 – Types of existing support beyond standard dermatology care

Items in this section were informed by previous research by Kanji (2019) and Wheeler and colleagues (2021) who investigated people's experiences of accessing psychological support.

Section 5 – Perceived acceptability of the MiDerm app

This section incorporated the seven domains of the TFA (Sekhon et al. 2017) and focused specifically on perceived acceptability.

Items focused on ideas for the content, design and functionality of the MiDerm app and were based on existing literature, mainly data on the contents of digital interventions that were extracted as part of the systematic review (Hewitt et al. 2022c).

Types of survey questions

The online survey included a mixture of closed and open-ended questions. All survey sections except section one contained Likert scale questions (Likert 1932), which are commonly used to measure beliefs, feelings and attitudes towards a phenomenon based on different values on a continuum (Likert 1932; Nemoto and Beglar 2013; Taherdoost 2022). Likert scales are easy to create, can generate large data sets quickly, and the data generated can be compared with qualitative data (Nemoto and Beglar 2013; Taherdoost 2022). However, Likert scales are prone to the following types of bias Taherdoost (2022):

- Central tendency bias – participants avoid selecting extreme response categories.
- Acquiescence bias – participants choose a response that they think will satisfy the researcher.
- Social desirability bias – participants select a response to portray themselves in the most positive light.

Likert scales are commonly comprised of five or seven responses (Taherdoost 2022). Having more points on a scale arguably reduces skewness in the data (Leung 2011) and is more likely to detect significant differences in data where they exist, plus they are more nuanced and help to capture the true attitudes and feelings of respondents (Taherdoost 2022). However, more items increases the likelihood of response fatigue where respondents experience boredom and tiredness when completing a lengthy survey, which can negatively influence response rates (Taherdoost 2022).

These points were balanced alongside the needs of the target group, for example, people with skin conditions often experience symptoms, such as pain and fatigue, which could influence their capacity to complete the survey. Fewer response options were included given that the survey comprised of multiple sections rather than just one scale. The priority was to make the survey simpler and quicker for respondents and in attempt to increase the response rate.

All sections of the survey included at least one optional free-text response box for any further comments the respondents wanted to make (see Appendix 29).

Methods

Design

A cross-sectional online web-based survey including optional free-text response boxes.

Participants

The survey was targeted at adults living with a skin condition anywhere in the world. Eligibility included:

- Aged 18 years and over.
- Have a condition that affects the skin.
- Proficient in the English language.
- Have access to the internet.

Recruitment

Information about the survey, including the URL, was disseminated in the same way as the details of the group interview study (see Chapter 3).

Sampling

Voluntary and convenience (snowball) sampling approaches were used (see Chapter 3).

Procedure

The survey was digitalised on the Jisc online survey platform and was open from 28/03/2022 until 31/07/2022.

Examples of the written and visual content used within social media posts are presented in Appendices 33 and 34, respectively. Participants were not offered an incentive for their participation.

People who clicked on the URL, were directed to complete the section on consent before they were able to access the main survey. The survey map, generated from the Jisc platform, is presented on the next page in Figure 11.

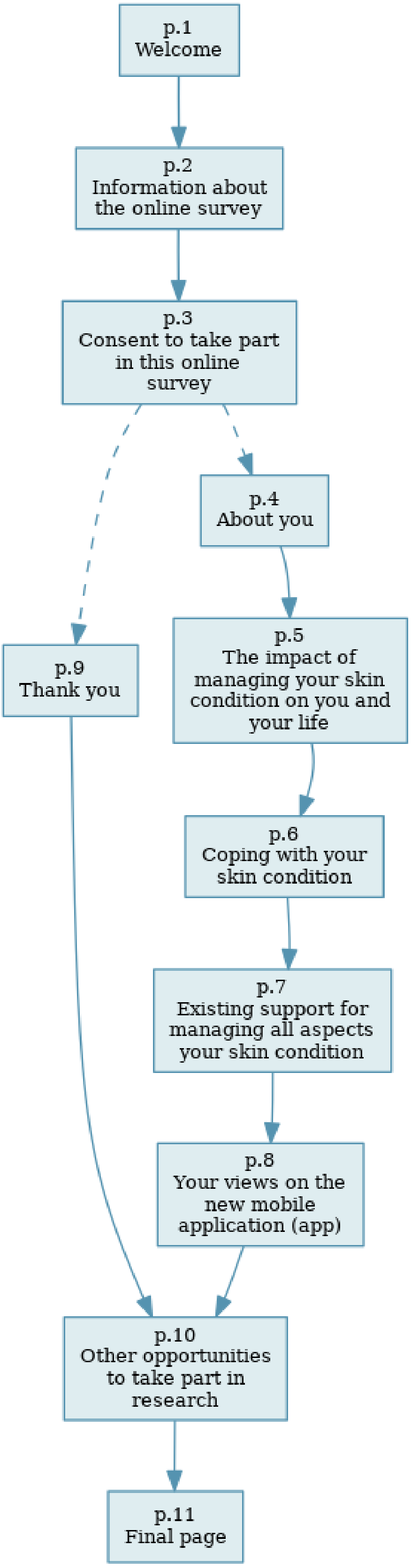

Figure 11: Online survey map produced in Jisc Online Surveys

Data analysis

Survey data were exported from the Jisc platform into a Microsoft Excel file before quantitative and qualitative data were split into separate files.

Quantitative data were then imported to IBM SPSS Statistics 27 and variables were recoded from string to numeric variables for testing. Descriptive statistics (frequencies and percentages) were calculated to describe the sample characteristics and quantify types of impact, coping strategies and behaviours, types of existing support, perceived acceptability and preferences for MiDerm.

Qualitative free-text survey responses were imported into NVivo 12 Pro. TA was deemed appropriate as the purpose of including open ended questions within the survey was to qualify respondents lived experiences rather than quantify them (Vaismoradi et al. 2013). Data were analysed at the semantic level from an essentialist/realist perspective in order to produce a rich and descriptive account of the views and experiences reported by participants (Braun and Clarke 2006; 2022). Data were coded deductively against the analytical framework of impact from our group's previous work (Pattinson et al. 2022) and the TFA (Sekhon et al. 2017), and inductively to capture relevant data that did not correspond to the existing frameworks. The wider team checked the codes for consistency and comprehensiveness. Codes were organised into themes aligned to the survey aims and a narrative summary was produced. TA procedures are described in detail in Chapter 3.

Results

The survey results are reported as follows:

- Internal reliability.
- Sample characteristics.
- Quantitative results.
- Findings from the thematic analysis of the qualitative free-text responses.
- A critical comparison of quantitative and qualitative data.

Sample characteristics

A total of 371 adults completed the online survey. One participant did not have a skin condition and was excluded. The remaining 370 responses were eligible for analyses.

Most participants identified as female (78.4%) and being of white ethnicity (90.5%). The age of participants ranged from 18 to 83 years and the mean age was 44.71 (SD = 14.07) years. Just under half of the sample reported having psoriasis (46.8%). Other skin conditions that were commonly reported included types of ichthyoses (15.1%) and eczema (4.9%), as well as lichen sclerosus (9.2%) and HS (8.9%). Twenty-eight participants (7.6%) reported living with one or more skin or joint conditions. Sample characteristics are presented below in Table 10. A list of the skin conditions reported is available in Appendix 35.

Table 10: Sample characteristics for online survey study.

Variable	*n*	%
Gender		
Male	77	20.8
Female	290	78.4
Other – non-binary	3	0.8
Ethnicity		
White (European descent)	335	90.5
Black (e.g., African, Afro-Caribbean	7	1.9
Latino (e.g., Latin American, Hispanic descent)	1	0.3
Middle Eastern (e.g., Arab, Persian, West Asian descent)	2	0.5
East Asian (e.g., Chinese, Korean, Japanese, Taiwanese descent)	3	0.8
South Asian (e.g., Indian, Pakistani, Sri Lankan, Indo-Caribbean)	3	.8
Southeast Asian (e.g., Filipino, Vietnamese, Thai, Cambodian)	6	1.6
Prefer not to say	2	0.5
Other ethnicities	10	2.7
Mixed White and Asian	3	0.8
Mixed White and South Asian	1	0.3
Mixed White and East Asian	1	0.3
Mixed White and African	1	0.3
Mixed White and Arab	1	0.3
Mixed background	2	0.5
Euro Indian	1	0.3
Skin condition		
Psoriasis	161	43.5

Ichthyosis	56	15.1
Eczema	18	4.9
Vitiligo	9	2.4
No melanin	1	0.3
Hidradenitis Suppurativa	33	8.9
Acne	2	0.5
Rosacea	1	0.3
Lichen Sclerosus	34	9.2
Lichen Planus	1	0.3
Pachyonychia Congenita	3	0.8
Epidermolysis Bullosa	1	0.3
Lupus Erythematosus	3	0.8
Pemphigus	3	0.8
Pemphigoid	2	0.5
Actinic Keratosis	1	0.3
Multiple skin conditions	29	7.8
Skin and joint conditions	11	3.0
Skin and mental health conditions	1	0.3
Country of residence		
UK	285	77.0
England	212	57.3
Wales	24	6.5
Scotland	28	7.6
Northern Ireland	7	1.9
UK non-specific	14	3.8
Ireland	24	6.5
The Netherlands	4	1.1
Germany	2	0.5
Denmark	2	0.5
Belgium	1	0.3
Romania	2	0.5

Malta	1	0.3		
Iceland	1	0.3		
USA	23	6.2		
Canada	5	1.4		
Argentina	1	0.3		
Australia	3	0.8		
New Zealand	1	0.3		
Nigeria	2	0.5		
Algeria	1	0.3		
South Africa	2	0.5		
Turkey	1	0.3		
Japan	1	0.3		
Russia	1	0.3		
UAE	1	0.3		
Bahrain	2	0.5		
India	1	0.3		
Indonesia	1	0.3		
Malaysia	1	0.3		
Not stated	1	0.3		
Age (in years)	**Minimum**	**Maximum**	**Mean**	**SD**
	18	83	44.71	14.07

UK, United Kingdom; USA, United States of America; UAE, United Arab Emirates.

Quantitative results

Descriptive statistics for the whole sample and by condition category are presented in Appendices 36-47.

Impact

Participants were asked about the ways in which having a skin condition(s) impacts them. This survey focused specifically on the impact of self-management.

The main impact reported was the time and effort that condition self-management required. Most participants either agreed (34.1%) or strongly agreed (58.9%) that managing their skin condition took time and effort.

Self-management also had a substantial physical and psychological impact and the results for these types of impact were similar. Many participants agreed (28.6%), and over half of the sample strongly agreed (55.7%), that managing their skin condition affected them psychologically. Participants either agreed (26.8%), or strongly agreed (51.4%), that this had physical consequences.

Almost three quarters of the sample (74.6%) agreed that self-management had affected their social life and the majority were in strong agreement (41.6%). Self-management also affected personal relationships with friends and family and romantic partners. The same percentage of participants (39.9%) agreed and strongly agreed that managing their condition affected their relationships. The results were slightly higher for the impact on romantic relationships. A quarter of the sample agreed (25.9%), and just under half strongly agreed (47.8%) that self-management had affected their romantic relationships.

Just under three quarters of the sample reported that self-management had affected their daily activities to some degree. Many participants agreed (31.6%), and more strongly agreed (43.2%), that the management of their skin condition impacted their daily activities. A similar percentage of participants agreed (34.9%) and strongly agreed (35.9%) that this impacted their leisure time.

Participants were asked about the financial impact of managing a skin condition. Many agreed (37.6%), and slightly fewer strongly agreed (34.9%), with the statement '*managing my skin condition… is expensive.*'

A high percentage of participants (60.8%) agreed that their life goals and ambitions had been impacted to some extent. Compared to other items, more participants neither agreed or disagreed with the statement *'managing my skin condition… impacts my life goals and ambitions.'* Of all the items on impact, this statement had the highest percentage (8.4%) of 'strongly disagree' responses, although this is still a small percentage.

Personal control

One question in the survey sought to understand the extent to which participants believed they could control their skin condition. Many respondents agreed (39.2%) that their personal actions could influence their skin condition. Slightly fewer strongly agreed (28.4%) with the statement on controllability. Some were ambivalent (18.9%) and the rest either disagreed (8.9%) or strongly disagreed (4.6%) with this.

Dysfunctional coping

Participants were asked about the ways in which they cope with their skin condition. The results for each type of coping are reported in separate sub-sections below.

Behavioural withdrawal. While some participants reported that they had not given up trying to deal with their skin condition (38.9%), others reported that they had given up trying to deal with their skin condition a little (30%), a medium amount (19.2%) or a lot (11.9%). As for giving up the attempt to cope with skin conditions, participants reported doing this a lot (9.2%), a medium amount (11.9%) or a little (23%), although more than half of the sample (55.9%) reported not doing this at all.

Substance use. Approximately three quarters of the sample said they had not used drugs or alcohol to make themselves feel better (74.1%) or to help them get through (76.8%). However, a small percentage (6.5% and 6.2% respectively) of participants reported using substances a lot to cope.

Denial. Most participants reported that they were not in denial about their skin condition (69.5%) and had not refused to believe what had happened to them (74.3%). The rest of the sample reported:

- Denying their reality a little (15.9%), a medium amount (8.1%) or a lot (6.5%).

- Refusing to believe their situation a little (14.6%), a medium amount (6.8%) or a lot (4.3%).

Self-distraction. Strategies for self-distraction were more common. Participants reported turning to work and other activities to take their mind off things a lot (12.4%), a medium amount (20.3%), a little (30.5%) or not at all (36.8%). They also reported consciously doing something to think about their skin condition less a lot (13.8%), a medium amount (20%), a little (28.6%) or not at all (37.6%).

Self-blame. Self-blaming was also common. Most participants admitted to being critical of themselves and reported doing this a lot (24.1%) a medium amount (24.6%) or a little (20%). Around a third of the sample (34.3%) said they had not criticised themselves. As for self-blame, a high percentage (57%) reported not blaming themselves for their skin condition, whereas others reported blaming themselves a little (18.4%) or a medium amount (14.3%), and approximately 10% did this a lot (10.3%).

Venting. Only a small percentage of participants (8.6%) reported venting their negative feelings a lot. Some did this a moderate amount (18.4%) but most participants did this a little (36.8%) or not at all (35.9%). Very few participants said things to let unpleasant feelings escape a lot (5.7%), some did this a moderate amount (13.5%), others a little (24.1%) and most never did this (56.8%).

Problem-focused coping

Active coping. Forms of active coping were reported. Participants stated they had tried to concentrate their efforts on doing something about their skin condition a lot (20%), a medium amount (30.3%), a little (32.7%) or not at all (17%). More reported that they took action to improve their situation often (29.7%), a medium amount (34.3%), or a little (26.6%). Approximately 10% said they had not done this at all.

Planning. Most participants also reported planning frequently. For the item *'I've been thinking hard about what steps to take'* some participants indicated they did this a lot (18.4%) or a medium amount (27.8%), versus others who did this only a little (32.4%). In response to the item *'I've been trying to come up with a strategy about what to do'* participants reported doing this a lot (15.9%), a medium amount (34.6%) or a little (29.2%).

However, one fifth of the sample reported that they never thought about what to do about their skin condition (21.4%) or tried to figure out a strategy (20.3%).

Informational support. In terms of getting help and advice from others, participants reported trying to do this a lot of the time (10.5%), a moderate amount (25.4%) or only sometimes (32.7%). Participants reported that they had received help and advice from others often (11.9%), a moderate amount (23.8%) or a little (34.3%). Approximately 31% reported they had never sought or received help and advice from other people in relation to their skin condition.

Emotion-focused coping

Acceptance. The most common emotion-focused coping strategy was acceptance. Participants reported that they had been learning to live with their skin condition a lot (37.3%) or a medium amount (35.1%), compared to others who did this only a little (18.9%), or not at all (8.6%). A similar pattern was found for accepting the reality of the situation. Participants reported doing this a lot (32.2%), a medium amount (32.7%), a little (21.4%), or never (13.8%).

Humour. Most participants reported that they never (48.4%) or rarely (22.2%) made jokes about their condition. Just over a quarter of the sample reported doing this a medium amount (19.2%) or a lot (10.3%). A similar pattern was found for the statement *'I've been making fun of the situation'* with few participants doing this a lot (8.9%) or a medium amount (13.5%), and more doing this only a little (19.7%) or not at all (57.8%).

Religion. Similar results were found for religion. Most participants indicated they did not pray or meditate as a means of coping. Others reported praying or meditating a little (13.8%), a medium amount (8.1%) or often (8.6%). More than three quarters of the sample said they had not tried to find comfort in their religion or spiritual beliefs as a means of coping (77.3%). A few participants (8.4%) reported doing this a little and a lot of the time, fewer did this a medium amount (5.9%).

Seeking emotional support. Seeking emotional support from others appeared to be less common in this sample. Approximately ten percent of participants reported receiving emotional support, or getting comfort and understanding, a lot of the time. Less than 20% reported receiving these types of support a medium amount. More participants reported that they rarely or never received emotional support (33% or 38.1%), or understanding and comfort (29.5% or 40.5%), from other people.

Positive reframing. Use of positive reframing as a way of coping was not often used. Forty percent of participants said they had never tried to see their skin condition in a more positive light. Others reported doing this a little (31.1%) or a medium amount (20.3%), and very few did this often (8.6%). More than half of the sample (52.2%) said they had not looked for something good in what was happening. Less than a quarter (23.2%) did this a little, and even fewer participants did this a medium amount (14.9%) or often (9.7%).

Health-protective behaviours

Sleep. Getting enough sleep was a priority for most participants, reporting a lot (21.6%), a moderate amount (37.8%) or a little (27.8%) compared to a few who said they never tried to get enough sleep (12.7%).

Self-learning. Learning about skin conditions and their management seemed to be a priority, as most participants reported spending time learning about these topics a medium amount (34.9% and 34.1%). Approximately 30% of the sample reported researching their condition and management strategies a lot and a quarter indicated doing this a little. Around 10% of participants reported that they had not spent time researching either topic.

Treatment adherence. Self-reported treatment adherence was variable. Many participants reported that they took their medication as prescribed a lot of the time (44.1%), a moderate amount (22.4%), or a little (16.2%). Some indicated they had not been taking their medication as prescribed (17.3%).

Physical activity. There were mixed results for physical activity. Several participants performed physical activity a lot (18.1%) or a medium amount (25.9%), but more than half of the sample reported that they had not been keeping physically active (23%), or only a little (33%).

Healthy eating. As for consuming a healthy diet, most participants reported eating healthy foods a lot (17.8%) and many a medium amount of the time (38.1%). Several participants reported eating healthy foods a little (29.2%) and some said they never ate healthily to cope with their skin condition (14.9%).

Volunteering and advocacy. Most participants (71.9%) did not take part in advocacy or voluntary work, but some reported engaging in such activities a little (12.4%), a lot (8.9%) or a medium amount (6.8%).

Health-threatening behaviours

Smoking. Most participants (81.4%) reported that never smoked cigarettes to cope with their skin condition. However, it was unclear if these individuals were smokers who did not use smoking as a coping strategy, or non-smokers. Few participants said they rarely (4.6%) or sometimes (3.8%) smoked cigarettes. Approximately 10% reported that they often smoked cigarettes to cope with their skin condition.

Other coping strategies relevant to skin conditions

Hiding the skin. Hiding the skin was done more often than not by many participants, who reported trying to do this a lot (32.7%), a medium amount (25.1%) or a little (22.4%), versus those who never did this (19.7%).

Existing support for people living with skin conditions

Medical care. Support from healthcare professionals (HCPs) was variable. Whilst some participants reported that they always (15.7%), or often (21.4%), received support from HCPs to manage all aspects of their skin condition(s), most indicated they occasionally (29.7%) received medical support. However, a quarter of the sample (25.1%) rarely received this, and a few participants (8.1%) reported never receiving professional support from health professionals.

Psychological support. Very few participants reported that they always (1.9%) or often (4.9%) saw a psychologist, therapist or counsellor in relation to their skin condition. A small percentage (7.3%) said they sometimes received professional psychological support, but for others this was rare (11.6%). Just under three quarters of the sample (74.3%) stated that they had never seen a psychologist, therapist or counsellor for support with managing their skin condition.

Social support. The results for social support were mixed. Several participants always (13.5%), often (20.8%) or sometimes (29.5%) received support from family and friends to manage their skin condition, whereas others rarely (22.2%) or never (14.1%) had this support.

Peer support. Participants were also questioned about forms of peer support, including established patient organisations and patient support groups on the internet and social media platforms. Very few participants reported that they always (3%) or often (6.8%) accessed support from a patient organisation. Some participants indicated they did so occasionally (12.7%) or rarely (14.6%), but most (63%) never accessed such support. These participants seemed more reliant on online support groups, as a higher percentage reported that they always (8.9%) or regularly (19.5%) received support from people online or on social media. Just under a quarter of the sample (24.1%) reported that they occasionally received this and for others this was rare (17.3%). Approximately 30% of participants had never received online peer support.

Use of digital and written self-help materials. A few participants reported always (1.4%) or frequently (8.6%) using written self-help materials, such as patient information leaflets, compared to others who used these resources occasionally (21.1%), rarely (24.3%) or not at all (44.6%). Use of digital self-help materials, such as websites or apps, was more common. Approximately 10% of participants reported always using digital self-help materials and a quarter of the sample used these frequently. Most participants (31.9%) indicated they sometimes used digital resources and some rarely used them (12.7%). Approximately 20% said they never used digital materials to help manage their skin condition.

Use of treatments. Most participants reported that they always (47.3%) or often (24.9%) used prescribed treatments, and a few (13.8%) reported occasional use. A small percentage reported rarely (5.1%) or never (8.9%) using medication prescribed by their doctor to manage their skin condition.

However, with all these forms of support, it was unclear whether those who reported never receiving support did so out of choice or were unaware of the types of support available to them.

Perceived acceptability of the MiDerm app

Most participants (68.9%) considered the idea of psychological support delivered via a new smartphone app acceptable or somewhat acceptable (11.9%). A small minority reported this idea was slightly unacceptable (1.4%) or not acceptable (1.6%). Some were undecided (16.2%).

Ideas for the MiDerm app

The participants were asked to share their opinions on the development of the app, including co-development with, and endorsement from, key stakeholders. Most considered collaboration with people with lived experience of skin conditions to be extremely (73%), very (10%) or moderately (2.4%) important. Only two participants (0.5%) reported this was not important. Collaboration with health professionals was deemed extremely important by almost three quarters of the sample (73%). Others felt this was very (17.3%), moderately (7.3%) or slightly (0.5%) important. Five participants (1.4%) indicated this was not important to them and two (0.5%) gave no response. Involving patient organisations in the development process was also of high importance. Many participants reported their involvement as extremely (54.6%), very (27.3%), moderately (14.3%), or slightly (2.2%) important. Three participants (0.8%) deemed this unimportant or did not answer.

Endorsement from key stakeholders was also a priority for most. Approximately three quarters of the sample (74.6%) reported endorsement from health professionals was extremely important, as was endorsement from patient organisations (67.6%) followed by health authorities (63.2%).

Participants were also asked to indicate how important they considered potential aspects of the app, including potential content, features and its design.

In terms of informational support, most participants wanted the app to increase people's awareness of skin conditions, to some extent. More than half of the sample (57.8%) felt this was extremely important. Only six participants (1.6%) stated increasing awareness was not important.

There was a clear desire among these participants for more information on skin conditions and the role of psychological processes, and practical tips for self-managing these aspects. Most participants wanted to better understand the links between mood and skin conditions. They rated this information extremely (54.9%), very (27.8%), moderately (11.9%) or slightly (3.5%) important, although six participants (1.6%) did not and one (0.3%) gave no answer. The provision of practical tips for mood management was deemed extremely (66.8%) or very (20%) important by most. Nine participants (2.4%) stated these were not important and one (0.3%) did not provide a response.

In terms of health behaviours, information on the impact of diet on skin conditions appeared to be a priority. Most participants reported this was extremely (57.8%), very (28.9%), moderately (10%) and slightly (2.2%) important, versus four participants (1.1%) who did not. The provision of practical tips on eating a healthy diet seemed slightly less important than educational material on this topic. Receiving practical tips was extremely (44.3%) or very (29.2%) important to some, but more participants reported this was of moderate (15.6%) or slight (5.7%) importance, and just under 5% deemed this unimportant.

An app offering information on the impact of keeping physically active on the skin was of importance to these participants, who indicated this was extremely (55.7%), very (31.9%), moderately (10%), or slightly (1.1%) important. Only five participants (1.4%) did not consider this information important. An app that gives practical tips on how to keep physically active was also desirable. Many participants reported this was extremely (56.8%), very (27.8%) or moderately (10.3%) important. Nine participants (2.4%) answered slightly or not important to this item, and one (0.3%) did not answer.

Compared to diet and physical activity, the provision of information and tips on reducing smoking and alcohol consumption seemed to be of lesser importance to these participants, although the percentages were not too dissimilar overall. Receiving information on the impact of drinking alcohol on skin conditions was seen as extremely or very important by approximately 40% and 25% of participants, respectively. Some participants considered this topic moderately (16.5%) or slightly (7%) important to cover in the app, whereas others (11.4%) did not. Similar to results for diet, offering tips on reducing alcohol intake appeared to be slightly less important than information on alcohol and skin conditions. Just over half of the sample stated that alcohol-related tips were extremely (30.5%), very (21.9%), moderately (19.2%) or slightly (8.9%) important. Just under a fifth of the sample did not think tips on reducing alcohol intake was important (19.5%). Although, collectively, many participants believed information on smoking and the skin was important to some degree, a higher percentage (18.1%) deemed this topic unimportant. A similar pattern was observed for including tips on quitting smoking; just under a quarter of the sample (24.3%) stated this was not important.

The converse was true for sleep. Although still important, a higher percentage of participants regarded receiving tips for improving sleep quality more important than information on the impact of sleep on skin conditions. Participants reported information on sleep and skin was extremely (49.7%), very (28.4%), moderately (16.5%) important. A few participants (2.4%) rated this either slightly or unimportant. Two participants (0.5%) did not respond to this item. Tips on sleep were rated as extremely (55.1%), very (30.3%), moderately (9.5%), slightly (2.7%), or not (2.2%) important, and one participant (0.3%) did not give their opinion.

There were several other aspects that the participants wanted the app to provide practical tips to support self-management. Approximately three quarters of the sample (74.6%) reported tips for general coping were extremely important, as were tips for managing itch (70.5%). Participants considered tips for improving treatment adherence to be extremely (54.9%), very (22.2%), moderately (14.3%) or slightly (4.9%) important, although a few (3.8%) did not. Tips on how to stay motivated were rated extremely (42.4%), very (30.8%), moderately (17.6%) or slightly (4.6%) important. Less than 5% of participants felt tips on motivation were not important and one participant (0.3%) gave no response.

The survey also included items focused on understanding, and coping with, the social consequences of having a skin condition. The provision of information on the social impact of skin conditions was rated extremely (50.3%), very (29.2%), moderately (13.2%) or slightly (4.3%) important. Eleven participants (3%) indicated this was not at all important. In terms of coping with the social consequences, similar results were observed for tips on managing social interactions and social anxiety. The former was regarded as extremely (42.4%), very (29.2%), moderately (16.8%) and slightly (6.2%) important, and 20 participants (5.4%) said this was not important. The latter was rated as extremely (45.4%), very (26.2%), moderately (15.1%) and slightly (6.5%) important, although 21 participants (5.4%) said this was not important and four (1.1%) did not specify. Most participants wanted the MiDerm app to offer an opportunity to connect with other people with skin conditions and regarded this as extremely (40%), very (26.8%), moderately (22.7%) and slightly (5.1%) important. Twenty participants (5.4%) said this was unimportant and it was unclear whether support from people living with the same, or different, skin conditions, or both was preferable.

Participants were asked to share their opinions on other potential features for the MiDerm app. Having the opportunity to self-monitor physical and psychological symptoms appeared to be important to these participants, and similar results were observed for both. Exactly half of the sample regarded tracking physical symptoms extremely important for the new app. Others indicated this was very (27%), moderately (14.6%) or slightly (4.3%) important. Thirteen participants (3.5%) said this was not important and two (0.5%) did not specify. Just under half of the sample (47.8%) reported self-monitoring mood and emotions was extremely important. Approximately a quarter of the participants (24.6%) considered this feature to be very important. Others rated this as moderately (15.9%) or slightly (5.7%) important. Approximately 6% of participants felt this was not important for the app.

Including interactive activities for users to complete was rated extremely (38.1%), very (28.4%), moderately (20%) and slightly (7.6%) important, although aproximately 6% of participants felt these were not at all important. Slightly fewer participants felt it was extremely (32.2%) or very (28.1%) important for the app to allow users to identify, plan and monitor personal goals, and slightly more participants reported this as being of moderate (22.7%) or slight (9.2%) importance. A few participants (7.6%) did not consider this activity important for the app, and one (0.3%) did not specify.

Providing users of the app with visual feedback on their personal progress was reported to be extremely (36.2%), very (28.4%), moderately (18.9%) and slightly (8.6%) important. A few participants (7.8%) said receiving personal progress updates via the app was not important to them.

Offering users virtual points or rewards seemed to be of some importance, but the results were more variable. Approximately 23% of respondents reported these were extremely or moderately important. One fifth of the sample said they were very or not at all important. Some participants (13.2%) regarded these as slightly important.

One survey item referred to having the option to receive digital reminders to use the app. Participants reported these were extremely (32.7%), very (25.7%), moderately (22.2%), slightly (8.1%), or not at all (11.1%) important, and one (0.3%) did not specify.

The participants seemed to value personalised content, as approximately half of the respondents (50.3%) considered tailoring the app to the individual user to be extremely important. Others rated this as very (28.9%), moderately (15.7%) or slightly (2.7%) important. Only eight participants (2.2%) rated this as not important and one (0.3%) did not provide an answer for this item.

Most expressed the importance of making MiDerm free to access and that no cost was an extremely (81.6%) or very (13.2%) important factor. A small percentage (4.1%) indicated this was of moderate importance. One participant (0.3) regarded this slightly important and three people (0.8%) did not consider this at all important.

Having a sense of personal control was pertinent to this group. Over half of the respondents believed it was extremely important that the MiDerm app gives users a sense of personal control (58.6%), a quarter of the sample (25.7%) regarded this as very important, some deemed this moderately (11.1%) or slightly (2.4%) important, and three participants (0.8%) said this was not at all important.

These participants appeared to value continued care. The item *'gives users a sense of continuity of care'* was rated as extremely (52.7%), very (26.2%), moderately (14.3%), slightly (4.1%). Very few felt this was not important (11.1%) and one person did not provide a response to this item.

Qualitative free-text responses

Of the 370 eligible survey responses, 178 (48%) participants responded to at least one open ended question in the free-text response boxes provided. Five themes were derived from these data. Theme titles are listed below. Themes are subsequently reported in detail with key supporting quotes. All quotes that were deemed pertinent to each theme are included in Appendix 48.

- The impact of skin conditions.
- The burden of self-management.
- Helpful and unhelpful coping strategies.
- Inadequacies in existing support.
- Perceptions and ideas on MiDerm.

Theme 1: The impact of skin conditions.

The impact of skin condition(s) was substantial, with participants reporting physical, psychological, social, occupational, educational, financial and daily challenges.

"It impacts every part of my life" (Epidermolytic Ichthyosis, female, 60 years, white, England).

Physical symptoms, such as pain, itch and mobility issues, impeded daily living. Itch especially and the time required for self-management disturbed sleeping patterns. Fatigue was reported as a physical symptom and psychological consequence of time spent thinking about and managing skin conditions.

"When it's at its worst I can't do much with my hands, and I'm not allowed to work and I feel crappy physically, then I can't sleep because I itch so much." (Multiple skin conditions, female, 35 years, England)

The psychological impact of visible skin conditions was profound and cognitive, emotional and behavioural consequences were reported. Hyper-awareness was common and impacted cognitive functioning and exacerbated fatigue and distress.

"It's a constant issue in my life that causes massive emotional stress. In any situation that is the first thing I have to consider, and it's really tiring." (Psoriasis, male, 33 years, Wales)

Symptoms, triggers and the progress of skin conditions were unpredictable and participants had concerns about the genetic basis of skin conditions and treatment side effects. Unpredictability went hand in hand with uncertainty, causing anxiety about the future.

"You never know when it will flare which causes anxiety" (Bullous Pemphigoid, female, 66 years, white, US)

The presence of a visible skin condition was psychologically distressing and fueled feelings of self-consciousness, which ultimately *"destroys self-confidence and self-esteem" (Multiple skin conditions, female, 63 years, white, England)* and led to low mood:

"Mentally I struggle with how it looks which gets me down" (Psoriasis, female, 27 years, white, England).

There was great variability in how individuals felt day to day:

"The way I feel today will be totally different another day due to the highs and lows of having a skin condition." (HS, male, 36 years, white, Republic of Ireland)

Extreme concern about the reactions of others drove participants to cover their skin, or use accessories, products and filters to change their physical appearance, to avoid attracting attention and to feel comfortable. However, the terms 'cover' and 'hide' were often used interchangeably and a lack of detail around when these behaviours were enacted made it difficult to determine whether this was always a helpful strategy.

"It effects on what clothes I can wear as I get paranoid people are staring if I don't cover up my psoriasis as it is red and scaly. So covering up makes me feel more secure." (Psoriasis and Osteoarthritis, female, 51 years, white, UK)

One participant explained that despite their skin now being clear, they continued to experience poor mental health; negative body image led to unhealthy eating behaviours and a self-diagnosed eating disorder. This is indicative of psychological scarring where the long-term effects go beyond the initial 'injury.'

"I am on biologics and my psoriasis is nearly in remission but I have lasting psychological symptoms. I have zero body confidence and I absolutely hate the way I look. […] I have problems with my weight, and I am undiagnosed with an eating disorder, I binge eat and I

> *am bulimic, which I am currently struggling with." (Psoriasis, female, 25 years, white, England)*

Mood and motivation reportedly fluctuated with changing symptoms. Typically, the more severe symptoms were, the worse people felt.

> *"Can cause waves of anxiety and depression when the symptoms increase or the condition progresses." (Lichen sclerosus, female, 35 years, white, England)*

Skin conditions had social consequences, affecting personal relationships with friends, family and romantic partners.

> *"My romantic relationships are affected by the trails of skin cells I leave" (Ichthyosis Vulgaris, female, 54 years, white, USA).*

Participants often encountered people staring at, commenting on, or asking questions about their skin, and a few experienced teasing and bullying. Others' reactions were challenging to deal with and could directly influence mood and behaviour; they increased the emotional burden and fueled social withdrawal and isolation, which also exacerbated loneliness.

> *"I have good days and bad days, its comments made by strangers that are hurtful and annoying." (Autosomal recessive congenital ichthyosis, male, 61 years, white, Scotland)*

One participant believed their skin condition affected their ability to perform their social role as a mother, causing distress.

> *"Being a mother. Trying to hug your children when you're either slathered in greasy steroid creams or in pain from the dry cracking skin. Or when you leave your flaking skin on them. It's awful. They like to stroke my arms but won't because of psoriasis. They look concerned when it bleeds. This is just a fraction of the pain it causes." (Psoriasis, female, 33 years, white, England)*

Having a skin condition impacted on education and careers. Some participants were unable to finish their education, work in certain environments, fulfil their job role, and pursue or progress in their preferred careers, evidencing CLCI.

> *"I dropped out of med school because my contact dermatitis was misdiagnosed for an extended amount of time […] I basically cannot work in a place where I do not have control of my exposure to allergens." (Contact Dermatitis, female, 40 years, East Asian, Canada)*

Theme 2: The burden of self-management.

Skin conditions were *"hard to manage" (Scalp psoriasis and Seborrheic Dermatitis, female, 42 years, Southeast Asian, England),* particularly for those experiencing distress:

> *"It can be very hard when dealing with mental health conditions to stay positive and keep going with treating it, as it can easily seem like a chore and an endless cycle and almost feel undeserving of it being healed." (Psoriasis, female, 29 years, white, England)*

Self-management was all consuming, requiring significant time, effort and planning. For most, self-management dictated daily living and choices, disturbed sleep and lessened time for preferred activities.

> *"Tending to Eczema doesn't just impact your life. It dominates it. Most decisions are based on "Will this cause more flaring? Will that hurt?" Etc." (Eczema, male, 29 years, white, Wales)*

Condition management also had a financial impact. Participants paid for prescriptions, over-the-counter products, suitable clothing and heating to help control symptoms, but had to prioritise these expenses depending on personal finances:

> *"I have to make hard choices on what additional therapies I can afford to pay for and receive. I have to ask and pay for help. I have to buy expensive clothes that do not exacerbate my skin condition" (Psoriasis and Psoriatic Arthritis, female, 51 years, white, Canada)*

Some individuals required help with management, which eroded personal autonomy, and demonstrates how the impact of condition management extends beyond the patient.

> *"The ability to be independent because a lot of the time you need help and support with changing dressings or getting dressed if it really bad so your identity and dignity is gone as well." (Hidradenitis Suppurativa and Psoriasis, female, 30 years, white, Ireland)*

Theme 3: Helpful and unhelpful coping strategies.

Participants employed various strategies to cope with skin condition(s). Most seemed motivated to self-manage, but lacked the knowledge needed to do so effectively. Many actively sought information for understanding, researching their skin condition and medical and lifestyle management strategies online. They performed behaviours that supported physical, psychological and social well-being, mainly keeping active and dietary change.

"Reading books such as The Hidden Plague. Doing an elimination diet and trying to figure out what food triggers the boils/make them worse." (Hidradenitis Suppurative, female, 40 years, white, Ireland)

"Sport, hiking, friends, family, pets, living life" (Lamellar Ichthyosis, female, 33 years, white, Belgium).

Making downward social comparisons is an emotion-focused coping strategy whereby people compare themself to others who they perceive to be worse off (Taylor et al. 1990). Downward social comparisons can be active or passive (Taylor et al. 1990). The former refers to when a person acts with the intention to cause someone physical harm or make them feel inferior (Taylor et al. 1990). Some participants described making passive downward social comparisons; the beliefs they held, or learned information, about themselves or others, improved how they felt about their situation.

"I have movement disorders which affect my quality of life more than my skin condition does. This puts my lichen sclerosus in some perspective." (Lichen Sclerosus and Granuloma Annulare, female, 64 years, white, US)

Several sought emotional support from others, including qualified professionals, such as counsellors, but mainly from people living with the same condition who could empathise.

"As my condition is rare, I find comfort in speaking to others with my condition about issues that plague me. I feel the opinions of people with non-visible differences are hollow, although well-meaning, they do not fully understand." (Epidermolytic Ichthyosis, female, 25 years, white, Wales)

Some engaged in activities which facilitated emotional processing, stress management and psychological well-being:

“I have been journaling my thoughts a lot over the past few years. It is nice to read back and see something that were really frustrating and upsetting me weren’t a big deal and how far I’ve come.” (Guttate psoriasis, male, 23 years, white, England)

A few participants reported health-threatening behaviours, such as using recreational drugs to cope with difficult emotions:

“I smoke cannabis to help with stress” (Hidradenitis Suppurativa, female, 39 years, white, Ireland).

Comfort eating is a well-recognised coping strategy that people, including those with psoriasis, commonly use to escape difficult emotions and improve mood temporarily (Pavlova et al. 2023). However, comfort eating can be more harmful to health and well-being in the longer-term, leading to overweight and obesity, both of which are associated with skin conditions and related comorbidities (e.g., CVD and type II diabetes), and are prevalent in dermatology patients (Yosipovitch et al. 2007; Armstrong et al. 2012). Being overweight or obese can also have a negative impact on poor body image and other psychological consequences, which are common in people with skin conditions (Pavlova et al. 2021). One participant reported comfort eating as a means of coping with their skin condition:

“I've been using chocolate, sweets cake etc to help me get through it” (Eczema, female, 41 years, white, England).

Some people living with some skin conditions report that sun exposure helps to reduce disease activity and severity (Magin et al. 2005; Fox et al. 2007). Some choose to spend time in the sun, or use sunbeds, despite the associated health risks, including premature skin ageing and sunburn which can lead to skin cancer (Wehner et al. 2012; Colantonio et al. 2014). One participant reported using sunbeds occasionally, which was effective, but it was unclear if they were aware of the risks associated with this:

“Occasional short stints in a sunbed as find helps” (Psoriasis, female, 34 years, white, Scotland)

Whilst these behaviours provided short-term relief, it was unclear whether the participants understood the longer-term risks for health and well-being.

Behavioural withdrawal is described as dysfunctional (Carver 1997) and maladaptive coping (Meyer 2001). Several participants described avoidance coping; they avoided situations where their skin would be exposed or difficult to manage, but covering the skin helped to overcome this.

"I avoid some situations where I would find it physically difficult to manage" (Lichen Sclerosus, female, 59 years, white, England).

The ability to cope was partly dependent on the number of years lived with a skin condition, life stage and whether the condition was inherited or acquired. Several participants noted their answers would be different if they were completing the survey as an adolescent or young adult, or around the time of condition onset, during the early stages of adjustment. Coping abilities reportedly improved with acceptance and adaptation over time and, in some cases, with professional and social support.

"It has been a journey. I have had vitiligo for 20 years. If you'd asked me these questions even 5 years ago the answers would be different as I was not coping with it very well at all and had not come to terms with it. I have now, thanks to therapy and time." (Vitiligo, male 37 years, white, England)

Theme 4: Inadequacies in existing support

Professional support for people with common, and especially rare, skin conditions, was limited. Poor access to standard primary and secondary care services increased the burden on individuals, especially during the SARS-CoV-2 pandemic.

"How awkward they [skin conditions] are to manage and the struggle of getting medical help" (HS, non-binary, 30 years, white, Ireland).

Treatment costs and side effects, as well as limited treatment efficacy and inequities in treatment access and availability, posed further challenges for condition management.

"Since moving to Ireland from the UK I've not had any medical help as its too expensive for any treatment here." (HS, female, 32 years, white, Ireland)

Those who were able to see a medical practitioner were often dissatisfied with the standard of care, particularly in the UK. One participant attributed this to the current structure of care and medical specialities working in silos instead of integrating expertise:

“It's difficult, and made more difficult by the separation of functions within the NHS, the concept of MDT's is good, however they really don’t work.” (Psoriasis, male, 43 years, white, England)

Much of the dissatisfaction was linked to poor communication from health professionals. Participants reported some practitioners were dismissive, poor listeners, unempathetic, focused on treating the skin complaint only, and one participant in the US was sceptical of the motives of practitioners.

“There isn't much help out there in general...treat the skin problem and goodbye.” (Pemphigus Vulgaris, female, 54 years, white, US).

Feeling understood improved satisfaction with care, but poor understanding of common and especially rare skin conditions among generalist and specialist medical professionals was a deterrent to seeking medical support and led to individuals managing alone or relying on loved ones for support.

“GP training doesn't even cover basic dermatology, I sat with an st3 who was reading as we went along and had zero experience with eczema which for such a common condition is disgusting.” (Eczema, female, 41 years, white, England)

Social support was also limited and unhelpful in some cases because friends and relatives could not truly relate to having a skin condition despite their best intentions.

“It is extremely difficult to get any emotional support as those around you don't understand the sheer irritation and pain you go through every day.” (Eczema, male, 29 years, white, Wales)

The provision of psychological support was limited. Many health professionals reportedly downplayed, or did not recognise, the psychological impact of skin conditions, preventing people from being referred to mental health services and accessing much needed support.

“There is simply no psychological support for this in my region. I've wanted to see a mental health specialist for ages, but I've been told me and my condition aren't a priority, despite it having severe mental consequences on my health.” (Psoriasis and Psoriatic Arthritis, male, 33 years, white, Wales)

The numerical survey data indicated that experiences of psychological support were rare and three participants elaborated. One received counselling and another saw a psychologist and a psychiatrist, but it was unclear whether these were public or private services. One had accessed private care and reported that dietary modifications and supplementation improved their physical symptoms and other health complaints, but it was unclear who provided the dietary intervention and what was involved, plus detail around the additional health benefits was lacking.

> *"I've been on a very restrictive diet and supplementation protocol for the past 2 years overseen by a private holistic healthcare professional. It has improved my skin about 80% and improved a lot of other health problems I was suffering with which I am very pleased about!" (Psoriasis, male, 23, white, England)*

Patient organisations and support groups on the internet and social media were a key source of informational and emotional support for people with skin conditions, although the quality of the information available online was considered variable:

> *"I have found the Facebook groups for my condition to be extremely helpful. I also participated on Stuff That Works for my condition, however I find the knowledge level is not as advanced in those communities. The American Contact Dermatitis Society has also been an important resource as well as an allergy page on Facebook…" (Contact Dermatitis, female, 40 years, East Asian, Canada)*

Overall, existing types of support were limited, and these participants conveyed a need and desire for additional support with self-management:

> *"Sometimes it would be nice for someone else's perspective. I find the GPs increasingly unhelpful. Sometimes you just need a little support and some advice" (Ichthyosis, female, 43 years, white, Wales)*

Theme 5: Perceptions and ideas on the MiDerm app

The qualitative free-text responses indicated that the idea of delivering psychological support via a smartphone app was mostly acceptable given the need and, in some cases, desperation, for psychology provision within dermatology. MiDerm was considered appropriate for current society where the use of apps is now commonplace.

“I think more needs to be done to support emotional/psychological impact of skin conditions so if it does that it would be good.” (Bullous Ichthyosis, female, 40 years, white, England)

Participants conveyed a willingness to learn about their skin condition so they could cope and manage more effectively.

“Information and knowledge is power, this needs to happen to help people like me who are struggling to cope.” (Psoriasis, male, 43 years, white, England)

They wanted educational content specific to skin conditions, including information on cost-effective treatments, dealing with itch and the role and management of health behaviours.

“Good as a mechanism for sharing latest research (global), foods or drinks which causes flare ups, study groups/research projects to join, details of the latest drugs/medications etc. what does not work for most - save time/money etc. […] I don't smoke and am a moderate drinker, however, details on how giving up/cutting down will help most people” (Palmoplantar Psoriasis, male, 47 years, white, England)

Two female participants reported there is currently little guidance or support for women with skin conditions on reproductive health, including the stages of pregnancy and menopause, suggested MiDerm could address this gap:

“There is little support around reducing steroid medication during fertility treatment and pregnancy, when this condition especially is flared up via procedures.” (Psoriasis, female, 30 years, white, England)

How information on health behaviour is communicated was important; the content needs to empower, inspire and give hope rather than instruct, advise, patronise or blame individuals, as some health professionals had done previously.

“Not blaming, I've had plenty of rude Drs & nurses over the years. I don't need lecturing on not eating, not drinking, not exercising, not meditating, being overweight. That's going to make me feel down & hate myself more.” (Ichthyosis, female, 44 years, white, Wales)

Signposting to existing support and services was also mentioned:

“Advice, or info on who to contact or where to go if struggling like a lot of people do mentally with skin conditions.” (Psoriasis, female, 27 years, white, England)

Many participants wanted an opportunity to monitor and reflect on their condition, the physical and psychological factors that affect it, and treatments.

> *"To track ALL appointments and treatments and add symptom side effects as well as mental awareness questions to answer...but not these check off things...that's not good enough. It has to be open ended questions and the ability to express the actual answers." (Pemphigus Vulgaris, female, 54 years, white, US)*

However, some were concerned that self-monitoring might cause people to become fixated on their skin condition instead of learning to live well with it and increase distress.

> *"The danger of this type of App is that the condition becomes a focus of your life if you are continually referring to it. The goal should be to forget the condition in your daily life and get on with living, an app may make you continually worry about the condition" (Lamellar ichthyosis, male, 68 years, white, England)*

Most liked the idea of being able to connect with others living with the same skin condition, who they could relate to, share experiences with and learn from.

> *"I think if you can talk or relate to some one that has it or some understanding of it would be a great help in more ways than one." (Epidermolytic Ichthyosis, female, 60 years, white, England)*

Although attitudes towards MiDerm were generally positive, participants were being asked to comment on an app that did not yet exist and some were uncertain about what the app would offer, how it would differ from existing apps and websites, and potential benefits.

> *"No idea if it [app] would be helpful for me or not until I see it" (Nonbullous Congenital Ichthyosiform Erythroderma, 58 years, female, white, Northern Ireland)*

Participants discussed nuances between skin conditions and queried whether MiDerm could comprehensively address multiple skin conditions, indicating poor awareness of common impacts.

> *"It would have to be all encompassing as I feel skin conditions can be dramatically different from each other" (Hidradenitis Suppurativa, female, 42 years, white, Ireland).*

Those who had lived with their skin condition for years generally felt more confident to self-manage and believed MiDerm would benefit younger people, and adults with late condition onset, in the early stage of adjustment.

"Probably useful to newbies" (Multiple skin conditions, female, 35 years, white, England)

Some were concerned that the app might give false hope to desperate individuals and could become a substitute for face-to-face support, which was not acceptable. Participants were firm in their view of MiDerm as a useful adjunct to standard medical care that should not mitigate, or overshadow, the persisting need for face-to-face psychological support.

"… I think it can't be assumed that these issues will all be solved by an app that provides support and advice and if this is to be presented to NHS commissioners it should be as an addition to medical support not in place of or as a first option. […] An app won't replace the need for sufficient medical support." (Psoriasis, female, 30 years, white, England)

There were perceived barriers to using MiDerm. One participant seemed frustrated by the growing use of apps, indicating some people may prefer other modes of delivery.

"I do not have a 'smart' phone and today everything is 'app' this and 'app' that. It would ok if the 'app' was not everything." (Congenital Ichthyosis, male, 56 years, white, England)

Participants, typically of older age, emphasised that some people do not own a smartphone and lack the confidence and skills to use digital technology:

"I am in my 60's and do not have a smartphone or am very IT minded." (Multiple skin conditions, female, 63 years, white, England)

A few were conscious of their current screen time and believed high consumption of technology may be a barrier.

"I spend most of my working day in front of a screen so I try to avoid screen time outside of this time." (Psoriasis, female, 59 years, white, England)

Physical symptoms, such as pain, were also perceived barriers. Suggestions for improving accessibility included installing voice control, ensuring the app works across digital technologies and flexible use.

"As many skin conditions can impact skin and touchscreen a web-based version may be more accessible or very easy to manage use with skin that makes mobile use painful or needs to be short time use or have audio voice control or link with Alexa etc?" (Psoriasis, female, 51 years, white, England)

Ultimately, participants wanted MiDerm to be*: "fun, simple to use, not distressing" (Ichthyosis, female, 44 years, white, Wales).* The perceived benefits of MiDerm for the self- and clinical management of skin conditions were discussed. MiDerm was considered an appropriate platform for delivering information to improve awareness and understanding of skin conditions:

"An app would be helpful to learn and make me aware of what the condition is." (HS, female, 46 years, white, Ireland)

It was regarded a convenient place for storing personal information and accessing credible resources, reducing the burden of searching for advice and guidance online.

"I'd love to have an app that I can go to that I know contains trusted information. Too many websites have conflicting information on management and treatment." (Psoriasis, female, 41 years, white, England)

One participant believed the app could foster self-acceptance and improve quality of life.

"The need for support will encourage acceptance in an individual, making his living enjoyable though with the disease" (Eczema, male, 22 years, black, England).

MiDerm was also perceived to be a springboard for purposeful conversations with healthcare professionals during consultations and a useful stopgap that could facilitate a sense of continued of care in-between medical appointments.

"This would be so beneficial to have between hospital appointments to keep records and stuff to be able to speak to doctors better." (HS and Psoriasis, female, 30 years, white, Ireland)

Discussion

This survey focused specifically on the self-management of skin conditions and demonstrated how this impacted all aspects of life. These data confirm our previous findings that skin conditions carry physical, psychological, social, financial, daily and occupational and educational consequences (Pattinson et al. 2022) and provides further evidence for CLCI (Warren et al. 2011).

Many reported they lacked the medical, psychological and social support they need to self-manage effectively and coped mainly by themselves. These data reinforce that current dermatology service provision does not adequately address the needs of patients beyond their physical skin complaint and there is a persisting and widespread lack of psychological support (APPGS, 2020).

Participants reported researching their skin conditions and management strategies and relied on online resources, support groups and digital self-help materials, but it was unclear how credible or accurate these sources were. This is consistent with other studies which demonstrate that patients are increasingly utilising the internet and social media for self-management support and guidance (Szepietowski et al. 2018; Thorneloe 2019; Borba et al. 2020; Petukhova et al. 2020).

Dysfunctional coping strategies have been observed in people with skin conditions previously. Behavioural disengagement is common and people often withdraw from health services and social and leisure activities due the presence of visible symptoms and related feelings of shame and embarrassment (Pattinson et al. 2022). People often self-blame and attribute the onset or development of their skin condition to their own actions (Bundy et al. 2014; Ip et al. 2021a). Addiction, including excessive alcohol consumption, drug abuse and gambling, are more prevalent in people with skin conditions, such as psoriasis, compared to the general population, although less is currently known about drug abuse (Zink et al. 2017). Dysfunctional coping strategies, including behavioural disengagement, self-distraction, venting and especially self-criticism were reported by respondents; a higher percentage reported criticising themselves than blaming themselves for their skin condition. Other strategies, including substance use (drugs and alcohol) and denial, were less common, although 25% to 30% of the sample reported employing these strategies to some extent, respectively. One participant explained using marijuana to relieve stress, but it was unclear whether most participants were referring to the use of drugs or alcohol or both.

Behaviour change plays an important role in the management of skin conditions and the associated risk of CVD in mainly inflammatory types (Ko et al. 2019; Sawada et al. 2021; Hu et al. 2022). This survey investigated health- protective and threatening behaviours that adults may perform to cope with skin conditions. Smoking is one health-threatening behaviour that can increase the risk (Naldi et al. 2005) and severity (Fortes et al. 2017) of some skin conditions, and is prevalent in this patient population (Lipa et al. 2021). Approximately 10% of participants reported that they smoked cigarettes to cope with their skin condition a lot.

Health-protective behaviours, such as keeping physically active, can reduce the risk of CVD, obesity, depression and anxiety (Warburton and Bredin 2017), all associated with the onset and severity of skin conditions like psoriasis (Sheppard et al. 2022). Over half the participants reported doing little or no physical activity, and just under half stated that they seldom or never ate healthy foods, but the reasons for this were unclear. Some barriers to exercise have been identified previously (Auker et al. 2020), and evidence for the role of diet in skin conditions is currently limited (Zanesco et al. 2022), but much of the existing evidence focuses on psoriasis. Research is needed to better understand people's attitudes towards, and experiences of, these health-protective behaviours to understand how to improve self-management.

Sleep disturbance is also common in people with skin conditions due to both physiological and psychological factors. Individuals report difficulty falling and staying asleep at night, and experience daytime fatigue as a result (Duan and Silverberg 2023). Fatigue is a common symptom of inflammatory skin conditions (Misery et al. 2020) and is currently under researched in dermatology (Skoie et al. 2015). Some participants reported sacrificing sleep for self-management, a process which contributed to psychological fatiguing, but many reported prioritising getting enough sleep. These findings suggest that people recognise the importance of getting enough sleep but find it difficult to do this.

Treatment non-adherence is common in dermatology (Feldman et al. 2017). Approximately 17% of this sample stated they had not been taking their medication as prescribed. However, prescribed medical treatment formed a major part of condition management for most participants, with only 9% reporting that they never used prescribed medication for condition management and a high percentage of participants who reported taking their medication as prescribed by their doctor. These data suggest that some adults could benefit from additional support to improve adherence. Our systematic review found that most existing digital interventions did not significantly improve treatment adherence, therefore, new approaches, which account for treatment beliefs and concerns, are needed (Hewitt et al. 2022c).

Our systematic review provided preliminary evidence for the acceptability of digital psychological interventions in dermatology, but rigorous qualitative research was limited (Hewitt et al. 2022c). The idea of psychological support delivered via a smartphone app was acceptable to these participants, who believed the MiDerm app would, to some extent, help to address the gap in existing service provision, meet patient need for support to deal with the emotional impact of skin conditions, and provide a sense of continued care in between medical appointments, which was important to these participants. The use of apps was considered usual within society and MiDerm specifically was perceived as a useful platform that could increase awareness of skin conditions and competence for self-management, as well as a convenient source of information that could mitigate the physical and psychological burden associated with searching the internet for credible advice and guidance.

Some participants, however, were uncertain about the app because they were unsure what it would include or deemed it less or not acceptable. The free-text responses indicate some possible reasons for this, including limited smartphone access and insufficient skills to use them. There were concerns that the app would become a replacement for face-to-face psychological support, the app was considered to be an appropriate adjunct, but not a substitute, for this. Some participants felt the app would lack personal relevance because they had already learned how to self-manage their condition over time and perceived it to be more beneficial for younger people and adults who had recently developed, and were adjusting to, a skin condition. However, there was a concern that the app might give desperate individuals a false sense of hope. This emphasises that whilst MiDerm may generally be an appropriate intervention, there must be clear boundaries and realistic expectations around its use and purpose (respectively), and potential barriers must be addressed. These findings related to MiDerm mirror those found in the group interview study.

What this study adds

The finding that skin conditions can substantially affect psychological well-being is not new (Wheeler et al. 2021) but these qualitative data allude to the phenomenon of 'psychological scarring' whereby poor mental health may persist despite physical improvement. They also suggest that the degree of psychological impact depends on condition severity. The latter is new but aligns with earlier results showing an association between severe psoriasis and increased depression risk (Chosidow et al. 2010).

Quantitative data showed that self-management dominated daily living, affecting engagement in preferred activities and personal finances, life choices and autonomy, yet the time and effort required for effective self-management was considered most impactful. Qualitative data indicated self-management was particularly challenging for people experiencing distress and disturbed sleeping patterns and led to psychological fatigue.

People with skin conditions commonly report experiencing a loss of personal control due to the unpredictable nature of symptoms and uncertainty around condition progression (Howells et al. 2019), yet over 65% of the present sample agreed that their actions could influence their skin condition, which is positive.

Hughes and colleagues (2021) previously investigated coping in people with skin conditions and found that females with skin conditions were significantly more likely to engage in avoidant coping than males. The present survey investigated how adults cope with skin conditions using the Brief COPE (Carver 1997). It did not test for gender differences but provides evidence for the use of dysfunctional (including avoidant), emotion- and problem-focused coping strategies, plus health behaviours, among a larger sample of adults with skin conditions.

Social acceptance has been recognised as an important factor for successful adaption to skin conditions (Zhang et al. 2019). Many participants reported trying to accept their skin condition, highlighting the importance of acceptance at the individual level. These qualitative data also revealed that making downward social comparisons had a positive impact on how adults felt about their situation. This is a helpful contribution given that upward social comparisons related to appearance can predict body dissatisfaction and shaming and mediate the relationship between time spent engaged with photo activity on Facebook and feelings of stigmatisation (Adkins et al. 2023).

The use of problem-focused coping strategies, including active coping, planning and informational support, were common and evidence motivation for self-management. However, approximately 30% had not sought or received informational support from others and several free-text responses emphasised the psychological burden of planning. Thus, whilst many adults proactively approached self-management, some may require additional support to identify and plan for self-management strategies that fit around their lifestyle and are not burdensome.

Strengths and limitations

This survey builds on existing studies investigating coping in adults with skin conditions using a validated measure of coping. It specifically addressed the role of health behaviours in coping. This is an important, and growing area of interest, in dermatology, but there is a lack of digital interventions targeting health, and particularly lifestyle, behaviours as identified in our recent review (Hewitt et al. 2022c). These results strengthen the case for, and could direct, the provision of dedicated lifestyle support within dermatology, which is limited in UK services (Massoud et al. 2021).

This survey involved 370 adults representing 16 skin conditions from 25 countries, demonstrating global reach. The total number of skin conditions may be higher given that 8% of the sample reported having multiple skin conditions. However, most participants were female, white ethnicity and from England in the UK, limiting generalisability and transferability to the wider population. In addition, 44% of respondents had psoriasis, which prevented testing for meaningful differences between skin conditions and restricted reporting to descriptive statistics for the whole sample.

PPI is recommended in dermatology research to ensure research that is carried out is relevant to patients (Heague et al. 2022). Members of the PPI group contributed to this study by reviewing the survey questions and most of their feedback (Appendix 9) was incorporated. However, the feedback stated that a ‘not applicable’ response option should be added. Whilst this was not possible for the Brief COPE, an established measure, it was my full intention to include this in the other sections of the survey, yet an oversight on my part meant the survey was published without this. This is problematic because some items, for example, those on religion and smoking, may not have been relevant to everyone but the participants had to respond irrespective of this.

Low response rates and missing responses are common problems in online survey research (Coulson 2015). In this survey, missing responses were noted for 21 items, but the number of missing responses was never more than four (1%) per item. All missing responses were observed in the final section of the survey relating to 'ideas for the app' suggesting some participants may have been experiencing survey fatigue, a factor known to negatively affect survey completion (Coulson 2015).

Identified next steps in the context of this research

The survey results suggest a smartphone app offering psychological support is likely to be appropriate for many, but not all, adults living with skin conditions. This is an important finding given that our systematic review found that most existing digital interventions were delivered via the internet and only four studies reported on interventions delivered fully, or in part, via mobile apps (Hewitt et al. 2022c). This supported the delivery of MiDerm via a smartphone app.

The results also provide a clear indication of specific content and features to include in the app. Many existing digital interventions included education on skin conditions and their management, primarily focusing on skin protection and treatment behaviours (Hewitt et al. 2022c). Behavioural interventions have addressed other health behaviours, mainly diet and physical activity, but these are generic rather than tailored to skin conditions and are often condition-specific (Pavlova et al. 2023). The same is true for lifestyle advice that health professionals reportedly impart to people with psoriasis during consultations (Trettin et al. 2021b). Respondents perceived the provision of information on the link between psychological and social processes and the skin important. They also considered practical support with diet, physical activity, sleep, general coping and managing mood and itch to be important. Other health behaviours, including drinking alcohol and smoking, were rated as important but not as highly by as many. These results were used to develop tailored educational material for MiDerm.

Survey respondents emphasised that the language health professionals used when discussing lifestyle factors was often advisory, blaming and patronising, which elicited feelings of frustration and defensiveness. This reflects previous findings that health professionals employ a routine and corrective approach using checklists instead of discerning what matters most to patients when discussing lifestyle (Trettin et al. 2021b). Thus, how information about health behaviour change was worded within the app required careful consideration and efforts were made to ensure the language used was motivational to encourage adults to change their lifestyle.

Whilst a tracking feature that allows users to monitor physical symptoms and emotions was important, some participants described how this could increase the psychological impact on users. Given that MiDerm aimed to improve psychological well-being, this suggested a self-monitoring feature needed to be carefully designed, or not included, to avoid exacerbating distress.

Personalisation was important to respondents, who wanted interactive activities, including goal setting and action planning and individualised progress updates. Tailoring digital interventions to the needs and preferences of users, although potentially costly, is recommended because it can improve engagement (Michie et al. 2017). This suggested that tailoring MiDerm to the individual user, as well as including content and features that are specific to skin conditions, might help to improve engagement.

Suggestions for future research identified from this study are covered in Chapter 9.

Practical implications

This study emphasises the almost complete lack of support for adults with skin conditions and strengthens existing calls for increasing psychology provision within dermatology (APPGS, 2020). Specialist support is needed but basic medical care should include some self-management and psychological support. It is important to ensure specialist support remains available to adults, even when their symptoms are controlled, to help those struggling with the persisting psychological consequences.

These data indicate more general types of support that existing services could provide as well as specialist support that requires trained professionals to provide. Participants expressed dissatisfaction at how health professionals approached the topics of lifestyle and behaviour change during consultations, stressing the importance of the language used. Health professionals need to be mindful of the words they use to have effective, meaningful and collaborative conversations on these topics instead of advising, instructing and preaching to patients. Dermatology specialists could benefit from completing further clinical communication skills training, such as the PsoWell™ training programme (Chisholm et al. 2017; Hewitt et al. 2021), to achieve this. In addition, this study shows that some people may need support to identify and plan strategies for self-management that fit with their current lifestyle. Action planning is an evidence-based behaviour change technique (Michie et al. 2013) that could be used to help people create realistic and specific plans for self-management. Action planning is covered as one of the four stages of MI in the PsoWell™ training and thus completion of this programme could enable dermatology staff to support patients to make tailored plans for change.

The survey also highlights areas where qualified practitioner psychologists could best support adults to cope with, and self-manage, skin conditions effectively and there are specific psychological approaches and techniques that practitioners could draw on to facilitate this. For example, types of dysfunctional coping were reported by these participants. Behavioural disengagement and venting have been found to be risk factors for psychological distress in people with psoriasis (Colombo et al. 2010). Practitioner psychologists could screen for dysfunctional coping strategies and support people to identify alternative approaches that support psychological well-being.

Another example is acceptance. Many participants reported they had tried to accept their skin condition and thus, could benefit from receiving therapeutic approaches designed to facilitate this. Acceptance and Commitment Therapy (ACT) helps people to accept difficult situations and emotions and commit to working towards meaningful goals and actions that are aligned to the individual's values. Zucchelli and colleagues (2018) concluded ACT could be a useful approach for people living with visible differences (Zucchelli et al. 2018). More recently, ACT has been found to significantly improve psychological outcomes in people with vitiligo (Daneshi et al. 2021) and psoriasis (Shahidi et al. 2022).

Self-criticism was also common in the present sample. A recent randomised controlled trial found that Compassion-Focused Therapy significantly reduced self-criticism in people with vitiligo (Fatollahzadeh et al. 2023). Therefore, the use of compassion-based approaches might be beneficial.

Many participants believed they could, to some extent, influence the progression of their condition through their own actions. The survey findings reinforce that control is a complex, multifaceted and subjective construct related to physical, psychological and social functioning (Howells et al. 2019). It is important to understand patients' personal level of personal control to help foster, and capitalise on, a high sense of control for effective self-management. This is another example of where a specialist service that understands the importance of beliefs in driving behaviour change is needed.

It seems people are increasingly turning to the internet and social media for guidance on self-management, although the quality, accuracy and credibility of the information available is questionable. People and organisations involved in supporting people with skin conditions should direct people to, and support them to identify, credible sources of information that promote safe and evidence-based approaches to self-management. Adults with skin conditions could benefit from a new digital medium that conveniently houses information for self-management.

Chapter summary

This survey provides further evidence for the cumulative impact of skin conditions, particularly the burden of self-management and the time and effort this requires. This burden may be greater for people experiencing distress and severe physical symptoms and evidences psychological scarring as a potential lasting consequence of skin conditions. Limitations and inadequacies associated with existing types of support were reported, yet many respondents believed they could control their skin condition and performed a range of dysfunctional, emotional and problem focused coping strategies and health-protective behaviours in response. The idea of a new smartphone app that delivers psychological support and specifically focuses on mood management and health behaviour change appeared to be acceptable, although the need and desire for specialist face-to-face psychological support remains. The next step was to develop MiDerm based on these results, with continued input from adults with skin conditions.

Chapter 7: Synthesis of online survey and group interview data.

This chapter includes a synthesis of the qualitative and quantitative data from the online survey and group interviews in order to triangulate the data. The topics of condition impact and management, existing support and participants' perspectives on the perceived acceptability of the MiDerm app are dominant. Appendix 49 presents an overview of the key findings of the quantitative and qualitative survey data and the qualitative interview data.

Data synthesis

Impact

Data from the online survey and group interviews supports the life impact of a range of skin conditions (Pattinson et al. 2022).

The concept of CLCI in psoriasis (Kimball et al. 2010) was introduced under Theme 1 in Chapter 5. These current data provide further evidence for CLCI in people with both common and rare skin conditions. These qualitative interview data provide clear examples of the relationship between psychological processes, including cognitions, emotions and behaviours, and social consequences associated with skin conditions. Our examples show how the presence of skin conditions can result in people living less fulfilling lives.

Female gender and younger age are both risk factors for CLCI, increasing risk for psychological and psychiatric comorbidities in some skin conditions (Von Stülpnagel et al. 2021). Evidence suggests women are more susceptible to poor adaptation to visible skin conditions because of the effect on appearance (Zhang et al. 2019). Both sets of qualitative data indicated women, children and younger people living with skin conditions, and adults who develop a skin condition later in life, were vulnerable to experiencing CLCI if appropriate interventions are not implemented. Most participants identified as female and these data suggest that the uncertainty around the impact of skin conditions on reproductive health (and vice versa) may lead to a greater burden for women compared to men.

Both data sets emphasise that interventions are needed to support adults, especially women and those with late condition onset, to live well with a skin condition.

Existing support

Survey respondents reported varying levels of support from health professionals and approximately 30% occasionally received this support for their skin condition. Qualitative free-text responses and interview data identify poor access to timely, free and local medical care, as well as poor access to, availability, choice and efficacy of existing treatments. This was exacerbated by the SARS-CoV-2 pandemic. These inequities were particularly evident for people with rare skin conditions. Services were described as poorly understood, largely modelled on the biomedical model of care, and lacking integration with other disciplines. Reactive and stepped approaches to symptoms and treatment (respectively) were seen to drive trial and error approaches to condition management, increasing patient burden.

Despite long-standing calls to support the psychological well-being of people with skin conditions, the provision of psychological support within dermatology services remains limited (APPGS, 2003; 2013; 2020). This has made it difficult for researchers working in this area to identify and explore the experiences of people who have accessed psychological support for their skin condition. Both the survey and interview data confirm the lack of psychological support for people with skin conditions. Interview data also offer novel insights into the experiences of a small number of adults who had received some form of psychological support mainly, although not always, in relation to their skin condition. The personal accounts emphasised physical, cognitive, emotional and behavioural benefits of psychological support, as well as practical, psychological and financial barriers to accessing such support. These need to be addressed to improve existing and develop new specialist services for adults living with skin conditions.

Together the studies provide a case for re-designing dermatology services in line with the biopsychosocial model of care. These qualitative data reveal some benefits of psychological support but reducing barriers is essential to improve access and to ensure support is specific to dermatology and appropriate for patients.

Social support from loved ones is important for coping with skin conditions and protecting psychological well-being (Chapter 5). Approximately 30% of respondents said they received support from friends and family occasionally. Both qualitative data sets indicate a potential reason for this. Generally, the presence of friends and family fostered feelings of safety and comfort and reduced stress. However, the inability of loved ones to relate to having a skin condition meant there was a 'glass ceiling' to the level of support they could offer and resulted in feelings of frustration when well-meaning friends and family offered advice on condition management, usually from a place of poor understanding. Friends, family and intimate partners are no substitute for medical and other health professionals, such as psychologists, who are trained to provide specialised support for patients.

Both the online survey and group interviews highlight the role of peer support in living well with a skin condition. Patient organisations and online patient support groups on social media offer sources of support, giving informational and emotional support not available elsewhere. Approximately 70% of respondents engaged, to some degree, with online groups, whereas 63% reported never accessing support specifically from a patient organisation. Both sets of qualitative data showed that an overwhelming amount of information and opinion is shared on these platforms, raising concerns for the accuracy and appropriateness of information on health and well-being and the safety of users.

Both data sets suggest adults take responsibility for managing their own skin condition and improving the standard of existing support and providing alternatives are both necessary to help adults to self-manage safely and effectively.

Self-management and coping

The Brief COPE (Carver 1997) identified a range of dysfunctional, problem- and emotion-focused strategies, as well as health-protective and some health-threatening behaviours in our survey sample. Both data sources emphasised coping was dependent on the number of years lived with a skin condition and the level of personal adjustment. Coping reportedly became easier with time, acceptance and the acquisition of knowledge, skills and confidence from pursuing a career and hobbies. Group discussions emphasised acceptance was key to taking back control and interrupting CLCI. Thus, there is a clear role for psychological approaches that aim to bolster self-acceptance.

Common dysfunctional coping strategies reported by respondents included self-criticism followed by self-distraction and behavioural disengagement. Qualitative data evidenced avoidance coping, for example avoiding social situations and covering mirrors.

As for emotion-focused strategies, both studies reported low levels of emotional support; 30-40% of survey respondents said they neither sought or received this. Interview data showed that emotional support from people with lived experience of skin conditions was mainly sought online and emphasised that peer support was valued because of the shared experiences and empathy.

Both qualitative data sources showed that some participants adults used downward social comparisons to make them feel better about their skin. Closer analysis of the interview data revealed that this may only be helpful in the short term and its use may have negative consequences in the longer term because individuals downplayed the burden and severity of their skin condition, which made them less inclined to seek professional support. Use of this coping strategy may reveal beliefs about the identity of their illness, which had a temporary positive influence on well-being, but negatively affected help-seeking behaviour.

Problem-focusing coping strategies, including planning, seeking informational support and active coping, were reported in both studies. Survey respondents rated the time and effort required to manage their skin condition as the main impact of self-management. Qualitative interview data indicated a potential reason for this; use of the CSM (Leventhal et al. 1984) helped to explain gaps in adults perceptions of their skin condition(s) and showed that the task of self-management was made harder for adults who lacked a complete understanding of their skin condition. Some adults did not recognise the extent to which the skin condition impacted them, especially psychologically, or that many of the associated consequences are commonly experienced (identity and consequences). Many participants had some, but limited, awareness of potential triggers (cause) and effective approaches to managing skin conditions, including treatments (controllability).

Many group interview participants explained how spending considerable time planning around their condition could negatively impact psychological well-being. Both studies made clear that self-management routines were all consuming and impacted daily choices and living, and the pressure to control symptoms contributed to the psychological burden.

Survey respondents also reported that self-management disturbed sleeping patterns, despite efforts to prioritise getting enough sleep. Together the data sources showed how self-management affected different aspects of life.

As for the controllability of skin conditions, both qualitative data sets confirmed that skin conditions are highly unpredictable. However, 68% of survey respondents believed to some extent that their own actions could influence their skin condition, emphasising some degree of personal control. Several participants in both studies reported focusing on health-protective behaviours, including keeping active, helped to improve physical, psychological and social well-being and led to a greater sense of personal control over skin conditions. These findings echo those of Howells et al. (2019) who found control was a multifaceted and subjective construct that is influenced by eczema activity and severity, psychological and social functioning, as well as approaches to eczema treatment and management.

Whilst some participants discussed the benefits of keeping active for their skin and general health, over half of the survey sample reported rarely or never being physically active. Both studies made clear that adults dedicated time and energy to managing symptoms on top of daily responsibilities, and it is likely that this reduced their time and motivation to take regular exercise and do other preferred activities. Some adults could benefit from support to incorporate leisure activities that are meaningful to them although barriers to exercise have been reported in psoriasis (Auker et al. 2020). Over 55% of survey respondents rated the provision of tailored information and tips on keeping active as extremely important for the app and some interviewees discussed de-bunking myths about the effects of exercise. These suggestions could help to encourage adults with skin conditions to keep active.

Both studies showed that inadequacies in professional support led to adults searching the internet for advice and guidance on their skin conditions and cost-effective treatment and self-management strategies. Interview data indicated other drivers, including poor understanding and seeking personal control. Furthermore, these data showed that conducting personal research to support self-management required a substantial amount of time and effort and amplified the burden of living with a skin condition. Searching different websites to find relevant information led to feelings of overwhelm and skepticism towards the quality of the available information. However, some participants reported pursuing potentially harmful strategies in the absence of appropriate evidence and guidance. For example, making dietary changes, including vegan, juicing and elimination diets plus time-restricted eating. These strategies were mainly met with little or no success, reducing self-efficacy for self-management, and reducing personal control. Thus, the qualitative interview data highlight that some adults may hold unhelpful underlying beliefs regarding a cure for their symptoms and how this can lead to them searching for a cure out of desperation or hope despite recognising that they were living with an incurable skin condition.

The survey showed that some adults performed health-threatening behaviours. Some respondents (6-10%) reported that they often smoked cigarettes or used substances (drugs and alcohol) as a means of coping with the skin condition. In addition, the qualitative free-text responses evidenced sun bed use to improve physical symptoms and emotional over-eating and recreational drug use for coping, although the numbers reporting these behaviours was low. These findings were exclusive to the survey demonstrating a potential benefit of anonymous reporting. They are important because they reinforce the role, and need, for professional and dedicated behaviour change support within dermatology.

Collectively, these data demonstrate that adults use various strategies and health behaviours to cope with skin conditions and improve their physical, psychological and social well-being. Generally, these adults took a proactive approach to self-management, but this task was challenging, and many could benefit from professional support to identify, plan and implement effective strategies that enable them to live well with their skin condition instead of being ruled by it. Although some coping strategies and behaviours were helpful in the short term, they may be damaging in the long term and thus adults need to understand how their behaviour can influence their health. Adults could benefit from additional support to find ways of coping that are health-protective and facilitate adjustment by reducing self-criticism and increasing self-acceptance.

App acceptability

Overall, both studies provide evidence for the *perceived* acceptability of the MiDerm app, demonstrating its potential for delivering psychological support to adults with skin conditions in the context of an increasingly digitised society, especially where professional support for this group of people is currently lacking. Participants in both studies considered MiDerm more appropriate for younger people and adults with late condition onset who are adjusting to having a skin condition. Continuity of care was valued and the app was viewed as a way of offering ongoing support in between consultations and over time. Some interviewees also saw the app as a tool to facilitate communication between patients and clinicians, including shared decision-making.

Due to the lack of a prototype, both studies highlighted some uncertainties around what the app would offer and its ability to cater for different skin conditions and meet varying levels of psychological need. Some respondents also expressed concerns about the app giving people false hope and it becoming a replacement, rather than an adjunct to, face-to-face psychological support for which there was a clear need and desire across the two studies.

Both data sources provide useful insights into what adults with skin conditions want and need in terms of additional support. From the group interview data we identified that ideas for app content aligned to the key concepts of SDT (Deci and Ryan 1985), including: *competence* to understand skin conditions and approaches for management; *autonomy* through the provision of tools and techniques for effective self-management; and *relatedness* to others living with skin conditions who were a key source of emotional and informational support.

The following aspects were addressed in the survey questions but not the qualitative free-text responses:

- Cost.
- Giving users a sense of control.
- Personalised content.
- Push notifications.
- Interactive activities.
- Virtual rewards.
- Input from people living with skin conditions.
- Input and endorsement from healthcare professionals.
- Input and endorsement from patient organisations.
- Endorsement from health authorities.

Some of these aspects were covered in detail in the group interview study. Using the topic of cost as an example, both studies underscore the important of producing an app that is freely available, but the interview data justified this by revealing this is necessary to improve accessibility.

In addition, both studies convey a role for key stakeholders, including patients, health professionals and authorities, and patient organisations, in developing and promoting MiDerm. These qualitative data show that it is the credibility and trustworthiness of key stakeholders which matters most. The qualitative interview data specifically indicates some potential benefits of co-development with the target group, including confidence that the app is relevant and maintaining user interest and engagement. This reinforces existing claims regarding person- and user- centred approaches to boost intervention acceptability (Yardley et al. 2015a) and supported the theoretical approach that was adopted to develop MiDerm.

Some group interview participants lacked a full understanding of skin conditions and their impact and management. Across the studies, participants showed a willingness to learn about skin conditions. Survey respondents indicated that the provision of information linking skin conditions and psychological processes is important for the new app and both data sources show that many adults believe bridging the gaps in their knowledge on the links between skin conditions and psychological and social factors might increase intentions for behaviour change and encourage the maintenance of habits that benefit the individual. Combining these studies provide support to claim that the MiDerm app is a suitable platform for housing evidence-based information and guidance that is specific to skin conditions, and that it could increase adults' competence (knowledge and skills) for self-management. These hypotheses remain to be tested in the next stage of app development.

Both qualitative data sources provided insights into potential barriers to initial and sustained app use. In addition, interviewees discussed solutions that could be implemented to enable this, most related to the content, functions and design of MiDerm. Barriers and enablers were mapped against physical and psychological competence, physical and social opportunity and reflective motivation, three established drivers of behaviour outlined in the COM-B Model (Michie et al. 2011b). Survey respondents indicated that current screentime use could be a barrier, whereas interviewees emphasised psychological barriers, including inaccurate beliefs, avoidant coping and self-stigma. The interview data in particular conveyed the importance of giving users choice, control and autonomy to use the app flexibly to suit their skin condition and lifestyle.

Finally, the qualitative group interview study was the only aspect of this research that addressed the potential design of MiDerm. The colour scheme was integral to generating a positive user experience and increasing inclusivity. Light shades of blue and green were favoured because these colours were associated with the calming feel that participants said MiDerm should foster.

Strengths and limitations

This synthesis demonstrates how data triangulation can be achieved. The survey and group interviews were run concurrently and were complimentary as they often addressed the same issues. The survey, however, also included items from an established measure of coping which enabled me to investigate specific coping strategies in the target population. The online survey was intended to reach the wider population of adults with skin conditions around the world. The group interviews were held virtually, giving people in other countries an opportunity to participate, but their main purpose was to probe for a deeper understanding of lived experiences of skin conditions. The mixed methods approach to data collection supported the triangulation of qualitative and quantitative data, generating a broad and comprehensive understanding specifically of self-management approaches, coping styles, current types of support, as well as attitudes and ideas for building MiDerm among adults living with common and rare skin conditions in different countries.

These studies produced a substantial amount of data and synthesising these data was challenging. Input from colleagues was integral to successfully and accurately synthesising these data, supporting investigator triangulation and offsetting potential personal biases (see Reflexivity in Chapter 5).

Since these data were collected and analysed, Younas and colleagues (2023) have published a paper which outlines a seven-step process for developing metainferences, or insights, from data generated from mixed methods research. Following this process could have facilitated a more systematic approach and transparency in reporting.

This research applied three psychological theories, enabling a systematic and evidence-based approach to addressing the different research aims. The combined application of the CSM (Leventhal et al. 1984), the TFA (Sekhon et al. 2017) and the COM-B Model (Michie et al. 2011b) supported theoretical triangulation and helped to form a clear and comprehensive line of argument that supports the development of MiDerm.

The high representation of some conditions, especially psoriasis, across these studies is a potential limitation. This point bears consideration for transferring and generalising the conclusions of this synthesis to the wider dermatology population and developing content for the MiDerm app.

Identified next steps in the context of this research

Ultimately, these studies provide support for the development of a smartphone app to deliver dedicated psychological support, including health behaviour change, for adults living with skin conditions.

Application of theory strengthened this research. Use of the TFA (Sekhon et al. 2017) facilitated the study of *attitudes* towards MiDerm, factors affecting *self-efficacy* to use it and the potential *effectiveness* of the app from the perspective of prospective users. It revealed that an app that is prescriptive could increase the *burden* on users but giving them choice over app features and ability to use the app flexibly, as and when they feel like it or need to, would lessen intervention burden. I found evidence of intervention *ethicality* and the idea of MiDerm mainly aligned with the values of the participants, although the app may be less useful to adults who feel adept in managing their condition. In addition, the qualitative interview data provided useful insights into *intervention coherence*. It was also apparent that some adults may not fully understand the common ways in which skin conditions can impact people, or what psychological support entails. Therefore, these data provide evidence for intervention coherence and condition coherence. The latter relates to the CSM (Leventhal et al. 1984), further supporting the usefulness of this model in this context.

However, the TFA (Sekhon et al. 2017) concept of *opportunity costs* was under utilised. Opportunity costs to using MiDerm may only become apparent when the app becomes available for use. The TFA (Sekhon et al. 2017) covers concurrent and retrospective, as well as perceived, acceptability of health interventions and thus, could investigate this further in future.

In addition, these studies show that many adults attempt to self-manage their condition but do not always have the competence or confidence to do so effectively, as identified from use of the COM-B Model (Michie et al. 2011b). Use of the COM-B model proved helpful and should form part of any behaviour change attempts.

Collectively, these examples show that the use of theory is important, especially the theory that best fits the research question.

Both studies provide insights into the areas where adults with skin conditions want and might need additional support. For example, the survey highlighted the issue of poor engagement with exercise and the desire for informational and practical support relating to keeping physically active. The group interview study added to this with adults emphasising the benefits of keeping active for their skin and general health and explaining that clarifying the reasons why keeping active is important for managing skin conditions could aid understanding and motivation for behaviour change. Overall, the provision of tailored evidence-based guidance on mood and behaviour management could help to increase personal competence and self-efficacy for self-management and this should be prioritised.

In addition, these data emphasise the importance of language and especially how behaviour change information is communicated through the app. Participants desired tailored and motivational content and said to avoid giving generic advice in a paternalistic manner. This supports the notion that behaviour change is more likely to occur if motivation for change comes from the individual instead of being imposed on them (Rollnick and Miller 1995) and supports the use of MI (see Chapters 2 and 8 for more information) as a framework for developing a behavioural component of the MiDerm app that respects the autonomy of users. Furthermore, it demonstrates that careful consideration must be given to how written content is worded. Message framing can influence behavioural intentions and change (Rothman and Salovey 1997) and, arguably, these principles should be considered when developing MiDerm to ensure its content encourages rather than discourages health behaviour change in adults with skin conditions.

Practical Implications

Collectively, these data emphasise the need for the provision of ongoing psychological support across the life course for people living with skin conditions. Some people may require tailored support and guidance to help minimise the impact of skin conditions when they first develop, support successful adjustment, and buffer the risk of CLCI.

The qualitative components of these studies indicate that common and rare skin conditions are poorly understood across society and emphasises the need to educate people about skin conditions, especially the impact they can have on the people who live with them. This finding may have been missed with a quantitative survey alone, demonstrating the added value of a mixed methods design. The finding carries important implications for dermatology education and service provision, mainly that an overhaul is needed to equip medical staff and students with the knowledge and skills to adopt patient-centred approaches and implement a biopsychosocial model of care across services and countries.

Furthermore, these qualitative data convey the need for the provision of high quality, credible and evidence-based information and guidance that is freely available to people with skin conditions on the internet and social media. Interviewees stated the need to implement measures and controls to safeguard the physical and psychological health of people seeking information and peer support online.

In addition, dermatology patient organisations play a valuable but, arguably, under recognised role in supporting people with skin conditions. Whilst the qualitative components of these studies convey the benefits of accessing informational, emotional and peer support via patient organisations, it seems they are currently under utilised and some skin conditions (i.e., acne) currently have few or no dedicated organisation. It is important that health authorities and providers recognise patient organisations as a key player in the broader support network for dermatology patients and funding is needed to sustain and improve existing organisations and develop new ones to ensure fair representation of common and rare skin conditions around the world. More research is needed on how patient organisations can play a role in healthcare provision.

Chapter summary

Both studies offer a good balance in terms of the quantity and quality of responses from prospective users of MiDerm and provides a steer for developing the app content, functionality and its design. They provide a useful example of how applying psychological theory can inform intervention planning, generating ideas for development and giving insight into key factors, including barriers and enablers, to consider moving towards optimising and implementing the MiDerm app for real world use.

Ultimately, this data synthesis provides evidence of the profound life impact of skin conditions and the struggles of self-management that adults face in the absence of adequate and reliable support from credible sources. The findings of the two studies were mainly complimentary and no major contradictions were found. Generally, the survey results provided an insight into key issues and preferences and the group interview findings elaborated on most of these, providing additional context and reasoning that helped to explain their relevance, and justify their importance, to MiDerm.

Overall, this synthesis indicates MiDerm may be an appropriate platform for delivering psychological support focusing on health behaviour change to adults with skin conditions. Next is to develop and design MiDerm in accordance with these data to meet the needs, preferences and desires of adults with skin conditions whilst minimising barriers to app use. Thereafter, app testing will be essential to ensure its suitability, usability and relevance for the global dermatology population and efficacy for improving health outcomes.

Chapter 8: Development of MiDerm

Defining complex behaviour change interventions

Complex interventions as defined by the MRC (Craig et al. 2008) are being increasingly used to address key health and social issues (Michie et al. 2016). According to Craig and colleagues (2008, p. 2), complex interventions:

- Contain several components that are related to, and interact with, one another.
- Target different audiences and/or work across several organisational levels.
- Target different behaviours in different audiences, including those who receive or deliver the intervention.
- Address various outcomes.
- Allow some flexibility and tailoring.

The MiDerm app is a complex DBCI because it:

- Includes three main components (informational, peer and behaviour change support) which are designed to support the self-management of skin conditions, whether they are used separately or, ideally, together.
- Is not targeted at one specific skin condition and has been developed to help adults living in different countries to self-manage and cope with psychological aspects that are ubiquitous across common and rare skin conditions.
- Aims to address different psychological processes, including beliefs, emotions and behaviours related to skin conditions. These are all outcome variables which, at some point in the future, can be measured to establish intervention efficacy.
- Addresses various health behaviours (i.e., smoking, drinking alcohol, diet, sleep, physical activity, treatment adherence, itch/scratching) and,
- Allows users to decide which behaviour(s) they want to change (if any) and,
- Is not prescriptive and can be used flexibly by users to suit their individual needs, preferences and circumstances.

The Person-Based Approach (PBA) to intervention development

A full overview of the PBA is depicted in diagrammatic form in Figure 12.

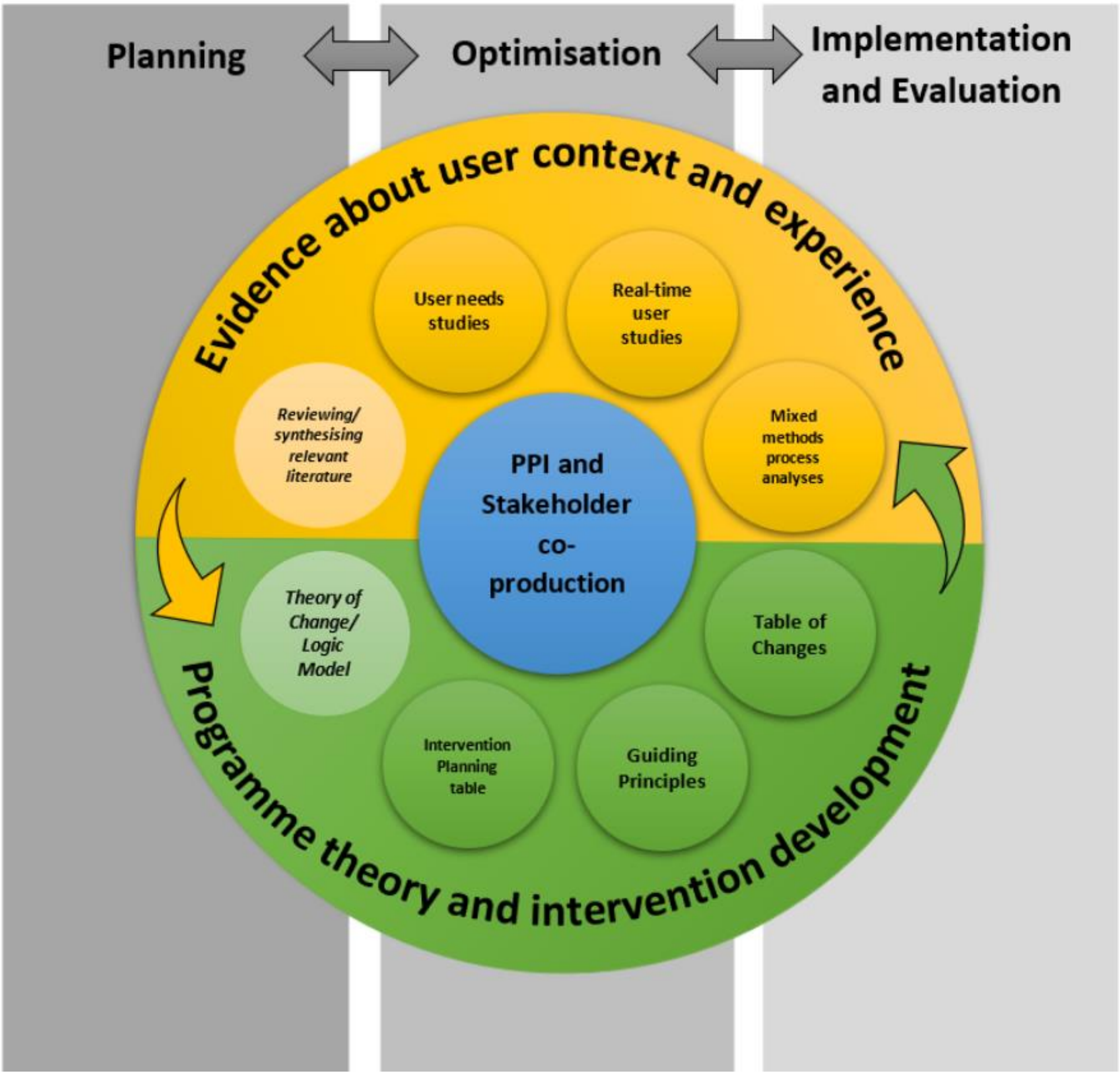

Figure 12: Overview of the Person-Based Approach reproduced from Yardley et al. (2015b)

Central to the PBA is the idea of incorporating and prioritising the perspective of the intervention target to ensure interventions are appropriate and engaging, as well as to promote autonomy and competence and a positive experience for the user (Yardley et al. 2015b; Morrison et al. 2018). PBA champions using qualitative (or mixed methods) research to gain a rich understanding of the target population, their context and views on potential behavioural components of an intervention, with a view to defining specific 'guiding principles' (i.e., the objectives and features of the intervention) that steer the development process (Yardley et al. 2015b; Morrison et al. 2018). The PBA is intended to be a flexible and iterative approach that also embraces other, evidence- and theory- based approaches, such as the Behaviour Change Wheel (Michie et al. 2011b). Using the PBA to supplement existing evidence and theory can enhance intervention acceptability, engagement and effectiveness once implemented (Yardley et al. 2015a; Yardley et al. 2015b; Band et al. 2017; Morrison et al. 2018). Several studies have shown how evidence-, theory- and person- based approaches can be successfully combined and practically applied to develop complex digital interventions for a range of health problems, including hypertension (Band et al. 2017), cognitive health (Essery et al. 2021), reducing unnecessary antibiotic prescribing (Santillo et al. 2019) and reulceration risk in people with a history of diabetic foot ulcers (Greenwell et al. 2018).

Reports documenting the development of complex interventions often inadequately describe the development process, components of the intervention, how key decisions were reached and how the intervention is proposed to work (Greenwell et al. 2018). The PBA facilitates comprehensive and transparent reporting of each of the key phases of intervention development by outlining (Greenwell et al. 2018):

1. Planning.
2. Optimisation.
3. Implementation.

Planning involves primary and secondary research evidence being collated and theoretical modelling is undertaken to ground the new intervention in existing evidence and theory (Yardley et al. 2015b). Theoretical modelling involves comprehensively defining the intervention, establishing guiding principles, behavioural analyses, and the development of a logic model.

Guiding principles narrow the focus of the intervention and keep development on track (Yardley et al. 2015b; Greenwell et al. 2018; Morrison et al. 2018). Whilst guiding principles are typically defined in the early stages of intervention development, they can be used throughout the process.

A behavioural analysis will identify target and subsidiary behaviors and map these behaviours, along with the intervention components, against existing evidence and behaviour change theory (Essery et al. 2021). Logic models are developed to show how the intervention is intended to work, including the potential psychological mechanisms of action. Logic models bring together existing evidence and behavioural analyses into a testable model that details the needs of and issues facing the target group, intervention components, active mechanisms and outcomes (Greenwell et al. 2018).

Intervention optimisation serves to gather feedback on the intervention from the target audience that is used to revise and improve the intervention. Qualitative research, such as think-aloud interview studies, are commonly employed to gather feedback on a prototype in real time (Yardley et al. 2015b; Morrison et al. 2018). Stakeholder consultation and engagement with PPI volunteers are also integral to optimisation, as previous research has demonstrated (Santillo et al. 2019; Essery et al. 2021).

Implementation refers to embedding an intervention, and using it as intended, within real world settings (Skivington et al. 2021). How an intervention will be implemented should be considered from the start of the development process (Skivington et al. 2021). Qualitative research methods are often used to identify potential barriers and facilitators to implementation before it occurs, or to capture feedback retrospectively following the implementation and practical use of an intervention (Yardley et al. 2015b; Morrison et al. 2018).

This PhD covers the planning phase of the development of the DBCI, MiDerm. Whilst factors related to optimising the implementation were considered throughout the current research project, as guidance recommends (Skivington et al. 2021), implementing and testing MiDerm was beyond the scope of the project due to time and resourcing constraints. However, some data gathered on barriers and facilitators from the primary and secondary research can be carried forward to inform and improve real world implementation of the app. Intervention optimisation and implementation are steps for future research, subject to funding.

Intervention planning

Intervention planning was the first major phase of this research and involved two main stages:

1. Gathering primary and secondary evidence to understand the experiences, needs and context of the target group.
2. Theorising and developing the intervention.

Phase 1 – Intervention planning: Gathering evidence.

Before an intervention is designed or built, it is essential that intervention developers acquire knowledge about the people who the intervention is intended for, specifically the views, needs, experiences and context of that group (Yardley et al. 2015b).

Therefore, the first step in developing MiDerm involved acquiring new and existing data to better understand the target group; adults living with skin conditions. The mixed methods systematic review of existing digital psychological interventions in dermatology (Chapter 4 and Appendix 10; Hewitt et al. 2022c) allowed us to learn from these in terms of effectiveness and appropriateness. This information addressed the gaps in existing support, mainly health behaviour change support and additional support delivered via apps.

Two primary research studies, online group interviews (Chapter 5) and a mixed methods online survey (Chapter 6) provided new knowledge of the impact of condition self-management specifically, and existing sources of support for adults with skin conditions, as well as their additional support needs and perceptions of the proposed intervention. These studies also built on the existing literature on barriers and enablers associated with digital psychological interventions, but identified those that may be specific to the MiDerm app.

The systematic review highlighted the need for new interventions for people with common conditions other than psoriasis and eczema and rare skin conditions. The primary research studies indicated that psychological support, especially health behaviour change support, was mostly absent from current dermatology provision, but adults with skin conditions desired tailored support for effective self-management. The online survey highlighted specific health behaviours for which support is required, such as physical activity. The online group interviews emphasised the importance of providing evidence-based information on the links between skin conditions and psychological processes, as well as practical tips for changing health behaviours associated with skin conditions. Participants valued and wanted peer support. These findings provided the foundations for defining the new digital intervention and on which initial decisions on its content, features and design were made.

Phase 2 – Intervention planning: Theoretical modelling

Theoretical modelling refers to identifying, clarifying and justifying the theory that informs complex interventions (Yardley et al. 2015b). The purpose of this is to determine how an intervention works and the active ingredients of the intervention which support it to work as intended (Yardley et al. 2015b). The stages of theoretical modelling for MiDerm outlined below are depicted in Figure 13.

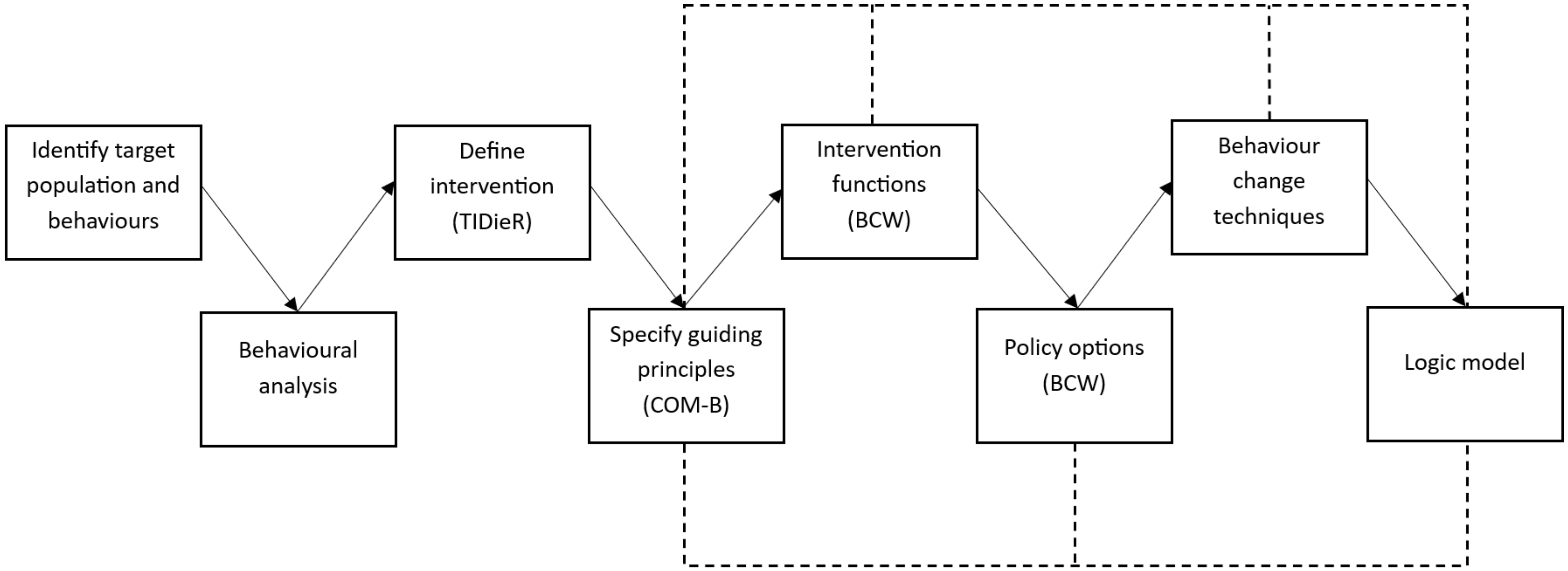

Figure 13: Stages of theoretical modelling of MiDerm

Defining MiDerm

MiDerm was defined using the TIDieR checklist and guide (see Chapter 4), which helped to produce a full and detailed description of the intervention to facilitate its evaluation, replication and implementation (Hoffmann et al. 2014). See Appendix 50.

There was, however, a lack of clarity during the current (planning) phase of intervention development regarding procedures for how users will access and engage with the app when it comes to further testing for research purposes and real-world implementation. Therefore, some sections were marked with 'not applicable (N/A) at this stage of intervention development'. These sections need to be updated later when the details are confirmed, subject to securing funding to further develop MiDerm.

Guiding principles for MiDerm

To establish the guiding principles information from the survey and group interview data was used to compile a list of the needs and barriers mentioned, as well as solutions, facilitators and advantages of MiDerm, that participants discussed. See Appendix 51.

In total, five intervention objectives were defined and mapped against components of the COM-B Model (Michie et al. 2011b).

Appendix 52 states the guiding principles for MiDerm and the corresponding issues/need that each objective aimed to address. This table shows the logical thought process starting with the problem identified through to how MiDerm aimed to address the problem with the intervention components. Guiding principles were reviewed independently by CB and CP and consensus was reached through group discussion iteratively throughout the development process.

Behavioural analysis

Performing a behavioural analysis is a process that involves identifying and defining the behaviour that an intervention will target, as well as any factors (barriers and facilitators) which influence the desired behaviour, and outcomes of interest that can be measured to determine whether the intervention achieved its aim (Public Health Wales [PHW] 2023).

Behaviour has been defined behaviour as:

> *"Anything a person does in response to internal or external events. Actions may be overt (motor or verbal) and directly measurable or, covert (activities not viewable but involving voluntary muscles) and indirectly measurable; behaviours are physical events that occur in the body and are controlled by the brain." (Davis et al. 2015, p. 327)*

Performing a behavioural analysis involves specifying the main behaviour(s) an intervention seeks to address, known as the 'target' behaviour, as well as any actions that lead to this, which are referred to as sub- or subsidiary behaviours (PHW 2023). Addressing subsidiary behaviours, including any barriers and facilitators to performing these, increases the likelihood that an intervention promoting the target behaviour is effective (PHW 2023).

Complex behaviour change interventions may be developed with one target behaviour in mind and may address the subsidiary behaviours leading to that behaviour, or the factors that influence whether the behaviour is more or less likely to occur.

There is no strict rule or formula for the number of behaviours an intervention should target. Deciding how many behaviours to address should be context-specific and based on the time, behaviour change expertise and resource available for intervention development (PHW 2023). There are different methods that can employed to identify target behaviours (PHW 2023), including:

- Behavioural systems mapping.
- Stakeholder engagement and consensus activities.
- Reviewing existing literature.
- Primary research involving the target population.
- Drawing on existing knowledge to list behaviour, mechanisms and outcomes.
- Selecting a known behaviour.

Once identified, the next step is to prioritise the behaviours and decide which is most likely to achieve the desired outcome considering the following (PHW 2023):

- The impact of changing that behaviour, particularly in relation to the desired outcome(s).
- How likely behaviour change is in the context of the target population and resource available.

- Potential ‘spillover’ effects (positive or negative) of changing one behaviour to other behaviours that are related.
- How to measure the behaviour and the practicalities of doing this in the target population.

Behavioural analysis of MiDerm

From the outset of this project, MiDerm was classified as a complex behaviour change intervention because it was anticipated that the new intervention would be comprised of different, but related, components. In the early stages, however, it was unclear what behaviours the intervention would target. It was important that this decision was influenced by and based on the needs, preferences and desires of the target population, in keeping with the ethos of the PBA (Yardley et al. 2015b). It was decided that MiDerm would be a multi-domain intervention targeting the following health behaviours:

- Physical activity.
- Diet.
- Sleep.
- Drinking alcohol.
- Smoking.
- Scratching (caused by itch).
- Treatment adherence.

This decision was based on a combination of methods, which are described and justified below.

My knowledge and experiences of working as a trainee health psychologist in (clinical and academic) dermatology highlighted that there was no single health behaviour that needed to be addressed, but that health behaviour change support was generally absent and needed.

My assertions were also supported by existing evidence on the following topics:

- The psychological impact of skin conditions (Chapter 1).
- The range of health behaviours known to influence CVD risk particularly in inflammatory skin conditions (Chapter 1).

- Long-standing calls for increasing psychology provision within dermatology and the lack of dedicated lifestyle support (Chapter 2).
- The capability, opportunity and motivation of health professionals to address psychological aspects of skin conditions, including behaviour change, with patients during consultations (Chapter 2).

My own experiences and the growing body of evidence clearly highlighted that health behaviours needed to be managed but support available within services was missing or inadequate, and thus additional forms of support were needed to help adults self-manage these aspects of their skin condition more effectively.

Whilst a complex digital intervention targeting multiple health behaviours was justified it was important to also include the preferences of adults with skin conditions who would receive the intervention before development commenced. The research studies conducted as part of this PhD provided that opportunity to explore. There was a clear need and desire among participants for evidence-based information and techniques that would improve their personal ability to identify and address health behaviours that influence their skin condition, as well as their mood. The high frequencies and percentages reported in the online survey also emphasised that adults with skin conditions deemed support for a range of health behaviours to be important.

The decision to focus on multiple behaviours rather than a single behaviour influenced the task of prioritising which behaviours the MiDerm intervention should target. The primary and secondary research offered some insight into the relative importance of these health behaviours from the perspective of the target population. The systematic review (Chapter 4 and Appendix 10), for example, flagged that existing digital interventions targeting treatment adherence were largely ineffective, which emphasised the need to prioritise new approaches for supporting treatment adherence (Hewitt et al. 2022c).

Group interview participants discussed trial-and-error approaches to self-management, including lifestyle factors, and often gave examples of changing dietary behaviours in the absence of clear guidance (Chapter 5). This indicated that MiDerm should prioritise the topic of diet in skin conditions.

Online survey (Chapter 6) participants were asked to indicate how important it was for the app to include information and tips on health behaviours specific to skin conditions and these topics were listed in order of importance from highest to lowest, see Appendix 53.

It is important to note that the online group interview study identified several perceived barriers and facilitators to adults accessing the app and revisiting it over time (behaviour change and maintenance). Future research is needed to confirm whether these barriers and facilitators translate into practice to address them appropriately.

Intervention functions

Intervention functions are high level categories that are used to classify how interventions change behaviour (Michie et al. 2014). The BCW includes nine intervention functions (Figure 5). It is possible for interventions to have more than one function (Michie et al. 2014). The guide to using the BCW to develop interventions includes examples of how constructs of the COM-B Model and relevant interventions functions can be linked (Michie et al. 2014). The guide also includes a matrix to inform decisions about which functions may be better suited to each component of COM-B (Michie et al. 2014). However, given that the components of the COM-B Model are inextricably linked, it is possible that any intervention function could lead to behaviour change (Michie et al. 2014). These resources were used to determine the functions of MiDerm. Appendix 54 includes an adapted version of the matrix of intervention functions (Michie et al. 2014). Tick symbols were superimposed onto the matrix to highlight the functions that MiDerm serves. Appendix 55 contains brief descriptions of the links between the COM-B constructs and intervention functions relevant to MiDerm.

Policy categories

The BCW also specifies seven policy categories (Figure 5) that should be considered when developing interventions to support their implementation (Michie et al. 2014). The policy category ‘service provision’ was considered appropriate for MiDerm.

Behaviour change techniques

The next step was to identify suitable behaviour change techniques (BCTs) that could be applied to change any of the target behaviours. A BCT can be defined as:

> *“a systematic procedure included as an active component of an intervention designed to change behaviour” (Michie and Johnston 2013, p. 182)*

According to Michie and colleagues (2011a), BCTs can be observed, replicated and are both irreducible and active ingredients of interventions that serve to elicit the desired behaviour. Specifying the active components of interventions can improve understanding of how they work, the effects they have and facilitate accurate replication (Michie et al. 2013). A BCT taxonomy, comprised of 93 BCTs across 19 groupings, was established from an international consensus study to provide developers with a systematic method for specifying interventions (Michie et al. 2013).

The BCT taxonomy (Michie et al. 2013) was used to identify the active ingredients that were suitable for meeting each of the guiding principles and intervention functions of MiDerm. Michie et al. (2014) have produced guidance on which BCTs are likely to be appropriate for particular intervention functions and offer examples of BCTs that are commonly coupled with each of the nine functions.

Each intervention objective was looked at individually and the BCT taxonomy was studied to identify any BCTs that were aligned to the corresponding intervention features and functions. The BCTs identified were then checked against the guidance by Michie et al. (2014).

Potential BCTs were summarised in a table, which was subsequently reviewed and scrutinised by CB and CP to ensure the proposed BCTs were appropriate and no relevant BCT had been overlooked. The BCTs were revised based on the feedback provided by CB and CP. The team met to discuss any BCTs for which there was disagreement, or a lack of clarity, and consensus was reached together. Appendix 56 presents the guiding principles and components of MiDerm with the corresponding COM-B constructs, intervention functions and BCTs.

Logic Model

MRC guidance recommends producing a logic model to support the development and evaluation of complex interventions (Skivington et al. 2021). Logic models pictorially demonstrate the psychological mechanisms by which complex intervention are intended or expected to work and influence the target behaviour(s) (Band et al. 2017; Greenwell et al. 2018; Essery et al. 2021). Visually representing the theory underpinning an intervention can supplement written reports and provide a useful tool for identifying future research questions, supporting intervention testing and transferability across settings, and facilitating understanding among decision makers (Skivington et al. 2021).

A logic model was created for MiDerm based on the current research findings, see Appendix 57. These primary and secondary data clearly evidenced the need for MiDerm among the target group and their preferred intervention components. They provided some insight into other elements of the logic model, including the proposed BCTs, potential mechanisms of action and suggested outcome variables, but future hypothesis testing of these is required.

Phase 2 – Intervention planning: Design and development

The second stage of intervention planning focused on the development and design of MiDerm. Here the steps involved in app design, content creation and build are described.

The role of key stakeholders

A range of key stakeholders contributed to the present research, including:

- Adults with lived experience of skin conditions.
- Leaders and staff from dermatology patient organisations.
- Qualified and trainee psychologists from the disciplines of health, clinical and counselling psychology with a mix of clinical and academic experience.
- Software developers and designers.
- Dermatology specialist staff from clinical and academic settings.
- A global industry partner (funder).

Stakeholder contributions ranged from developing study materials and app content, to study promotion and building the app.

Procuring expertise in software development

An external partner (Logic Software Ltd) was chosen based on expertise and recommendations from colleagues. The process of commissioning for the app development involved legal, technical and academic staff forming a development team with project management timelines.

Naming the intervention

Naming the app involved an extensive search for domain names (Appendix 58) and in consultation with the PPI group we identified MiDerm as the appropriate name to convey the nature of the app.

App content development

The major step in developing MiDerm was creating written, visual and audio material. This process was collaborative and required input from a range of key stakeholders with different expertise, including:

- Members of the wider research team (CD, CP, CB) with expertise in health psychology (clinical and academic).
- PPI contributors who were experts in the impact of skin conditions due to their personal lived experiences.
- Staff from Logic Software with expertise in software development and design.
- Qualified and trainee psychologists working in the field of dermatology or psychodermatology.
- Dermatology specialist staff working in academic and clinical settings.
- Leaders of patient organisations who advocate for, research and support people with skin conditions.

The roles that each of these stakeholders played in this process are described within this chapter.

The first step in producing the written content for the MiDerm app was to decide which topics to cover. Topics were decided based on the results of the online survey and group interviews and thus, the educational material within the app reflected the preferences and needs of adults living with skin conditions.

Using the findings of the primary research studies, potential topics were mapped against the app ‘sitemap’ that Logic Software produced to show the structure of the sections of the app. This helped to establish whether the content that was planned fit with the structure that was originally proposed, and where changes were required.

In total, there were twelve topics covered, see Appendix 59. Producing content on each topic involved:

- Drawing on existing scientific literature to verify this information and amend where necessary.
- Reading and critically analysing existing literature to expand on the information I had already written and to draft sections on a topic that I had little or no prior knowledge of.
- Producing graphics to help explain and clarify concepts and processes that I had written about.
- Creating a reading list including all the evidence that I drew on to write the section with URLs.
- Writing and structuring the text according to psychological principles of information processing and learning (more details below).
- Seeking feedback and input on the content from the research team.
- Revising the content in accordance with the feedback received.
- Repeating this process until the content was agreed and finalised.

Motivational Interviewing (MI)

MI is an established consultation style that can be used to increase an individual's internal motivation and capability for behaviour change (Miller and Rollnick 2013). MI offers a useful structure for supporting people to explore ambivalence and achieve their goals for behaviour change in four iterative stages (Miller and Rollnick 2013):

1. Engaging the patient.
2. Focusing the consultation.
3. Evoking reasons for change.
4. Planning for change.

The 'spirit' of MI (Miller and Rollnick 2013) posits that:

- Approaches to behaviour change should be collaborative, not confrontational.
- The reasons for and solutions to changing behaviour should be evoked from the individual, rather than telling them what to do.

- The role and autonomy of the individual in changing their behaviour should be respected.

The key principles of MI (Miller and Rollnick 2013) include:

- Expressing empathy.
- Developing discrepancy between past or current behaviour and desired behaviour.
- Rolling with resistance to change.
- Supporting self-efficacy for behaviour change.

There are also specific MI techniques that practitioners can use to support behaviour change, such as:

- Open-ended questions.
- Active listening.
- Reflections.
- Summarising.
- Affirmations.

MiDerm was developed in accordance with the stages, spirit, principles and techniques of MI, although this was not a real-time interactive consultation so adaptations had to be made and the principles were used where possible.

The use of ‘Mi’ in the name MiDerm reflects the MI approach.

A brief introduction was written for each section of the app. The introductions listed the main objectives of that section so it is clear to the user what topics the section will focus on.

The educational content within the library was structured to affirm what adults with skin conditions are likely to already know, before introducing new information, helping to develop discrepancy between existing and new knowledge. In addition, open-ended questions or statements were included to engage users with this content. Below is an example of this from a section of the library called ‘psychology and the skin’:

> *We all know that… skin conditions can impact on well-being.*
>
> *But did you know… How you think and feel about your skin condition can influence how you respond to it and the symptoms you have.*

Each library section included an activity called ‘be your own psychologist’ which was designed to support users to complete their own psychological problem formulation including the following features (British Psychological Society 2011):

- A summary of the key issues that the client is facing and links between these.
- A plan of intervention.
- Professional opinions and strategies that are grounded in psychological theory and principles.
- A degree of flexibility to allow for re-formulation whenever necessary.

Whilst psychological principles and models of behaviour change, mainly the COM-B Model (Michie et al. 2011b), were included within the app to aid understanding of behavioural drivers and influences, it would be unreasonable to expect non-psychologists to produce a formulation that is theoretically informed. Therefore, the theoretical aspect of psychological formulation was not a requirement for the formulation activity. Instead, the formulation activity was designed to guide adults through the processes of:

- Assessing current behaviour and developing discrepancies with desired behaviour.
- Thinking about and evoking reasons for change.
- Planning for behaviour change.
- Evaluating progress with behaviour change.

The formulation activity was repeated across the library sections to:

- Reinforce the learning of this practice.
- Encourage critical self-reflection.
- Build competence and self-efficacy for self-management.
- Evoke solutions to problems from the individual.

The section of the app offering behaviour change support included established BCTs, such as goal setting and action planning, to support users to effectively plan for change. The goal setting and action planning activities were modelled on existing training materials that were previously developed for health professionals involved in psoriasis management (Chisholm et al. 2017; Hewitt et al. 2021).

Other established psychological techniques were also incorporated into the behaviour change section to support self-efficacy and reduce the risk of behavioural relapses or lapses. More specifically, an activity on Implementation Intentions (Gollwitzer 1999) was included. Implementation intentions, or 'if-then' plans, are used to support people in pursuit of a goal to consider potential barriers, factors and situations that may influence this, and to establish a plan that can be implemented to overcome these and stay on track (Gollwitzer 1999; Gollwitzer and Oettingen 2020). Implementation intentions can also:

- Drive people to strive for a goal.
- Help people to overcome influences that have the potential to hinder goal attainment.
- Reduce the likelihood of people giving up on plans for achieving a goal, even if they are failing.
- Foster personal capability to strive towards future goals (Gollwitzer and Sheeran 2006).

Where possible, app content was written in a way that encourages, rather than instructs or persuades, people to change. This was important given that participants had expressed frustration at health professionals instructing them in generic lifestyle advice during consultations. Options and ideas were presented for users to consider, ultimately giving users autonomy to identify and decide on an appropriate solution(s) to change their behaviour.

The final activity at the end of each section of the library was designed to encourage users to reflect on what they had read and summarise and reinforce the main learning points in their notes page within the app. Open questions were included in the title and guidance in this section to prompt the reflective activity, for example: 'Pause – what did you learn in this section?' and 'What was the most helpful thing?'.

We used strategies that would support adults to process and retain information from the app that could improve their knowledge and skills and subsequently influence their behaviour. 'Chunking' information is an active learning strategy to improve how the information is processed, understood and memorised (Fountain and Doyle 2012; Thalmann et al. 2019). Each section and sub-section were all clearly labelled with headings and subheadings. Key points were also summarised in short sentences, rather than lengthy paragraphs, and lists to ensure written content was easy to read and remember and to enable adults to scan for and identify information that was most relevant to them (Moran 2016).

Patient stories

Five members of the PPI group made a significant contribution to developing content for the peer support section of MiDerm, which contained 'patient stories'. Including these stories in the app would give users an insight into how other people coped with and managed skin conditions effectively.

To ensure that the stories included in the app were authentic and captured the realities of self-management, members of the PPI group were invited to take part in a co-development activity involving an online semi-structured interview and share their lived experiences. This was not a research *study* given that the data were not formally analysed or written up for publication, the interview recordings were used as app content only. Interviews were organised and run in the same way as the group interviews and the procedure is described in Chapter 3. Appendix 60 contains reflexive accounts of the interviewers (RH and CD).

Editing was undertaken to emphasise the key strategies covered in each interview, and to avoid repetition both within and across the interviews. Secondly, individuals were asked at the end of their interview to state three key points that they had mentioned and felt should be the focus of their interview. These points were considered during the editing process. Finally, the interviews lasted between 45 to 77 minutes and thus were shortened to make them more digestible for app users.

The CSM (Leventhal et al. 1984) was used as a framework for understanding how each person responded to their skin condition(s). With a colleague (CD) I met to discuss each interview in turn and before deciding which parts of the interview would feature in the patient story. The following factors were considered when deciding the timings:

- The context, clarity and relevance of the point being made.
- How statements made by the interviewee might be interpreted by others.
- The length of each section.
- The overall flow of the interview.

Time stamps, topics addressed, justifications and decisions for round one and two of editing are documented in Appendix 61 and 62, respectively.

The patient stories section of MiDerm contained five interviews in total which reflected the experiences and advice from adults living with psoriasis (x2), eczema, acne and scarring, and rosacea.

Signposting

A signposting page was also developed directing adults who use MiDerm to existing resources that aim to support the self-management of skin conditions; most participants described experiences of conducting lengthy and extensive searches to find relevant information for self-management online and saw the app as a useful platform for storing evidence-based guidance from credible sources that would be easy and convenient for adults to access (see Chapter 5).

A list of existing resources for self-management plus recommendations from other key stakeholders, including experts in the field of dermatology and psychodermatology, was established from across clinical (public and private), academic, third sector and industry settings across the UK, US, Germany and Canada. The ten PPI contributors were also included given their lived experience of skin conditions.

Personalised emails were sent asking individuals for (ideally free) existing services, interventions and resources that they considered suitable and/or regularly recommended to patients. In total, 40 experts were contacted and 26 responded to the email invitation to contribute to this task. Twenty-one experts, including one PPI contributor, provided recommendations.

All the recommendations from experts were collated and reviewed (see Appendix 63) to determine what was included in the signposting page. Judgements were based on the credibility of the source and whether the support on offer was evidence-based. Existing types of support that were prioritised for inclusion in the MiDerm app are presented in Appendix 59. Many of the suggested resources included the websites of patient organisations with the leader’s consent. A copy of the signposting information, the links to websites, and copies of the patient organisation logos were emailed to Logic Software to build into the app.

Push notifications

Push notifications are features of apps that notify users about a message or update when the app is closed and not in use. Push notifications were discussed within the online group interview study; mixed opinions were expressed, although the consensus believed that push notifications could remind people to use MiDerm, providing the messages they contain are motivational, not instructional, and users are able to choose the frequency and timing of delivery (Chapter 5).

These findings highlighted that push notifications could potentially encourage users to revisit the app after first access, thus supporting behavioural maintenance. It was agreed that MiDerm would utilise push notifications, however, it was important to ensure the messages they contained were appropriate and reflected the preferences of adults with skin conditions.

Eight PPI contributors and five leaders of the patient organisations who were supporting this project were invited via email to submit at least one positive message that they thought would inspire, motivate or offer hope to users of the app. Recipients were asked not to include any personal information in their messages and received the following questions which aimed to serve as prompts for the activity:

1. What would you say to motivate or inspire other people living with your skin condition?
2. What advice would you give to other people living with your skin condition?
3. What would you say is most important for living well with a skin condition?

In total, four PPI contributors, and the leaders of four patients organisations, contributed to this activity. The wording of the messages was edited so that they were less instructional and more encouraging.

The principles of message framing (described in Chapter 5) were applied to structure the push notification messages focused on health behaviour. However, none of those focused on alcohol reduction, most included information on diet or treatment adherence. These messages were framed in terms of the benefits of performing them, for example: ‘Eating healthy foods, such as green vegetables, lean proteins, oils and wholegrains, could help your skin'. More research is needed to establish whether this framing approach is effective in this context.

After the messages had been edited, they were prioritised for inclusion within the app because many of the messages were similar and thus, prioritisation was necessary to avoid repetition, and the messages selected reinforced the educational material included within the app, thus supporting learning.

Motivational messages for push notifications that were submitted are presented in Appendix 64.

Intervention design

Intervention design occurred in parallel with content development. Meetings with app developers discussed a potential structure for the app based on the preliminary findings of the online survey and group interview studies, as well as a potential branding, including the app name, logo and design.

A draft sitemap depicting the main sections of the app and the links between these (Figure 14) was subsequently edited and condensed the sitemap into nine screens and the key features or functions of each (Figure 15):

1. Welcome.
2. Main menu.
3. Profile (app personalisation).
4. Diary (add diary entry/add note).
5. Behaviour change support (add goal/add action plan).
6. Signposting.
7. Library (patient stores, physical factors, psychological factors).
8. Search.
9. Help.

This sitemap was used to create wireframes of the app and screen templates. Wireframes are basic visual representations that depict the essential components and features of software (see Figure 16). The interactive online platform called 'Balsamiq' allowed us to review and comment on the wireframes.

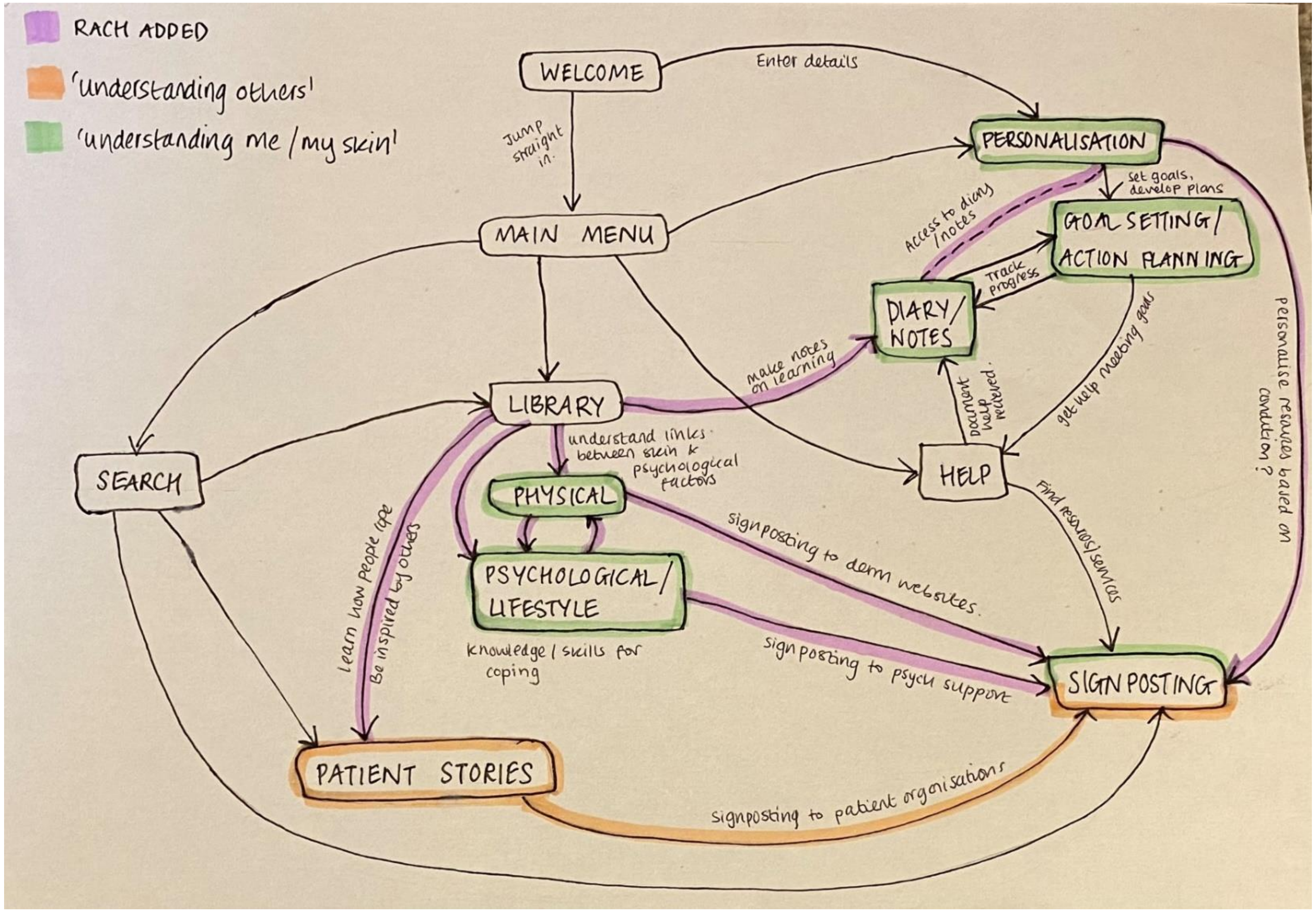

Figure 14: Draft of app sitemap produced in design meetings

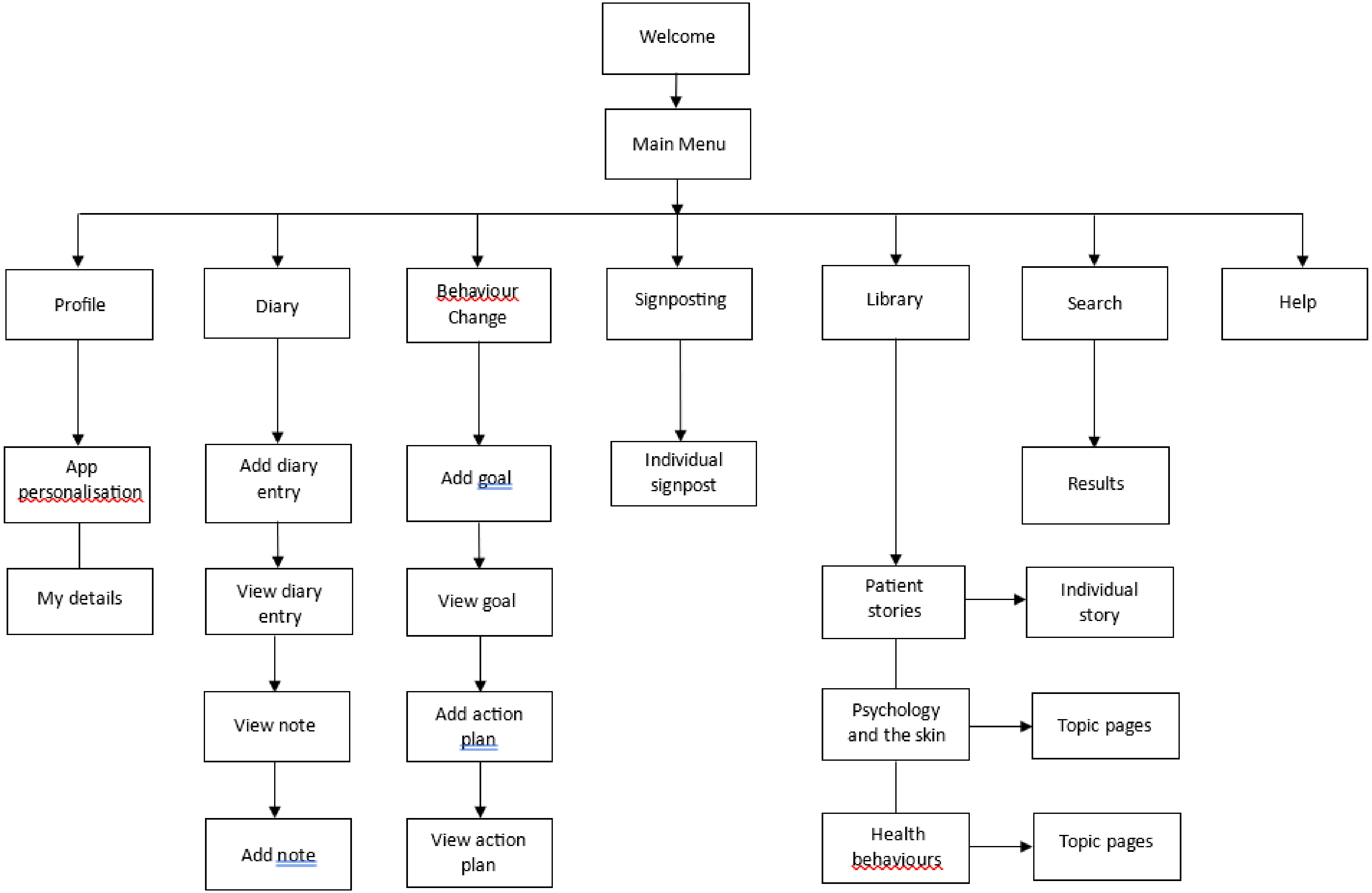

Figure 15: App sitemap produced by Logic Software.

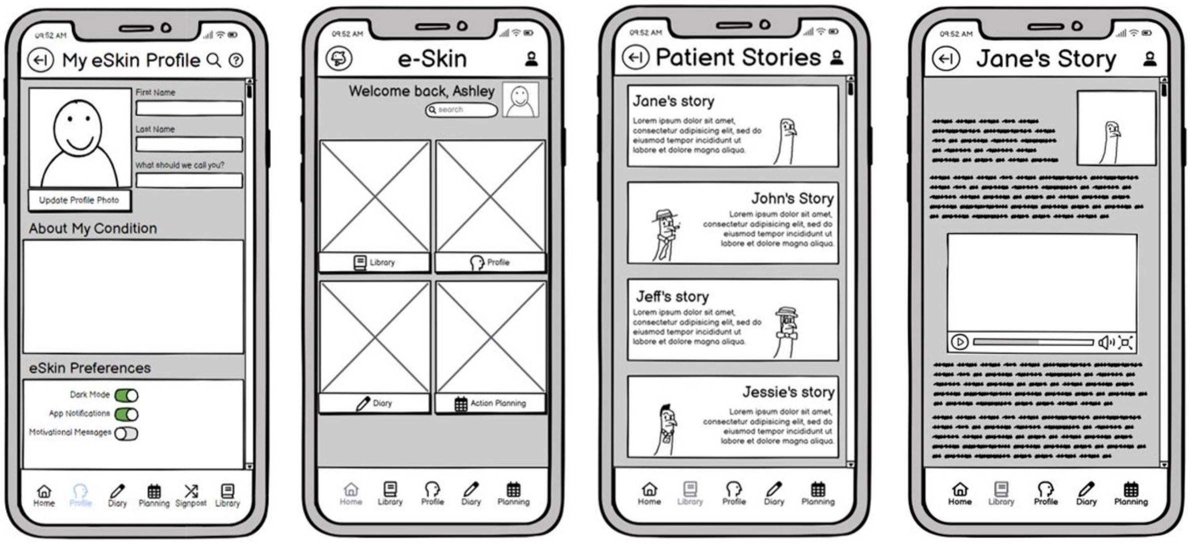

Figure 16: Wireframes for the MiDerm app, as presented in the platform Balsamiq.

The second meeting with development partners included an overview of the design ideas and preferences expressed by participants in the group interview study (Chapter 5) who used this information to produce a general colour palette for the app (Figure 17).

Figure 17: General colour palette designed for the MiDerm app

In June 2023, I hosted a PPI meeting to obtain feedback on the wireframes and potential colour schemes and logo designs. presented in the figures above. App screens were designed in accordance with the preferred logo and colour scheme (see Figure 18).

Figure 18: The colour scheme and logo for the MiDerm app as selected by PPI group members

After several rounds of revisions to the home page screen, Logic Software created a set of screen templates which reflected the design preferences that had been agreed previously. These were added to the Balsamiq platform for review. The final changes related to keeping the font and the font size and colour the same to ensure consistency across the app. Logic Software subsequently produced a full set of screen templates and these were approved. The full set of app screen templates are presented below in Figure 19.

Building MiDerm

Building the MiDerm app took approximately eight weeks. Logic Software coded all the written, visual and audio material into the app and the design was based on the approved screen templates. Completion of the build marked the end of the second and last phase of intervention planning and concluded this research project.

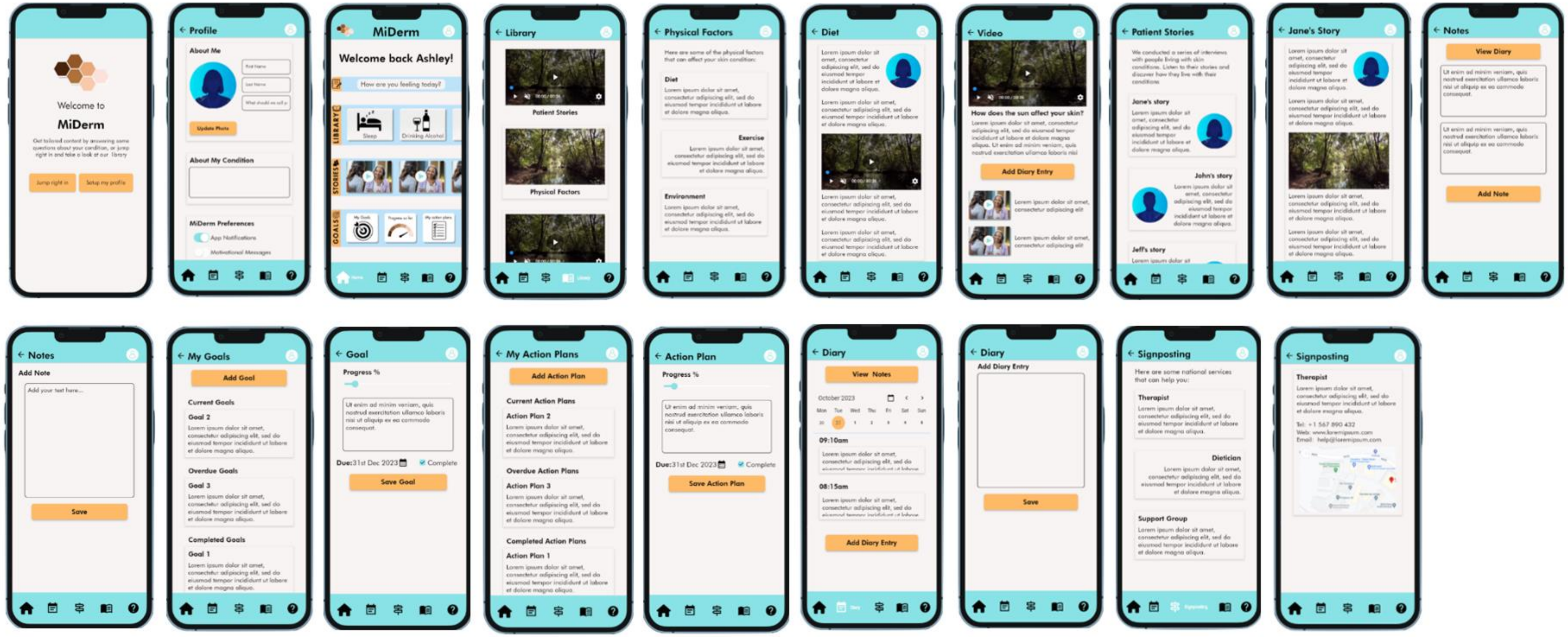

Figure 19: Full set of screen templates for the MiDerm app

Chapter summary

This chapter outlined the process that was taken to plan and develop the prototype of MiDerm. It demonstrates how following the PBA facilitated a rigorous, collaborative and iterative approach to digital intervention development that was grounded in evidence and theory and incorporated the perspectives of multiple stakeholders, mainly adults with skin conditions who the intervention is intended for. This chapter concludes the planning phase of intervention development and the current research project. Next in this programme of work is to optimise and evaluate MiDerm before it can be implemented and made available to adults with skin conditions globally.

Chapter 9: General discussion

Summary of research

This thesis outlined the development of MiDerm, a complex DBCI to support adults living with skin conditions. In the first phase of intervention planning, primary and secondary data were gathered and synthesised (Phase 1, Chapters 4-7) and used to inform intervention content, features and design that were built into the smartphone app (Phase 2, Chapter 8), the medium for intervention delivery. The outcome of this project is a prototype of MiDerm, a theory and evidence-based digital intervention comprised of tailored informational and behaviour change support and peer support in the form of patient stories.

The views, experiences and preferences of adults with skin conditions were central to this research. The rigorous mixed methods design facilitated the triangulation of qualitative and quantitative data, representing both a range and richness of perspectives from the target group. The PBA provided a systematic structure for gathering evidence, stakeholder collaboration and integrating existing psychological theory into the intervention development process. Participant data provided a strong foundation for future evaluation, development and implementation of MiDerm.

How the studies meet the aims and objectives

Data from these studies were used to identify and develop intervention components which adults with skin conditions indicated were both necessary and desirable for self-management. A prototype of MiDerm was subsequently produced. However, there are caveats to this to acknowledge.

The intervention was intended for a global audience and the studies that make up this project did achieve global reach, representing 30 countries overall. However, participants were predominantly from the UK and those outside of the UK were mainly from developed and westernised countries. MiDerm was not intended to be condition-specific. It was designed for use by adults living with common and rare skin conditions to address psychological consequences that are common across many of these conditions (Pattinson et al. 2022). The project represented 24 skin conditions in total, but there was greater representation of psoriasis, vitiligo and ichthyoses.

MiDerm is an evidence-based and theoretically informed DBCI, but further research is needed to evaluate the prototype and develop it further prior to real world implementation.

Contribution to existing literature

This research project contributes to the literature both by reinforcing existing evidence and building on established findings.

Skin conditions are complex long-term conditions with far reaching impacts across all aspects of life. Most people who live with them are underserved by healthcare services, largely because dermatology service provision follows a biomedical model of care, and people must self-manage all aspects of their condition as a consequence. Many health professionals recognise the importance of adopting patient-centred approaches to management, but this rarely translates into practice. People report they are met with a level of care that is inadequate for meeting psychological needs, concerns and their preferences are dismissed, making them less inclined to seek professional support.

Whilst the prospect of improving symptoms and well-being motivated these participants to self-manage, most lacked the support they needed to do this effectively. The main impact reported was the time and effort that self-management required and the knock-on-effect that this had on adults' physical and psychological health, daily routines, personal finances, leisure activities and relationships. Both the practical task of controlling symptoms and researching skin conditions, triggers and management strategies online, including treatments and lifestyle, were time consuming and effortful. This led to trial-and error approaches to management, which could be costly, often unsuccessful and resulted in frustration and despair. Whilst the presence of a visible skin condition alone can damage psychological well-being, self-managing skin conditions can substantially increase the existing psychological burden. Psychological intervention is needed to improve emotional well-being and support those who are struggling to plan and implement effective self-management strategies.

Our findings reinforce the prominence of the biomedical model with its lack of psychological support. They also highlight limitations of social and peer support, drawing particular attention to the quality of information that is freely available online and whether this is accurate and safe. Participants attributed flaws in existing types of support to a poor general understanding of skin conditions and their potential impact. The latter provides strong justification for addressing this issue both within the medical community and general public.

This thesis identified gaps in existing support and methodological flaws within the field of dermatology.

The finding that receiving psychological support can improve cognitive, emotional and behavioural functioning and equip individuals with knowledge and skills for coping is new. Previous studies focused on the lack of psychological support for people with skin conditions and the cost-effectiveness of psychodermatology services whereas this research identifies the benefits of psychological support reported by adults who had accessed services. Notably, the benefits reported were achieved from working with health professionals with expertise in psychology, but not necessarily in skin conditions. The latter raises the questions of what benefits could be achieved when adults are supported by psychologists with specialist knowledge and interest in dermatology. Ultimately, these findings strengthen the growing case for increasing psychology provision within dermatology and establishing specialist services that are delivered by health professionals with expertise in dealing with the psychological aspects of skin conditions specifically.

Key findings from the mixed methods systematic review showed that whilst digital interventions targeting psychological outcomes within dermatology may be effective and acceptable, they were generally limited to specific skin conditions, educational support alone and did not use techniques to change lifestyle behaviours. It highlighted a lack of qualitative research in the context of intervention development. The online survey and group interviews revealed insights into types of informational, emotional, behavioural and peer support that could enable adults to live well with skin conditions, as well as the factors which may influence use of the intervention once it is developed. MiDerm may be appropriate for this population but will not and should not completely fill the gap in psychology provision within dermatology. The need and desire for dedicated psychological support that is delivered in person remains relevant.

Since our systematic review was conducted, other studies have been published on digital interventions in dermatology, some addressing psychological outcomes. These intervention studies were identified by re-running the original search strategy using the same databases whilst adjusting the time period. The new papers were not scrutinised in the same systematic way as those in the original review, thus it is possible that some do not meet the strict eligibility criteria that was used previously to determine articles for inclusion. For example, a paper by Zvulunov et al. (2023) which reports on the Atopic App for children with eczema and focuses on physical and feasibility outcomes only. Instead, the key study characteristics and findings were documented in Appendix 22, which was a manageable way of keeping on top of the broader literature that has since emerged in this field.

Little has changed since our review was published. With hindsight publishing a pre-print may have been helpful. The recent studies are all condition-specific, with the majority targeting people (some including young people) usually with eczema (Greenwell et al. 2022; Andrade et al. 2023; Gudmundsdóttir et al. 2023; Kern et al. 2023a; Kishimoto et al. 2023; Weigandt et al. 2023; Yasuda et al. 2023) followed by psoriasis (Garzorz-Stark et al. 2021; Brandl et al. 2022; Fortune et al. 2022) and other conditions including XP (Walburn et al. 2023), acne (Ip et al. 2021b) and visible differences inclusive of some skin conditions (Norman et al. 2022; Zelihić et al. 2022). MiDerm is intended for use across common and rare skin conditions so sets it apart from other existing interventions.

We found only four interventions were delivered entirely by, or in combination with, smartphone apps (Hewitt et al. 2022c). Although not surprising, it is clear from Appendix 22 that the use of smartphone apps as a medium of intervention delivery is increasing.

None are as inclusive as MiDerm, which targets several health behaviours. Some newer interventions draw on psychological therapeutic approaches, including CBT (Fortune et al. 2022; Kern et al. 2023a), mindfulness (Gudmundsdóttir et al. 2023) and self-compassion (Kishimoto et al. 2023). Those that address health behaviours focus on the following:

- Delivering questionnaires on lifestyle factors and stress (Garzorz-Stark et al. 2021)
- Daily activities relating to nutrition and exercise (Gudmundsdóttir et al. 2023)
- Treatment adherence, trigger and scratch management (Greenwell et al. 2022)
- Sleep (Yasuda et al. 2023)

The results build on the preliminary evidence for intervention effectiveness (Hewitt et al. 2022c) and are promising. Some studies noted improvements in physical outcomes, including symptom severity (Fortune et al. 2022; Gudmundsdóttir et al. 2023; Kishimoto et al. 2023) and psychological outcomes, including depression, anxiety, QoL, stress, shame, mindfulness, self-compassion, treatment adherence and sleep quality (Fortune et al. 2022; Gudmundsdóttir et al. 2023; Kishimoto et al. 2023; Yasuda et al. 2023).

The PBA (Yardley et al. 2015b) was used to develop digital self-management interventions for young people with eczema (Greenwell et al. 2022) and acne (Ip et al. 2021b). These studies and the research on MiDerm provide examples of how to develop complex DBCI for people with skin conditions. MiDerm, however, offers the novel contribution of it being a multi-condition and multi-domain intervention targeting a range of health behaviours.

Strengths and limitations

Study design

The mixed methods design offers a useful contribution to the dermatology literature by demonstrating how different research methods can be combined to develop digital interventions.

Qualitative research in dermatology is steadily increasing (Pascual et al. 2023). Two recent articles on this topic have argued that qualitative methods are useful for engaging with patients across countries, cultures and contexts (Pascual et al. 2023) and should be used to support the development of educational materials for patients (Foster et al. 2022). Both found that qualitative research to date has focused on exploring personal experiences of skin conditions (Foster et al. 2022; Pascual et al. 2023). Our mixed methods systematic review showed that qualitative research was lacking in the context of intervention development in dermatology and where qualitative studies had been conducted, they were poorly reported (Hewitt et al. 2022c). Qualitative methods were used to understand the experiences of adults living with skin conditions but also to gather opinions and ideas from this population to inform the development of MiDerm.

The convergent mixed methods design helped to achieve data, investigator, theoretical and methodological triangulation (Chapter 3), ultimately enhancing and broadening understanding of what matters most to adults with skin conditions.

The role of theory

Without a clear theoretic foundation, identifying the mechanisms through which complex digital interventions work can be challenging (Michie et al. 2017). Studies included in the systematic review lacked theory and / or descriptions of theory (Hewitt et al. 2022c). We used theory throughout the planning and execution of the studies and this was clearly reported for transparency.

Basing interventions on multiple theories can be problematic due to overlap between theoretical constructs (Cane et al. 2012). We attempted to integrate several theoretical models and frameworks across the two project phases to enhance data collection and support the systematic development of MiDerm, as well as the identification of barriers and facilitators and some potential mechanisms of action for future testing.

The current research demonstrates how a person-centred approach to developing complex interventions (O'Cathain et al. 2019) can be achieved through the application of theory. Furthermore, it shows that using research methods and theories which prioritise the voices of the target audience ensures that these remain at the heart of the development process. This increases the likelihood that complex interventions are relevant, appropriate, practical and effective for the target group (Yardley et al. 2015a). The research on MiDerm goes further than previous studies (Ip et al. 2021b; Greenwell et al. 2022) by providing insight into the use of an established framework that supports the exploration of the acceptability of health interventions (Sekhon et al. 2017) from idea conception through to implementation.

The Theoretical Domains Framework (TDF) can support implementation research, specifically the identification of psychological, social and environmental influences that influence behaviour change mainly in health contexts (Michie et al. 2005; Cane et al. 2012). The BCW guide (Michie et al. 2014) covers use of the TDF to understand behavioural influences, however, it is an optional step as COM-B can provide early insights that can be evaluated further using the TDF later in the development process. Use of COM-B Model alone in this research was, therefore, sufficient. Application of the TDF could inform future research to optimise and evaluate MiDerm ready for implementation.

The role of health psychology

The development of interventions in dermatology are generally led by dermatologists with academic and/or clinical experience. However, MiDerm was developed by health psychologists with knowledge and experience in managing skin conditions. Health psychologists are specially trained in the biopsychosocial model of health and illness (Cleanthous et al. 2013) and to develop and evaluate complex behaviour change interventions for individuals and populations using rigorous research methods and theory (Anderson 2019). The skill set of a health psychologist was, therefore, appropriate to lead and deliver interventions such as MiDerm.

Team science

Collaborative, inter-disciplinary efforts are needed to successfully tackle and overcome major and complex health problems and is the cornerstones of a team science approach (Stokols et al. 2008). However, a team science approach is not typically adopted for the purpose of completing a PhD, which is to become an independent researcher. This PhD adopted a team science approach, provided a supportive learning environment and helped to improve the rigour and quality of this research.

Stakeholder engagement

The contributions of a range of stakeholders were considered a major strength of this research. Those described within this thesis provide useful examples of how stakeholders can be successfully engaged and input to behaviour change research and intervention development.

However, the software developers worked in short, intense periods of work called ‘sprints’ and this contrasted with the slower pace at which the research was carried out to ensure its quality and due to the rate at which internal processes and other University teams operated. In addition, use of abbreviations and technical language is a recognised barrier to engaging stakeholders (Byrne 2019). The lack of a common language across stakeholder groups from different fields and areas of expertise was challenging. This was especially true in relation to the collaboration between the researchers and software developers. There were occasions where mutual understanding was assumed. It later transpired that there were gaps in communication and additional meetings had to be scheduled to establish meaning.

PPI

The transparent reporting of the substantial contributions of PPI members is another strength, as PPI is a core component of health research (Aiyegbusi et al. 2023) and in this context so that research outputs are of relevance to the dermatology community (Heague et al. 2022). The diversity within the group will have likely helped to ensure the relevance of this work to adults living with common and rare skin conditions from different backgrounds (Heague et al. 2022).

Aiyegbusi et al. (2023) published useful considerations for PPI (and engagement) in research. Despite implementing several of these suggestions, issues still arose throughout this research. Without appropriate resources and training, approaches to PPI were trial-and-error and it was a case of 'learning on the job' for the researcher(s) and PPI contributors. Engagement with and contributions from PPI members fluctuated and responses from members dipped towards the end of the project when two contributors with vitiligo withdrew from the group without reason.

Formal evaluation of PPI impact in research is challenging (Aiyegbusi et al. 2023). PPI members were asked to share their honest opinions of the successes and challenges of being part of this research to understand how to improve the PPI experience in future. PPI reflections are summarised in Appendix 65.

Addressing current research priorities in dermatology

Positively, this research aligned to some of the top research priorities in dermatology at the time as set by Priority Setting Partnerships. It covered psychological impact and MiDerm was designed specifically to address the gaps in psychological support in dermatology, particularly behaviour change.

Sample

The systematic review did not prioritise the inclusion of papers on the intervention development process, yet most papers did not cover patient input to development. An advantage of this research is that across the two studies 413 adults with common and rare skin conditions participated and MiDerm was based on the opinions of these individuals.

However, the sample was slightly imbalanced geographically – most participants were from England, UK – and towards female gender, white ethnicity and with mainly psoriasis followed by vitiligo and ichthyoses. Thus, these findings and app content may be more applicable to adults with these characteristics.

Participants were recruited using non-probability sampling approaches and those who volunteered likely possessed different characteristics, or had different agendas, to those who did not (Sharma 2017). Caution is advised when generalising and transferring these findings, particularly those pertaining to MiDerm, to the wider dermatology population.

Dermatology patient organisations played a key role in recruiting research participants. This offered substantial benefit by providing direct access to patient populations and, in conjunction with recruiting online, increasing reach. This strategy differed in many of the studies that we reviewed which recruited from clinical dermatology settings. Recruiting through patient organisations and clinical settings bears consideration for future research.

Online recruitment exposed the issue of ‘imposter’ or ‘fraudulent’ participants (Hewitt et al. 2022d). Imposter expressions of interest were not exclusive to this research (Drysdale et al. 2023; Pellicano et al. 2023; Ridge et al. 2023; Gibson and Beattie 2024), with incidences increasing since the shift towards online research during the SARS-CoV-2 pandemic (Ridge et al. 2023). Incentivisation has been postulated a reason for this (Drysdale et al. 2023) but suspicious requests were received despite no financial incentive being offered and taking measures (e.g., targeted advertisements) to mitigate these risks. This then raises the question as to if there are real people behind these requests, what is their motivation? This question is inherently difficult to answer and researchers are likely to approach their work with skepticism (Drysdale et al. 2023). Stakeholders, including researchers, academic institutions and research authorities and councils, must collaborate to safeguard research integrity and those involved. Recommendations for dealing with imposter participants should also be implemented (Lawlor et al. 2021; Roehl and Harland 2022; Drysdale et al. 2023; Pellicano et al. 2023).

Implications for future research

This PhD identified several avenues for future work. It focused on developing a digital intervention that is suitable for adults, yet MiDerm was perceived to be most beneficial for people who are adjusting to life with a skin condition, including younger people and adults with late condition onset. Some might argue that the findings related to these vulnerable groups would warrant targeting MiDerm at them rather than adults. Whilst this point is valid, there remained a strong justification for creating a new intervention for adults only. The mixed methods systematic review evidenced clear gaps in digitally delivered self-management support for adults that should be addressed (Hewitt et al. 2022c). Most participants had lived with their skin condition for several years and it is likely that adults who have recently acquired a skin condition will have specific support needs and desires for an app that were not covered here. The same is true for children and young people, who are likely to have different support needs to adults which need to be explored. Qualitative research studies that are specific to these two populations is, therefore, needed. In addition, developing an intervention for younger people would also require involvement from different stakeholders, including parents/carers who likely support children and contribute substantially to the management of their skin conditions. It is encouraging to see recent studies focused on psychological interventions for children, young people and their families (Greenwell et al. 2022; Sivyer et al. 2022; Hughes et al. 2023). Additional targeted research is needed to develop tailored versions of the app that meet the needs and preferences of these groups to support adjustment.

This PhD highlights the need for further research in specific groups, including cisgender women and adults with acne. Most of the group interview participants were female and these data indicate that skin conditions may carry additional burdens and increased risk of CLCI for women, mainly due to the uncertainties associated with the skin and reproductive health. There was an assumption that changes in the skin that coincided with pregnancy and hormonal contraception use were associated with hormonal changes throughout their menstrual cycle or the menopause. Whilst guidance is available on pregnancy for some conditions, including eczema (Weatherhead et al. 2007) and epidermolysis bullosa (Greenblatt et al. 2022), evidence-based information on female reproductive health in the context of skin conditions is largely absent and these participants reported that women seek and rely on information from other women as a result. Further exploration of women's views, experiences and needs is required to inform and provide direct support for them inside and outside of clinical settings.

It was surprising that so few people with acne volunteered to participate in the present studies. By partnering with Global Skin to recruit participants, it became apparent that currently there is only one acne specific patient organisation operating that is located in Canada. The organisation also represents people with rosacea and thus, there is currently no patient organisation that is dedicated to representing people with acne. This may explain the low numbers of people with acne. However, these studies were also advertised on several social media platforms by members of the research team and PPI group, as well as patient organisation. Thus, the question around why there is poor engagement from people with acne remains. Alternative, more creative strategies are needed to engage people with acne. In addition, research studies exploring adults' personal models of acne and support needs are also required to determine how best we can support them, including via the MiDerm app.

Our team have since completed an additional qualitative online semi-structured study with eight adults living with acne and post-inflammatory hyperpigmentation to understand their views and experiences and identify how to improve the trustworthiness of an app that is funded by an industry partner; a potential barrier to app use found in the group interview study and a previous study (Sangers et al. 2021). Some of these findings have relevance for MiDerm and are included in Appendix 66.

Certain skin conditions, including psoriasis followed by ichthyoses and vitiligo were well-represented across these studies. Future research on MiDerm should aim to involve people living with different skin conditions to ensure the app is relevant and appropriate for people with other common and rare skin conditions. It should also prioritise investigating whether impact, support and coping, significantly differ by skin condition to determine if and where more tailored support is needed. The survey was only available in English and replicating the survey in other common languages could help to increase reach further and gain insights into the perspectives, experiences and ideas of adults whose first language is not English.

Furthermore, this research provides evidence for the usefulness of the CSM (Leventhal et al. 1984) to explore patient's personal models of skin conditions and psychological response to them. It demonstrates the importance of accounting for patients' beliefs about their illness and how these influence their approach to coping with, and managing, their skin condition. The CSM usefully informed our further research on acne and could be used to understand other skin conditions.

Efforts are also needed to reduce the digital divide (Chapter 5) that exists across social groups, including people of colour, older age, low socioeconomic status and people who live in rural geographical areas (Sanders and Scanlon 2021). Across the survey and interview studies, and the study on acne and PIHP&S that was subsequently conducted based on these findings, had low representation of people of colour. Future research should prioritise the inclusion of people of colour to ensure MiDerm is relevant and accessible to adults with skin conditions irrespective of race or ethnicity.

From this research we produced a list of health behaviours that were considered important to participants which will continue to inform the work on MiDerm and could be used by dermatology researchers to identify behavioural targets for new interventions.

Around half of the survey sample reported that they rarely or never exercised, or ate healthily, to support self-management. Understanding the barriers and enablers to performing these health behaviours could inform the development of new behaviour change interventions that encourage adults with skin conditions to be more active and eat foods that support skin health.

A few survey respondents indicated they use substances, including drugs, as a means of coping. Addictive behaviours, especially drug abuse, is an underestimated and under researched problem in dermatology (Zink et al. 2017). More research is needed to understand if, how and why recreational drugs are used by people with skin conditions.

Few survey respondents reported venting their negative feelings aloud, but some commented that they expressed and reflected on their emotions by journalling. Between 30% and 40% stated they rarely or never sought emotional support from others, but it was unclear why. These qualitative data allude to some potential reasons, including embarrassment, dismissal by health professionals, and a preference for peer support, but research is needed to understand specific barriers and facilitators to adults seeking emotional support for skin conditions to increase engagement where it is available.

Some of the participants suggestions for MiDerm, for example, an app that facilitates (asynchronous or synchronous) communication between adults with skin conditions, were beyond the scope and resource of the current project. However, these offer a useful starting point for adapting MiDerm or developing new DBCIs in future which focus on facilitating peer support and communication.

The Brief COPE is an established generic measure of coping that has been validated for use within different populations. However, it is unclear whether the original factor structure of coping is specific and appropriate for our population of interest. Structural equation modelling, including confirmatory factor analysis, is needed to determine whether these data fit the original factor structure. In addition, conducting an exploratory factor analysis is important to investigate if and how the additional items on health behaviours relate to the main concept of coping.

This project successfully and comprehensively completed intervention planning, the first major phase of intervention development according to the PBA (Yardley et al. 2015b). This body of work lays the foundation for the next phase of development, it provides an evidence base and theory led platform for intervention optimisation and evaluation. Several useful considerations (barriers and facilitators) for implementation were identified and these data could inform and be evaluated further within the next developmental phases.

The next step is to optimise MiDerm to ensure it is suited to the target group and the authors of the PBA (Yardley et al. 2015b) recommend cognitive interviewing as a qualitative method for exploring the acceptability and feasibility of an intervention prototype before longitudinal approaches are used to evaluate it against outcomes (Morrison et al. 2018). The 'think-aloud' technique will allow prospective users to voice thoughts about the intervention prototype as they engage with it in real time (Yardley et al. 2015b; Morrison et al. 2018).

MiDerm should also undergo testing to determine whether its use improves patient health outcomes, including the potential outcomes within the intervention logic model (Chapter 8) and those that are important to prospective users and other key stakeholders (Skivington et al. 2021). A mixed methods approach would be appropriate for understanding not just *if*

MiDerm works, but *how* it works and any barriers and enablers that influence this across different contexts and settings (Skivington et al. 2021). A potential strategy would be to conduct a before and after study to determine the effectiveness of MiDerm using established health outcome measures and a nested survey or qualitative interview study to further evaluate acceptability, usability and effectiveness from the user perspective. Our research group have developed PRIDD, a PROM of the impact of dermatological conditions (Pattinson et al. 2022; Pattinson et al. 2023a; Pattinson et al. 2023b; Trialonis-Suthakharan et al. 2024), which could be used to test the effectiveness of MiDerm. Process evaluations and studies addressing cost-effectiveness could be considered in the future at the stage of implementation (Skivington et al. 2021).

This thesis emphasised the importance of stakeholder engagement in developing and disseminating the MiDerm app. The qualitative interviews highlighted that the app could serve as a useful tool to support information recall and facilitate shared decision-making during consultations. As this research focuses on a digital intervention for patient self-management, future research is necessary to establish what health professionals think about the app to support its implementation.

With future research in mind, it is important to acknowledge some unforeseen issues that arose from recruiting participants online. We received several suspicious automated requests for participation (Hewitt et al. 2022d) and similar experiences have been reported elsewhere (Pozzar et al. 2020) and anecdotally by some colleagues conducting psychodermatology research. Irrespective of the topic under investigation, researchers in this area should be aware of the drawbacks of recruiting participants online and take steps to protect participants and ensure their own safety. Some strategies that could help to mitigate this in future include the use of a generic study email address and a CAPTCHA system to distinguish human responses from computer-generated ones.

Next steps for developing MiDerm

Alongside future research, there are ethical and governance issues to consider relating to intellectual property and how best to protect that arising from MiDerm, including:

- Trademark registration to distinguish the app name and logo from others.

- Copyrighting app content to prevent its use or modification by others without permission.
- European Conformity, more commonly known as CE marking, to demonstrate that MiDerm as a product conforms to European legal standards and is eligible for free trading within the European market.

Michie and colleagues (2017) have recognised intellectual property as a key challenge in developing and evaluating DBCIs in health, as this is a new area and there is a lack of established guidance on how developers manage intellectual property. Thus, this task is unlikely to be straightforward and expert legal advice should be sought to satisfy potentially competing demands relating to research, ethics and commercialisation.

Ongoing collaboration is necessary to ensure MiDerm is using latest technology and evolving with the rapid advancements in digital technology (Michie et al. 2017).

Implications for practice

These research findings have important implications for dermatology at the levels of service provision and patient care.

These participants clearly wanted MiDerm, and any app, to supplement additional psychological support and not replace it. They desired support from qualified psychologists with expertise in managing skin conditions. Lack of specialist psychodermatology services (see Chapter 2) illustrates this problem in current dermatology provision (Misery et al. 2023). Future research should identify the best service design features.

Generic information on behaviour change was deemed inadequate and participants sought freely available information online and trialled self-management strategies that were potentially unsafe. Personal beliefs about illness and treatments should be routinely assessed (Mizara et al. 2012; Chiang et al. 2015; Howells et al. 2018) so that understanding the patients personal model of their condition is not assumed and the information and resources shared during consultations are tailored to their needs.

Implications for patient organisations

This project involved input from dermatology patient organisation leaders. Participants considered patient organisations as trusted sources of informational and emotional support and a gateway to peer support, although many were not affiliated with or were unaware of dedicated organisations. Inequities in the availability of organisational support were evident for common and rare skin conditions. Surprisingly a Canadian organisation called Acne Action was, at the time of writing, the only operating organisation dedicated to supporting people with acne and post-inflammatory hyperpigmentation and scarring (PIH&S), despite the high global prevalence of acne (Layton et al. 2021). Funding is needed to address inequities in organisational support and establish dedicated organisations for common and rare skin conditions across countries. We believe this PhD thesis will raise awareness regarding the need.

Dermatology patient organisations evidently play a crucial role in supporting patients and dermatology research by increasing reach and access to patient populations, on top of their existing advocacy role. They are a key contributor to the wider dermatology support network, but their role is currently undervalued and under-recognised within medical dermatology and health authorities. Greater awareness of the support patient organisations can offer at the individual, service and political level is needed, as is stakeholder collaboration to set out how these organisations can best support patients locally.

Implications for education

This research has implications for the provision of education for medical and other health professionals, people who have a skin condition and general publics.

Medical education

This research makes clear that specialist training programmes are needed to upskill medical and other health professionals in the use of patient-centred approaches to support effective clinical communication and management of the psychological aspects of skin conditions. It strengthens recent calls to train dermatology professionals in psychodermatology (Misery et al. 2023).

The European Society for Dermatology and Psychiatry (ESDaP) offers a Psychodermatology Diploma (Misery et al. 2023), but it is unclear whether this programme has been rigorously evaluated and the extent to which health behaviour change is covered, if at all. The PsoWell™ training programme (see Chapters 2 and 4) coaches MI to address health behaviour change during standard consultations and is both effective and acceptable to clinicians (Chisholm et al. 2017; Hewitt et al. 2021). PsoWell™ could be adapted to improve professional competence in behaviour change across skin conditions.

Education for patients

Greater awareness and understanding of the pathology and psychology of skin conditions was believed to improve self-management. Provision of evidence-based information on the role of psychological processes and skin is needed to enable adults to learn how mood and behaviour can impact their skin and act accordingly.

People with skin conditions could potentially benefit from receiving PsoWell™ training that gives them basic techniques to engage dermatology professionals in shared decision-making and work collaboratively towards making changes to treatments or lifestyle. There is also a question around whether patients could benefit from basic training that enables them to independently identify quality guidance from credible sources. Although how this would work in practice and whether these suggestions are acceptable is currently unknown.

Education for the public

There is a clear argument for educating the general public about skin conditions and their impact as many of the reported limitations of existing types of medical, psychological and social support were attributed to poor awareness and understanding. Public campaigns are required to disseminate relevant information to local, national and international audiences, as some participants suggested (Chapter 5). The Psoriasis Shout Out (UoM 2014) is a comprehensive awareness campaign dedicated to psoriasis and is an example of an approach that could be adopted to raise public awareness.

Implications for policy

Despite countless calls for increasing provision of and access to psychological support within dermatology and specialist psychodermatology services (APPGS 2003; 2013; 2020), little has changed and it has been argued that:

> *"Only a concerted effort to foster international advocacy, research and education campaigns will ensure that the voices of those with skin disease are heard at the global level" (Flohr and Hay 2021, p. 190)*

This research is at least a step in the right direction and demonstrates both a concerted and collaborative effort to represent the voices of adults with skin conditions globally with involvement from academic, industry and third-sector partners. It emphasises that DBCIs are not enough and the need for face-to-face psychology services remains a priority. It is essential that policymakers are made aware of this evidence and act accordingly upon it.

Conclusion

The work presented in this thesis reports on the co-development of a complex DBCI for adults living with skin conditions with substantial input from patients. Intervention development followed the PBA and this thesis successfully completed intervention planning, resulting in the prototype of a new smartphone app called MiDerm comprised of tailored education to bridge the knowledge gap between skin conditions and psychology, dedicated health behaviour change support and peer support to facilitate effective self-management. This research employed a mixed methods design and is an example of best practice for developing digital interventions in dermatology using a combination of complimentary theory-, evidence- and person- based approaches. It provided strong evidence for the *perceived* acceptability of MiDerm and justifies the continuation of this work as part of a programme of research to evaluate, optimise and implement the intervention globally in accordance with adults' needs and preferences.

This thesis contributes to understanding the life impact of skin conditions, including the additional burden of self-management, indicating that certain people require additional support with adjustment as well as self-management to offset CLCI. It highlights clear gaps and limitations associated with healthcare, social support and online peer support, and evidences the understated role of peer support at the organisational level. Collectively, this thesis points to the need for a biopsychosocial approach to managing skin conditions. The provision of specialist medical education and training, the integration of health psychology provision within dermatology services and the establishment of specialist psychodermatology services could support high quality patient-centered care. Digital interventions such as MiDerm may go some way to improving the provision of credible support that is freely available to adults with skin conditions, but do not mitigate patient need, or offer an absolute solution to persistent calls, for face-to-face psychological intervention.

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Chapter 11: Appendix

Appendix 1: Global estimates of the prevalence of some common and rare skin conditions

Skin Condition	**Estimated Prevalence (%)**	**Reference**
Acne vulgaris	9.38*	Heng and Chew (2020)
Atopic dermatitis	2 - 10	Laughter et al. (2021)
Psoriasis	0.14 – 1.99	Parisi et al. (2020)
Vitiligo	0.5 - 2	Bergqvist and Ezzedine (2020)
Skin cancer	0.03**	Urban et al. (2021)
Ichthyoses	Ichthyosis Vulgaris: 0.02-1.26, X-Linked Ichthyosis: 0.01-0.08 Other types: 0.00008-0.007	Gutiérrez-Cerrajero et al. (2023)

*Global prevalence for all ages

**Types of skin cancer include melanoma and keratinocyte carcinoma.

Appendix 2: Types of impact

Physical

Skin conditions are associated with a range of physical symptoms and can vary in their presentation and severity. Many, but not all, are typically characterised by visible symptoms, which alter the appearance of the skin, and physical disablement (APPGS, 2003). Plaques, redness and dry skin, for example, are typical of psoriasis and eczema. Skin discolouration, due to changes in the pigment Melanin, and increased sensitivity are common to conditions such as vitiligo, hyperpigmentation and albinism. Fluid-filled blisters are typical of conditions including pemphigus, bullous pemphigoid and epidermolysis bullosa (EB). Several invisible physical symptoms have also been reported across skin conditions, mainly pain, physical discomfort, fatigue and, in some cases, itch (Ghio et al. 2021).

Fatigue has been defined as “an overwhelming sense of tiredness, lack of energy, and a feeling of exhaustion” (Krupp and Pollina 1996, p. 456) and can affect people physically and psychologically (cognitively and emotionally) (Skoie et al. 2015; Dures et al. 2017; Sawada et al. 2021). Fatigue is commonly experienced by people living with skin conditions, such as psoriasis (Skoie et al. 2017; Ballegaard et al. 2020) and eczema (Yu et al. 2016) although it is often overlooked by health professionals (Skoie et al. 2015). This may be due, in part, to the lack of research and poor understanding of this phenomenon in dermatology (Skoie et al. 2015).

In addition, pain, sleep disturbance and depression are all known to affect fatigue (Skoie et al. 2015). Research on fatigue has, so far, focused on people with inflammatory and autoimmune conditions, including psoriatic arthritis (Dures et al. 2017). People who have psoriasis and psoriatic arthritis tend to report higher levels of fatigue than people who have psoriasis alone (Ballegaard et al. 2020). Disease activity and severity are not always related to fatigue - some people with rheumatoid arthritis (RA), for example, report high levels of pain and fatigue even though their condition is less active and levels of inflammation are low (Skoie et al. 2015). In addition, the severity of fatigue has been associated with pain, depression and smoking in psoriasis, but not disease severity (Skoie et al. 2017). Fatigue can have a major impact on people’s lives as it interferes with daily, social and leisure activities, including work and studying (Skoie et al. 2015), and affects mood (Dures et al. 2017). Fatigue should, therefore, be a main consideration in the management of skin conditions and psychological approaches are needed to help tackle cognitive and emotional fatigue (Dures et al. 2017).

The term ‘comorbidity’ is used to describe the simultaneous occurrence of two or more distinct health conditions (Valderas et al. 2009). Various physical and psychological comorbidities have been associated with skin conditions, which increase the burden on patients (Basra and Shahrukh 2009). Psoriasis is associated with increased risk of skin cancer, psoriatic arthritis, and metabolic syndrome, which includes type II diabetes, obesity and insulin resistance (Kimball et al. 2008; Bundy et al. 2014; Johnston et al. 2018). Other skin conditions, such as hidradenitis suppurativa (HS), are associated with spondyloarthropathies and IBD, whilst people with eczema are more prone to asthma and allergies (Bulger et al. 2021).

Furthermore, low-grade inflammation is one of the strongest risk factors for CVD (Arnold et al. 2021). Several skin conditions are also associated with CVD due to shared inflammatory processes (Bulger et al. 2021; Hojman and Karsulovic 2022). Evidence is strongest for psoriasis and HS (Tzellos et al. 2015; Hojman and Karsulovic 2022) but eczema, bullous pemphigoid, lupus erythematosus and acanthosis nigricans have also been associated with CVD (Bulger et al. 2021). Emerging evidence has shown some skin conditions (e.g., rosacea and vitiligo) are directly linked to higher incidences of cardiovascular events (e.g., atherosclerosis and myocardial infarction), whereas others (e.g., acne and xanthelasma palpebrarum) are indirectly linked through the progression of diabetes and obesity and related factors (Hojman and Karsulovic 2022).

Health behaviours are actions which can influence health and well-being. Health behaviours are typically thought of as being protective or threatening; health-protective behaviours, such as taking regular exercise and wearing sunscreen, positively impact on health whereas health-threatening behaviours, including smoking and sunbed use, can have negative consequences for our health. Long-term conditions, such as CVD, diabetes and obesity, have been associated with a range of health behaviours, including smoking, alcohol consumption, sedentary behaviour and poor diet (Public Health England 2017).

These health behaviours can also increase the risk and severity of skin conditions (Sawada et al. 2021; Hu et al. 2022). Alcohol consumption, for example, is moderately associated with skin cancer risk (Gandini et al. 2018), and smoking and a high Body Mass Index (BMI) ≥ 25 kg/m^2 are associated with more severe androgenetic alopecia (Fortes et al. 2017). People who smoke are more likely to develop psoriasis, androgenic alopecia, contact dermatitis, and hand eczema than non-smokers (Lipa et al. 2021). Individuals living with psoriasis, HS and androgenic alopecia who smoke are also more likely to experience worse skin symptoms than non-smokers (Lipa et al. 2021). People with skin conditions often present with higher rates of behavioural risk factors for CVD, including smoking (active and non-active), excessive alcohol consumption, poor sleep and obesity-related behaviours, such as poor diet and sedentary behaviour, compared to the general population (Naldi et al. 2005; Hayes and Koo 2010; Armstrong et al. 2012; Al-Jefri et al. 2017; Henry et al. 2017; Dauden et al. 2018; Henry et al. 2019; Manolis et al. 2019; Bulger et al. 2021; Hojman and Karsulovic 2022; Yeroushalmi et al. 2022; Li et al. 2023). Thus, people with skin conditions should be routinely screened for CVD (Bulger et al. 2021) and professionally supported to modify related health behaviours to help prevent CVD (Hojman and Karsulovic 2022) and other long-term conditions, as well as the onset and worsening of skin conditions.

Social

Within society, visible skin conditions are largely misunderstood and are publicly stigmatised (Germain et al. 2021). People often hold inaccurate perceptions (it is contagious) or superstitious beliefs (it is a curse) about skin conditions and make assumptions about the hygiene of patients, many of whom receive negative comments and experience stares, bullying, discrimination, social exclusion and isolation (Dalgard et al. 2018a; Germain et al. 2021; Pattinson et al. 2022), as a result. The stigmatisation of skin conditions is likely to have worsened with the rise of new media and the portrayal of appearance-related ideals within society (APPGS, 2020). Some patients internalise the negative perceptions of others and self-stigmatise, which can increase psychological stress (Gupta and Gupta 2003) and the social burden for individuals (Germain et al. 2021).

Many people with skin conditions report difficulties initiating and maintaining friendships and romantic relationships, as well as with intimacy and sexual function (APPGS, 2013; Feldman et al. 2014). People often miss out on social and leisure activities due to feelings of social anxiety and lack confidence to go out in public (APPGS, 2013; Feldman et al. 2014). Skin conditions can inhibit people's ability to perform daily tasks resulting in a loss of personal autonomy and this, sometimes, means individuals have to rely on significant others for care and support (Pattinson et al. 2022).

Financial

There are substantial economic costs and pressures associated with skin conditions and patients frequently must cover additional costs to manage their condition effectively (APPGS, 2013). These costs include medical care and treatments (Ryskina et al. 2018; APPGS, 2020; Greenwell et al. 2021), depending on geographical location and local health systems (Ip et al. 2021a), over-the-counter skin care products and medicines, as well as clothing, food, make up and household products that are suitable for the skin, may be more expensive (APPGS, 2003; Pattinson et al. 2022). Many patients have to take time off work due to the severity of their symptoms, or to attend appointments related to their condition, which often results in a loss of earnings and an inability to save for expensive purchases (e.g., holidays and property) (Pattinson et al. 2022).

Daily living

People's ability to go about their daily lives often depends on the state of their skin; when symptoms are worse, individuals struggle to carry out daily tasks, such as work, childcare and doing chores (Teasdale et al. 2021; Pattinson et al. 2022). In addition, daily routines and schedules tend to revolve around condition management and avoiding triggers (Teasdale et al. 2021; Pattinson et al. 2022). Often the management of skin conditions requires adherence to specific treatment regimens, which typically take a substantial amount of time and effort to complete and can have a negative, knock-on-effect on other areas of life, including sleep quality, work and leisure time, as well as personal choice and autonomy (Bundy et al. 2014; Greenwell et al. 2021; Teasdale et al. 2021; Pattinson et al. 2022).

Appendix 3: Overview of project phases and the respective research methodology and methods

Project Phase	**Stage of intervention development according to the PBA (Yardley et al. 2015b)**	**Aim**	**Research methodology**	**Method for data collection**	**Data analysis**
1	Planning (secondary research)	Identify research problem and solution	Mixed methods	Systematic review	-
	Planning (primary research)	Understand research problem and solution	Qualitative	Online group interviews	Thematic Analysis
		Investigate research problem and solution	Mixed methods	Online survey	Descriptive statistics and Thematic Analysis
2	Planning (theoretical modelling)	Define intervention, establish guiding principles and identify behaviour change principles and techniques.	-	-	-

	Planning (development and design)	Develop and design digital intervention	-	-	-

Appendix 4: Codebook for qualitative thematic analysis of group interview data

Theoretical concept	Codes and sub-codes	Description
Theoretical Framework of Acceptability (Sekhon et al. 2017)		
Affective attitude		"How an individual feels about the idea of the intervention or a particular aspect of it."
Burden		"The perceived amount of effort that is required to participate in an intervention or aspect of it."
Ethicality		"The extent to which the hypothetical intervention or aspects of it fit with an individual's value system."
Intervention coherence		"The extent to which a person understands the intervention and how it works." This may be evident in personal descriptions of the app content, design, function and purpose.
Opportunity costs		"The extent to which benefits, profits or values must be given up to engage in the intervention."
Perceived effectiveness		"The extent to which the intervention or aspects of it are perceived to be likely to achieve their purpose."
Self-efficacy		"Confidence in oneself to perform the behaviour(s) required to use the intervention."
Analytical framework on the impact of dermatological conditions (Pattinson et al. 2022; Pattinson et al. 2023b)		

Cognitions			Beliefs about cause, identity, controllability and curability, consequences and timeline of skin conditions (Leventhal et al. 1984).
	Cause		Beliefs about perceived or actual causes of skin conditions, including triggers.
	Original cause		Factors that people believe to be the root cause or underlying mechanism that resulted in the development of their skin condition.
		Biological	Belief that there is a biological reason for the skin condition such as a poor immune system.
		Curse	The individual believes that they have the skin condition because they are cursed, it is their kismet or karma, or a punishment.
		Environmental	Belief that environment factors (e.g. allergens, lace, pollution) cause the condition.
		Genetic	Belief that the skin condition is genetic or hereditary.
		Health risk	Belief that the skin condition occurred as a result of a predisposition (i.e., the skin condition is a known or unknown comorbidity of another condition they have) or by engaging in risky behaviours (e.g., unhealthy lifestyle behaviours).
		Lifestyle	Belief that lifestyle factors (e.g., poor diet) cause skin conditions.

		Self	Belief that the individual caused the skin condition because they lacked something in their worth or character including self-blame.
		Stress	Belief that the skin condition occurred as a result of acute or prolonged psychological, social, financial, or physical stress. (Stress referring to a state where people felt that the demands of a situation exceeded their ability or resources to cope with it).
		Unknown	The individual doesn't know what caused the skin condition.
	Triggers		Factors perceived to exacerbate skin conditions.
		Environmental	Belief that environment factors (e.g. allergens, lace, pollution) cause symptoms to flare.
		Food	Belief that certain foods causes symptoms to flare.
		Mood	Belief that certain moods or changes in mood trigger the skin condition (not including stress).
		Stress	Belief that stress causes symptoms to flare.
		Topical agents	Belief that products (not treatments) that are applied to the skin or hair cause symptoms to flare. If the products are treatments treatment efficacy should be considered instead.
Consequences			The believed consequences of the condition, including the physical, psychological, social, financial or daily impact that they have. This captures the degree of impact too (minor, moderate or major) and

		could refer to broader impacts of a condition beyond the individual (i.e., to friends, family and colleagues).
	General impact	The ways in which having a dermatological condition impacted aspects of daily life and functioning.
	Career	The effect of having a skin condition on a person’s career.
	CLCI	A person's life course has been affected by them having a skin condition.
	Daily routine	Descriptions of how the skin condition directly or indirectly impacts one's daily routine or activities such as the ability to drive, get groceries etc.
	Dependence	Relying on others to help with everyday tasks.
	Employment discrimination	Comments indicating that an individual has been treated differently by others in the workplace (e.g., employer or colleagues) because of having a skin condition.
	Everyday choices	The condition influences a person’s choices (e.g., choice of clothes, hairstyle or products).
	Expenses	Costs the individual with the skin condition incurs as a result of their skin condition. This may include paying for prescriptions or over the counter medication, cost of new clothes or treatments etc.

	Leisure	The skin condition directly or indirectly effects whether the person can participate in leisure activities, such as sports or going on holiday.
	Life choices	Skin conditions influencing a person’s life choices (e.g., having a family, career).
	Loss of earnings	The loss of earnings or wages due to living with a skin condition.
	Study	Education or studies are affected due to having a skin condition.
	Treatment consequences	References to treatment causing practical problems; for example, by taking up time or being messy.
	Physical impact	Primary and secondary physical impacts of the skin condition, including symptoms and physical consequences that are not symptoms (respectively).
	Fatigue	Consequences of the physical (e.g., changes bandages) and mental effort (e.g., hypervigilance, planning) required to manage condition.
	General health	Skin condition impacts on a person’s general health.
	Mobility	Impaired mobility, dexterity, hearing or vision due to having a skin condition.
	Pain	Comments reflecting experiences of physical discomfort, soreness or irritation as a result of having a skin condition.

	Sensitivity	References to the skin being sensitive to external factors, for example, to touch or when exposed to light or changes in temperature.
	Sleep disruption	References to the skin resulting in poor sleep quality or a lack of sleep.
	Symptoms	Physical symptoms associated with skin conditions.
	Psychological impact	Cognitive and emotional consequences of having a skin condition.
	Attractiveness	Perception that the skin condition has altered how attractive the individual is.
	Belonging	Feeling different from other people and the importance of being part of a group or community.
	Concentration	Expressions of finding it hard to concentrate, maintain focus or pay attention to detail. This is acknowledged as a consequence of the condition not a symptom of the condition.
	Confidence	Lacking, or a changed sense of, self-confidence due to having a skin condition.
	Disgust	Feels of disgust towards the self or the skin.
	Feeling exposed	Perception that the skin condition draws unwanted attention.

		Identity	Comments which indicate a person has absorbed their skin condition into their identity or concerns that other people define them by their skin condition.
		Loneliness	Feeling lonely or alone.
		Loss of control	Feeling out of or a loss of control because of a skin condition.
		Paranoia	Comments about feeling like people are looking at them or talking about them. This code is different from other people's reactions because it is not necessarily true but is how the person feels.
		Pressure	Perception or examples of feeling pressure to perform, behave or appear as people without a skin condition do.
		Rejection	Feeling or being rejected by others.
		Resent	Feelings of resent towards skin condition.
		Resilience	Belief that living with a skin condition has made the individual strong, able to handle burdens and recover from them.
		Self-conscious	Comments about feeling self-conscious.
		Self-identity	Comments about changes in identity. For example, having a skin condition changes the person or how they express themselves.
		Stress	Reference to stress or feeling unable to cope or respond to threats or demands. Participants may use stress and distress interchangeably so don't rely only on the word stress.

	Uncertainty	Feeling confused or uncertain about the skin condition.
	Social impact	
	Discrimination	Discrimination follows stigma and is the unfair or unjust treatment of an individual.
	Dismissal	Feeling dismissed or abandoned by others or the healthcare system.
	Impact on others	Perception that the skin condition has had an impact of the individual's friends, family, colleagues etc.
	Initiating social relationships	Difficulty initiating new acquaintances or friendships. In
	Intimacy	How the condition affects a person's ability or opportunity to be intimate with others.
	Other people's reactions	How other people react to a person with a skin condition (e.g., stares, comments, questions, assumptions, bullying or discrimination). This also covers how people with skin conditions respond to others' reactions.
	Relationships	Having a skin condition has negatively impacted on close relationships, for example, with family members.
	Romantic relationships	Having a skin condition affects a person's ability to form new relationships, expectations of relationship or causes a breakdown in relationships.
	Social anxiety	Worry or anxiety experienced during social situations.

	Social isolation	Lack of contact, physically or socially, with others whether voluntarily or involuntarily.
	Social life	Having a skin condition negatively affects a person’s social life.
	Social roles	References to the challenges associated with performing roles important to me (e.g., to be caregiver, parent, partner, employee or student).
	Vulnerability	Difficulty getting close to or being vulnerable around other people.
	Identity	The name of a skin condition and the symptoms people associate with it.
	Altered sensation	Changes in how the individual experiences touch and/or temperature; for example, being extremely sensitive and responsive to hot and cold.
	Colour	Comments about the skin changing colour or redness.
	Comorbidities	Comorbidities associated (or perceived to be associated) with the skin condition e.g., arthritis listed as a symptom of psoriasis, skin cancer.
	Discomfort	Experiencing physical discomfort.
	Disfigurement	Descriptions of altered appearance, particularly of the skin, nails or hair.

	Dry skin	Comments about skin being dry. Ashy is a synonym used for dry skin particularly by people of colour.
	Fatigue or loss of energy	Describing tiredness, exhaustion, lack of energy or weakness, particularly if this isn't alleviated by sleep.
	Hair loss	Comments about loss of hair or balding.
	Hot or burning	Descriptions of a burning sensation in the skin or body.
	Itch	The sensation and physical act of itching.
	Oily skin	Comments about oily skin.
	Pain	Painful sensation in affected areas or other areas.
	Peeling	Descriptions of skin peeling.
	Pigmentation	Descriptions of loss or changes in pigmentation including the development of white patches.
	Plaques or lesions	Dry or inflamed plaques or lesions
	Pompholyx	Descriptions of pompholyx: tiny itchy blisters that may weep fluid – in people with eczema.
	Rashes	Descriptions of rashes may include scaly, bumpy, itchy, or otherwise irritated. Rashes are distinct from plaques or lesions which are generally demarcated.
	Rough or scratchy skin	Descriptions of skin being rough or scratchy (not in terms of itch but rather in the texture of the skin).

	Sensitivity to the sun	The skin condition causes sensitivity to the sun.
	Severity	Description of severity of condition (e.g., mild, moderate, severe).
	Spots	Comments about spots.
	Weeping	Fluid leaking from affected areas (e.g., wounds, burns, blisters).
	Controllability or curability	Whether something can be done to control or cure the condition. This includes person control (the influence of the individual and their actions on their condition and decisions around treatment) and treatment control (the influence of treatments on the condition and clinical outcomes). In addition, do people feel that they can control how much their condition affects their life.
	Personal control	Beliefs that a person can influence their own skin condition. IPQ-R (Moss-Morris et al. 2002) items for personal control subscale: • There is a lot which I can do to control my symptoms. • What I do can determine whether my illness gets better or worse. • The course of my illness depends on me. • Nothing I do will affect my illness. • I have the power to influence my illness. • My actions will have no effect on the outcome of my illness.
	Lack of trust in body	The belief or feeling that their body cannot be trusted.

	Self-efficacy	Confidence a personal has in their ability to influence their condition.
	Treatment control and outcome expectations	The belief that treatment can influence a skin condition. IPQ-R (Moss-Morris et al. 2002) items for treatment control scale: • There is very little that can be done to improve my illness. • My treatment will be effective in curing my illness. • The negative effects of my illness can be prevented (avoided) by my treatment. • My treatment can control my illness. • There is nothing which can help my condition.
	Decisions about healthcare	The extent to which the individual believes they were able to make decisions about their care including treatments.
	Treatment consequences	Side effects (positive or negative) of the treatments available or actually taken.
	Treatment efficacy and choice	Perceptions of treatment efficacy and the range of treatments available.
	Timeline	Beliefs relating to the trajectory of a skin condition (e.g., acute, chronic, cyclical). Includes beliefs and expectations about the duration of a condition, and the variability and predictability of symptoms.

	Duration	Time since onset of condition.
	Flares	The sudden appearance or worsening of symptoms.
	Life stages	How the impact varies, in severity or type, across life stages.
	Progression	How the condition is expected to progress, including improvements, deterioration and the development of comorbidities.
	Symptom variability or predictability	The variability or predictability of the condition.
	Trigger variability or predictability	The variability or predictability of the triggers of the condition.
Emotions		Affective responses to the skin condition and evaluation of the (potential) emotional impact of the condition. Positive, neutral and negative emotional responses.
	Negative	• Participant thoughts or comments about illness, awareness of having the illness, or reminders about illness that trigger negative emotions. • Feelings of depression or low mood, being upset, irritated, angry, afraid, embarrassed, ashamed or anxious in any way.
	Anger	
	Betrayal	Feeling that their body has betrayed them.
	Frustration	Feeling that their will or goals are being denied. Can be related to the skin condition (e.g. frustration about having the skin condition, frustration with flares or treatments) and to other phenomena such

		as frustration with clinicians or others knowledge of the skin condition.
	Hostility	Feeling or expressing unfriendly or aggressiveness towards themselves or others, for example, being rude to clinicians.
	Annoyed or irritated	Feelings of annoyance or irritation.
	Anxiety and fear	
	Anticipatory worry	Anxiety regarding possible or future experiences or situations related to having a skin condition.
	Clinician exaggeration	Fear or anxiety results from information, sometimes exaggerated, provided by clinicians.
	Fear	
	Current and future morbidities	Expressions of feeling fearful or anxious regarding current comorbidities or development of them in the future.
	Economic	Fear of financial loss or not being able to manage financially as a result of the skin condition.
	Genetic	Fear of the condition being hereditary and ‘passing the gene’ on to children.
	Medical consequences	Fear of negative consequences of medication or treatments.
	Guilt	

	Brought on	Feelings of guilt regarding the skin condition. This could be feeling guilty for bringing the skin condition into the family and perceived or real consequences of that (e.g. family ostracised by community).
	Parent	Feeling guilty that they have passed the skin condition on to their children.
	Survivor guilt	Feeling guilty that their skin condition is less severe or has fewer consequences (e.g. death) than that of others with the same skin condition or other conditions.
	Hypervigilance	Descriptions of a heightened sense of alertness with regard to the skin condition. Frequent thinking, planning and engaging in behaviours to manage the skin condition.
	Perceived worry	Worrying that other people will worry about them because of the skin condition.
	Preoccupation, rumination or obsession	The person expresses that they spend a great deal of time thinking about the skin condition or ruminating which has a negative impact.
	Desperation	Comments or alluding to being desperate for something. Often a cure or effective management.
	Distress	Comments about being distress, defined here as depression and anxiety or general negative emotions, rather than specifically

		depressed or anxious. Participants may use stress and distress interchangeably so don’t rely only on the word distress.
	Emotional pain or hurt	References to feeling emotional pain or hurt.
	Jealousy	
	Low mood and depression	
	Depression	Reference to depression.
	Hopeless or helpless	Negative feelings towards the future, and feeling that nothing can be done to influence the condition.
	Lack of self-efficacy	The individual expresses that they lack or do not have confidence in their ability execute behaviours to meet certain goals unrelated to the skin condition (i.e. not personal control) as a result of the skin condition.
	Lack of self-esteem	An unfavourable attitude towards oneself. The individual may express feelings of low self-worth or value or negative appraisals of their own appearance, beliefs, emotions and behaviours.
	Low mood	Expressions of low mood, feeling low in spirits or a general loss of interest in things.
	Low motivation	Reference or examples of lack of motivation.
	Sad	Feelings of sadness
	Self-harm	Intentionally damaging or injuring oneself.

	Suicidality	Suicidal ideation (serious thoughts about taking one's own life), suicide plans and suicide attempts.
	Shame and embarrassment	
	Shock or surprise	Comments about feeling shocked or surprised about the skin condition.
	Neutral	Participant thoughts or comments about illness, awareness of having the illness, or reminders about illness do not trigger psychological coping mechanisms (e.g., worry) or any emotions.
	Positive	Thoughts or comments about illness, awareness of having the illness, or reminders about illness that trigger positive emotions.
	Empowered	A skin condition, or how a person copes with their skin condition, makes them feel empowered.
	Gratitude or appreciation	Feeling grateful or appreciative because of the skin condition.
Coping		The cognitive, emotional and behavioural process of managing and adjusting to the skin condition in an attempt to return to normal functioning (Lazarus and Launier 1978). Coping strategies described and measured by the most commonly used coping measures, COPE (Carver 1997) and the Ways of Coping Checklist (Folkman and Lazarus 1988) are:

		- Active coping (e.g., 'I've been taking action to try to make this situation better'). - Planning (e.g., I've been trying to come up with a strategy').
	Approach coping strategies	Confronting the problem, gathering information, and taking direct action (Roth and Cohen 1986). Approach strategies allow for appropriate action, and noticing and taking advantage of opportunities to make the skin condition more controllable (Roth and Cohen 1986).
	Active coping	
	Advocacy	Participating in advocacy work either formally (e.g., through patient organisation) or informally (e.g., answering questions, educating others).
	Cover, conceal or camouflage	Developing strategies to conceal the skin condition so it's not visible to allow the individual to return to normal functioning.
	Enhancing wellbeing	Activities to enhance wellbeing, feel calm, stress reduction.
	Healthy behaviours	Engaging in healthy behaviours, such as eating healthily, taking physical activity, reducing smoking and not drinking alcohol or taking drugs.
	Seeking information for self-management	Actively seeking information for how to manage the skin condition.

	Seeking information for understanding	Researching to better understand the condition.
	Hope	Reference to hope or optimism as a coping strategy.
	Humour	Making light of or making jokes about the skin condition.
	IDGAF	Comments about not caring what people think of them anymore and this allows them to cope better.
	Planning	References to making plans
	Positive reframing	Reframing the skin condition and living with the skin condition in positive terms.
	Religion	Turning to faith as a way of coping
	Stages of coping	Describing a journey or timeline of stages of coping. Sometimes compared to stages of grief.
	Using emotional support	Seeking out others for emotional support, not necessarily people with lived experience of skin conditions.
	Looking for people with shared experience	Seeking out other people with skin conditions for emotional and instrumental support.
	Avoidance coping strategies	
	Behavioural disengagement	Withdrawing from normal behaviours

	Hiding	Developing strategies to hide the skin condition that negatively impact the individual, such as self-isolation, wearing unattractive clothes.
	Limiting challenges	Not engaging in anything deemed a challenge, remaining in comfort zone at all times, in an attempt to reduce emotional impact.
	Limiting choices	Allowing the skin condition to determine or limit choices such as where to socialise in an attempt to reduce emotional impact.
	Denial	Reference to denying one's condition
	Distancing	
	Lack of engagement with healthcare	Being uninterested in or unwilling to appraise their health or to engage in healthy behaviours.
	Escape or avoidance	Trying to escape or avoid a skin condition. This might be avoiding seeing the skin (e.g., covering mirrors) or thinking about the condition or escaping the feelings and reality of having a skin condition.
	Sarcasm	Use of sarcasm when talking about the skin condition.
	Self-control	Trying to control thoughts, feelings and behaviours related to condition.

	Self-distraction	Actively choosing to think about other things or performing behaviours that allow a person to take their mind away from their condition.
	Substance use	Reference to using alcohol or drugs.
	Unhealthy lifestyle behaviours	Engaging in unhealthy behaviours, such as poor diet, smoking or a lack of exercise, with the view to mitigate the impact of the skin condition (e.g., not exercising to avoid itching).
Other		
	Acceptance	Comments about accepting a skin condition.
	Time	Coming to accept a condition with the passing of time.
	Awareness	General awareness of skin conditions among patients, families, health care services and society. A potential mediator/moderator of impact.
	Medical awareness	The need for better awareness or knowledge of skin conditions in the medical community (e.g., lack of research).
	Before and after	Comments about life before and after the onset of the condition.
	CLCI	Evidence of CLCI or MLCDs.
	Dirty or clean	This code is used to track comments about dirty and clean so that we can see reflect on what this might mean and where it fits later.

	Individual differences	Individual differences or personality traits as a mediator/moderator of impact.
	Normal	Comments about what is “normal”. This can be from the participants’ point of view of normal or how other people perceive normal.
	Services	
	Clash of beliefs	The meeting of opposing beliefs regarding the skin condition. Example: clinicians express a medical belief that is at odds with the cultural beliefs about the skin condition.
	Diagnosis	References to diagnoses of a condition.
	Accuracy	Discussing how accurately clinicians have been able to diagnose the skin condition. For some, they might have had multiple, incorrect diagnoses.
	Timing	Discussing the timing of the diagnosis of the skin condition. Particularly in reference to how quickly a diagnosis is made following symptom onset and the consequences of the time difference between onset and diagnosis. For example, in terms of severity, progression and variability of symptoms.
	Equity of access	Discussing to what extent equity of access to affordable, high quality, culturally and linguistically appropriate care in a timely

		manner exists and whether/how social, economic, demographical, or geographical factors interact with this.
	Individual	Factors related to services on the individual level.
	Access to treatment	Whether the person is personally able to access treatment. For example, whether they are physically capable of attending medical appointments due to disability. (This may be perceived to have consequences for the progression of the condition)
	Information provided by health professionals	Comments about the quality of the information given by clinicians. For example, references made clinicians focusing information only on medical treatments and not discussing triggers.
	Lack of engagement with decision making	Discussing the extent to which clinicians involve or share decision making with people with skin conditions. For example, whether the patient is able to be involved in choosing which treatment is administered or treatment goals.
	Scepticism	A lack of trust or scepticism of services or clinicians. For example, a belief that clinicians purposely behave and manage the condition in a way that brings continued income.
	System	

	Availability of additional support	References to availability of psychological, emotional, mental health support or other types of support related to the management of skin conditions.
	Availability of standard medical care	The extent to which services (e.g., access to dermatologist, treatment etc) are available to people with skin conditions.
	Organisation of care	How, and the extent to which, care is co-ordinated with other services; for example, how well dermatology and rheumatology services are co-ordinated for people with psoriatic arthritis.
	Treatment	
	Discrepancies in goals, outcomes and expectations	Expressions of differences between clinician and patient expectations, goals and appraisal of outcomes.
	Social support	The extent to which friends and family support a person with a skin condition. Social support may be a mediator or moderator of impact.
	Being known	A code to track comments about feeling that the experience of having a skin condition is easier around people they already know as opposed to strangers.
	Tough, struggle or battle	This code is used to track the use of this language so that we can see reflect on what this might mean and where it fits later.
COM-B Model (Michie et al. 2011b)		

Capability		“The individual’s psychological and physical capacity to engage in the activity concerned. It includes having the necessary knowledge and skills.”
	Physical	Behaviour is influenced by the person’s knowledge of and skills to perform it.
	Psychological	Behaviour is influenced by the person’s ability to engage in the necessary thought processes, including understanding the behaviour and reasoning for performing it.
Opportunity		“The factors that lie outside the individual that make the behaviour possible or prompt it.”
	Physical	Behaviour is influenced by a person’s physical environment.
	Social	Behaviour is influenced by a person’s social environment and the social factors that influence how they think about a behaviour (e.g., culture, social norms and language).
Motivation		“Brain processes that energize and direct behaviour, not just goals and conscious decision-making. It includes habitual processes, emotional responding, as well as analytical decision-making.”
	Automatic	Behaviour is influenced by motivation that is automatic, does not require thinking about and arises from our emotions and impulses.

	Reflexive	Behaviour is influenced by motivation that arises from logical thought, evaluation and planning.

IPQ-R, Illness Perceptions Questionnaire – Revised (Moss-Morris et al. 2002)

CLCI, Cumulative Life Course Impairment

MLCDs, Major Life Changing Decisions

COM-B, Capability, Opportunity, Motivation – Behaviour Model (Michie et al. 2011b)

Appendix 5: Open codes derived from thematic analysis of group interview data

Theoretical concept	Codes and sub-codes	Description
Common-Sense Model of Self-Regulation (Leventhal et al. 1984)		
Cognitions	Beliefs about psychological support	Poor understanding of what is meant by psychological support, what it entails or the different types available.
	Beliefs about impact	Comments that suggest a person is unaware of how their condition impacts them or their life, or downplays the extent to which they have been impacted by their condition.
	Identity	
	Blistering	References to blisters on the skin.
	Flaking	References to skin flaking off.
	Scarring	Scarring due to skin condition.
Emotions	Alexithymia	Difficulty identifying or describing emotions.
Coping	Approach coping strategies	
	Downward social comparisons	Perceiving oneself to be in a better or more fortunate position than others as a way of rationalising or coping with a skin condition.
	Personal qualities > appearance	Recognition of personal strengths, values and qualities and valuing these more than physical appearance.

	Body functionality > appearance	Recognition of what the body can do and valuing this more than physical appearance.
	Self-management	General comments about condition self-management, including how self-management impacts people.
	Confidence to self-manage	How confident a person feels in their ability to manage their skin condition(s).
	Definition of self-management	Personal definitions/conceptualisations of self-management.
	How to improve self-management	How to help people to self-manage their skin condition(s) more effectively.
	How to increase personal control	How to help people to feel more in control of their skin condition(s).
	Role models	Seeing or hearing how other people manage their skin condition effectively. This is often associated with an increased sense of confidence in one's ability to self-manage their skin condition.
	Adjustment	Learning to live with a skin condition. This might be referred to as a journey or process that occurs overtime.
Illness coherence	Personal models – health professionals	Beliefs, attitudes, feelings and experiences which, collectively, inform how health professionals perceive and manage skin conditions.
	Personal models – people with skin conditions	Beliefs, attitudes, feelings and experiences which, collectively, inform how people perceive and manage their skin condition(s).
	Knowledge of skin conditions	People with skin conditions do not fully understand their skin condition, associated co-morbidities, or triggers.

Other	Scepticism – information online	Scepticism towards information on self-management on the internet and social media.
	Scepticism – people online	Sceptical of the motives of people online, particularly in relation to selling treatments or products for the skin.
	Acceptance over time	Learning to accept a skin condition over time.
	Acceptance – reluctance	Unwillingness to accept condition. A person may express that they accept their condition, but the language used indicates hesitancy or reluctance.
	Social context	
	Covid-19	Comments about Covid-19 and its impact.
	Stigma around help seeking	Public or self- stigma around seeking support, particularly in relation to mental health.
	Attitudes towards mental health	Existing or changing attitudes towards mental health.
	Services	(Existing code)
	Access to additional support	General comments relating to accessing types of support other than standard medical care, including psychological, emotional, mental health support.
	Additional support – benefits	Advantages, effectiveness or positive experiences of additional support.
	Additional support – negative experience	Disadvantages or negative experiences of additional support.
	Additional support – private	References to accessing additional support in the private sector.
	Additional support – cost	References to the costs of additional support.

	Additional support – unnecessary	The belief that additional support is not needed to live well with a skin condition.
	Additional support – never considered	Comments which indicate that a person has never considered accessing or asking for additional support.
	Additional support – never offered	Comments which indicate that a person has never been offered any form of additional support in relation to their skin condition(s).
	Additional support – never received	Comments which indicate that a person has never received or accessed additional support for their skin condition(s).
	Lack of specialist or dedicated support	Additional support is generic, not tailored to skin conditions.
	Availability of additional support	The extent to which additional support is available to people with skin conditions. For example, differences in the availability of psychodermatology services across countries, or in urban versus rural areas.
	Information from health professionals	The quality of the information given by health professionals, or the topics they focus on during consultations. For example, references made clinicians focusing information only on medical treatments and not discussing triggers.
	Peer support	The role people with skin conditions play in supporting people with the same skin condition.
	Patient organisations	The role of patient organisations in supporting people with skin conditions.
	Online peer support	The role of online peer support in supporting people with skin conditions. This might include groups and influencers on social media or online forums.

Theoretical Framework of Acceptability (Sekhon et al. 2017)		
Affective attitude	Affective attitude	How an individual feels about the idea of the new app, a particular aspect of it (existing code).
	Positive attitude	Positive comments about the app. Could reflect beliefs or emotions.
	Neutral attitude	Remarks about the app that are neither positive or negative. Could reflect uncertainty.
	Negative attitude	Negative comments about the app. Could reflect beliefs or emotions.
Burden	Burden	The perceived amount of effort that is required to engage with the app, or an aspect of it (existing code).
	Mental effort	References to the mental resources required. Relates to cognitive and emotional factors.
	Physical effort	References to the physical effort required.
	Burden on intervention provider	The perceived amount of effort that is required to develop, deliver or maintain the app, or an aspect of it.
No theoretical framework or model		
App development	Engagement	Factors related to how people engage with the app, including perceived barriers and facilitators.
	Focus of app	Preferences for what the app should cover in relation to living well with a skin condition.

	Trustworthiness	How trustworthy the app is considered to be plus factors that might make the app more or less trustworthy.
	Credibility	The extent to which the app and its developers need to be credible.
	Personal data	Views or concerns about inputting personal data into the new app, including perceived barriers and facilitators, and data storage, protection and use.
	Personal choice	The extent to which users have a choice over their use of the app and its settings.
	Flexibility	Use of the app is not prescriptive; users can use the app flexibly as and when they wish.
	Ideas for the app	Ideas for the content, functionality and design of the app.
	Content	Ideas for written, audio, visual and interactive content.
	Design	Suggestions for how the app should look and feel, including the colour schemes, layout, branding, text size and fonts etc.
	Functionality	Comments on technical aspects (e.g., sign up/in process) and features (e.g., algorithms, push notifications) of the app.
	Health behaviours	Ways the app could support health behaviour change.
	Psychological support	Ideas on the types of psychological support that the app could offer.
	Social support	Ideas for how the app could support people socially.
	Name of app	Ideas for the name of the app.
	Tracking function	Comments about tracking or self-monitoring physical symptoms, psychological processes (thoughts, feelings, behaviours) or triggers.

	Language	References to how app content is worded and the extent to which this is important to people. Relates to message framing.

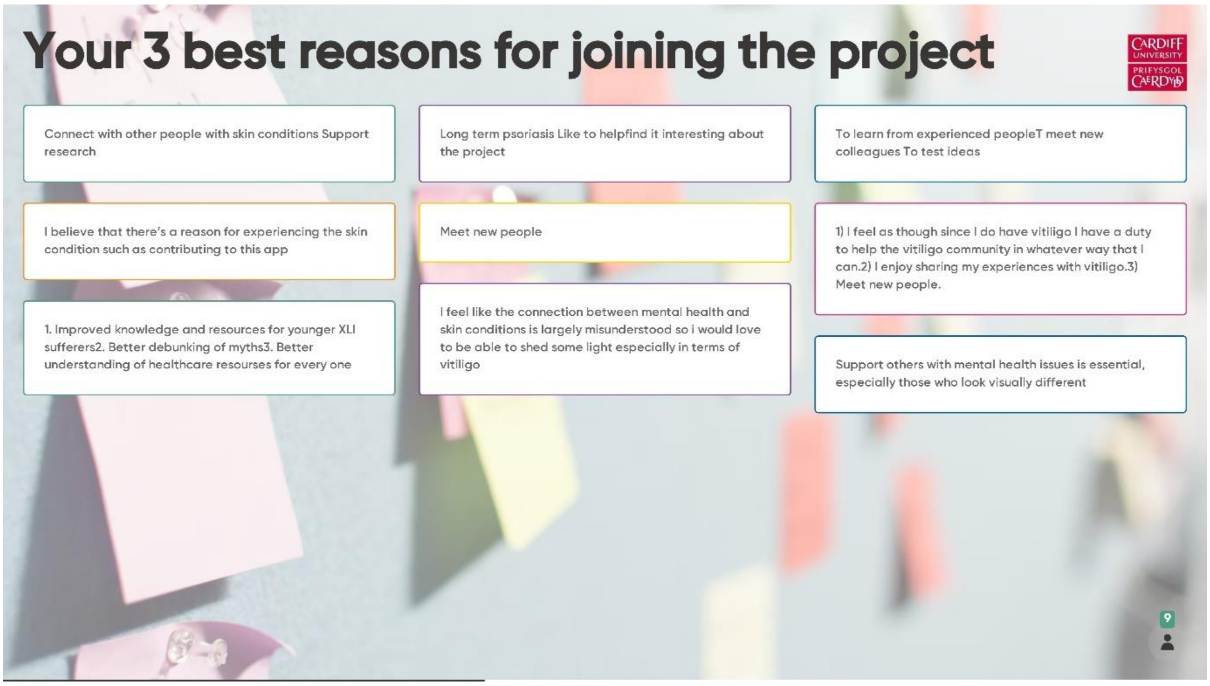
Appendix 6: Patient and Public Involvement group characteristics

Categorial demographic variable	***N***	**%**
Gender		
Female	6	60
Male	4	40
Ethnicity		
White	5	50
Black	2	20
Mixed (black and Latino)	1	10
South Asian	1	10
East Asian	1	10
Age (years)		
18 – 24	2	20
25-29	2	20
30-39	2	20
40-49	1	10
50-59	1	10
60-69	2	20
Skin condition		
Eczema	3	30
Psoriasis	2	20
Vitiligo	2	20
Ichthyosis	1	10
Rosacea	1	10
Acne and Post-inflammatory hyperpigmentation	1	10
Country		
England	7	70
Wales	1	10
Scotland	1	10
USA	1	10
Education level		

Post 16	6	60
Post 18	2	20
Post 21	2	20
House income (per annum)		
21 – 30k	1	10
31 – 40k	1	10
51 – 60k	1	10
61 – 70k	2	20
71 – 80k	1	10
Prefer not to say	2	20

Continuous demographic variables	**Mean**	***SD***	**Minimum**	**Maximum**
Years lived with condition	27.71	19.56	3	64

Appendix 7: PPI welcome meeting – results of Mentimeter activities



Your 3 best reasons for joining the project

Connect with other people with skin conditions Support research

I believe that there's a reason for experiencing the skin condition such as contributing to this app

1. Improved knowledge and resources for younger XLI sufferers2. Better debunking of myths3. Better understanding of healthcare resourses for every one

Long term psoriasis Like to helpfind it interesting about the project

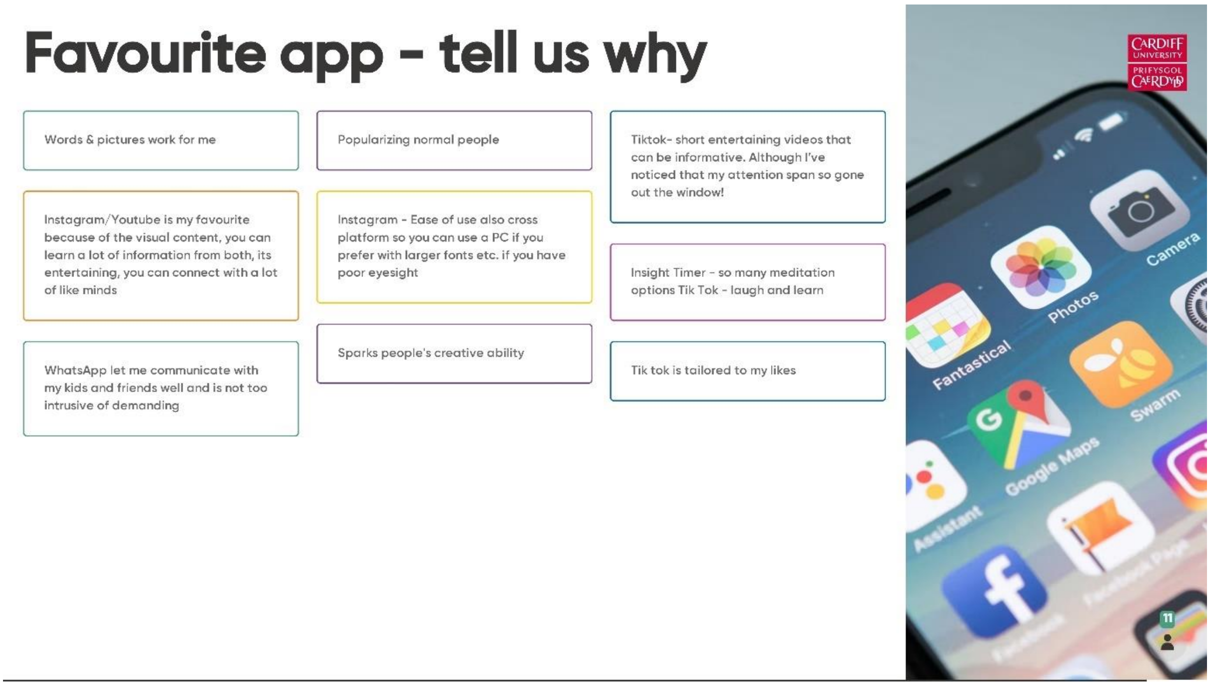
Meet new people

I feel like the connection between mental health and skin conditions is largely misunderstood so i would love to be able to shed some light especially in terms of vitiligo

To learn from experienced peopleT meet new colleagues To test ideas

1) I feel as though since I do have vitiligo I have a duty to help the vitiligo community in whatever way that I can.2) I enjoy sharing my experiences with vitiligo.3) Meet new people.

Support others with mental health issues is essential, especially those who look visually different



Favourite app - tell us why

Words & pictures work for me

Instagram/Youtube is my favourite because of the visual content, you can learn a lot of information from both, its entertaining, you can connect with a lot of like minds

WhatsApp let me communicate with my kids and friends well and is not too intrusive of demanding

Popularizing normal people

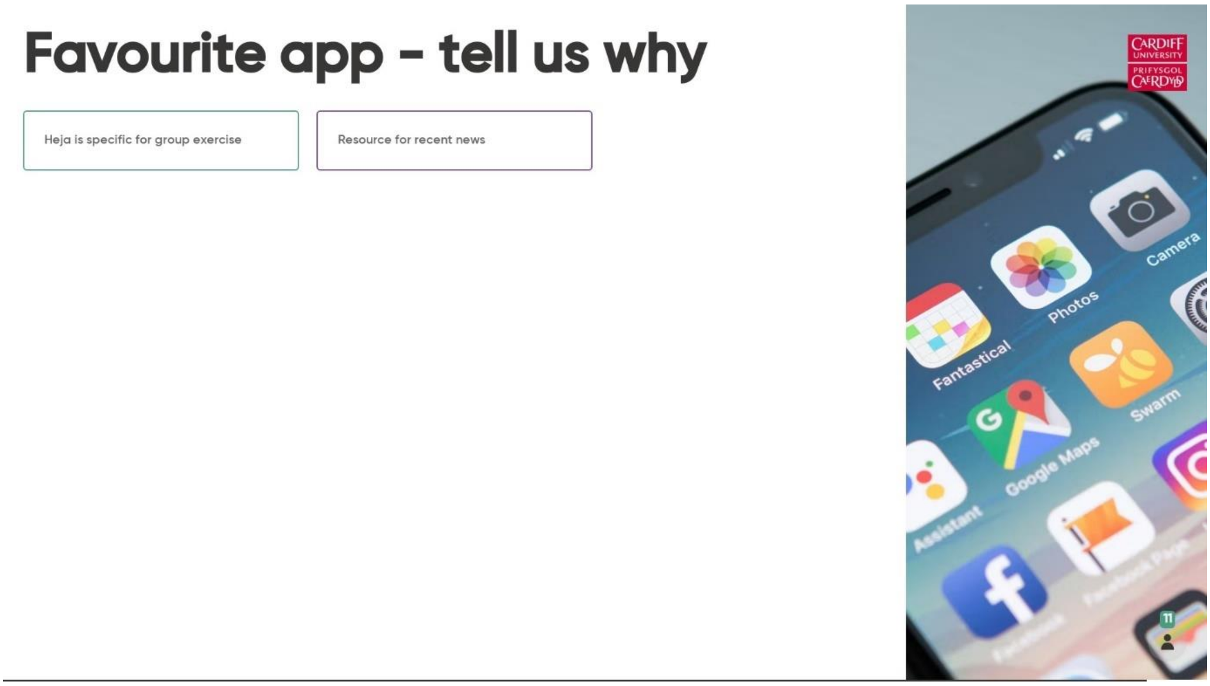
Instagram - Ease of use also cross platform so you can use a PC if you prefer with larger fonts etc. if you have poor eyesight

Sparks people's creative ability

Tiktok- short entertaining videos that can be informative. Although I've noticed that my attention span so gone out the window!

Insight Timer - so many meditation options Tik Tok - laugh and learn

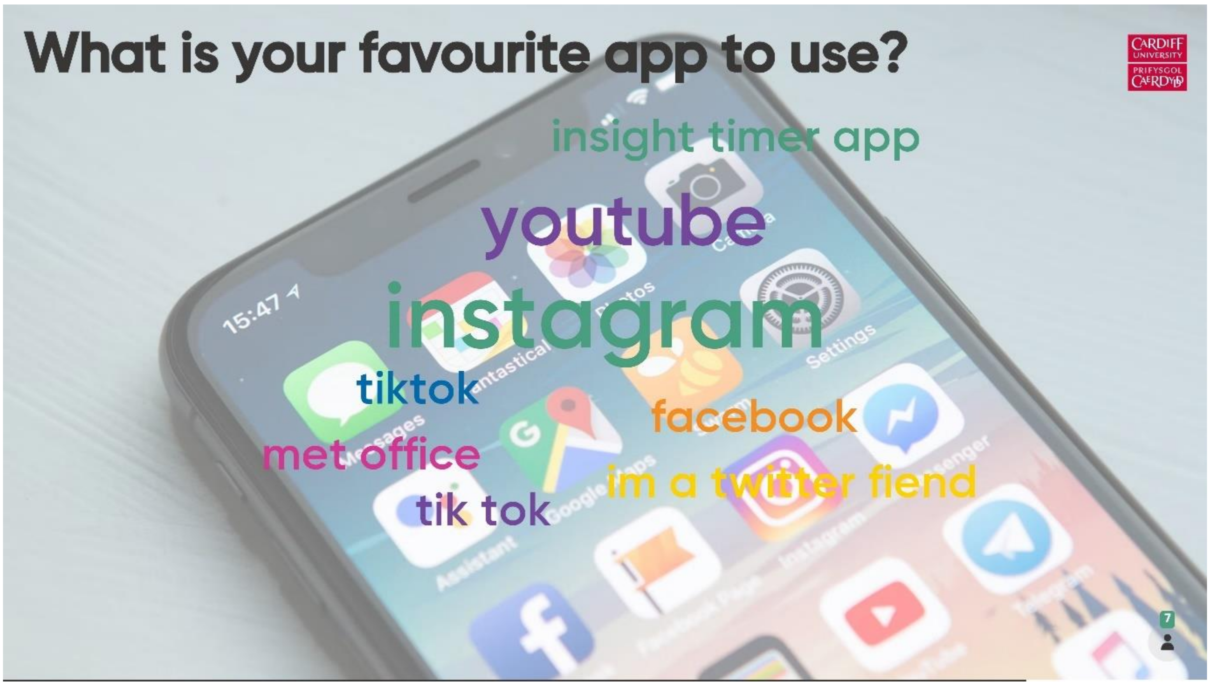
Tik tok is tailored to my likes



Favourite app - tell us why

Heja is specific for group exercise

Resource for recent news



What is your favourite app to use?

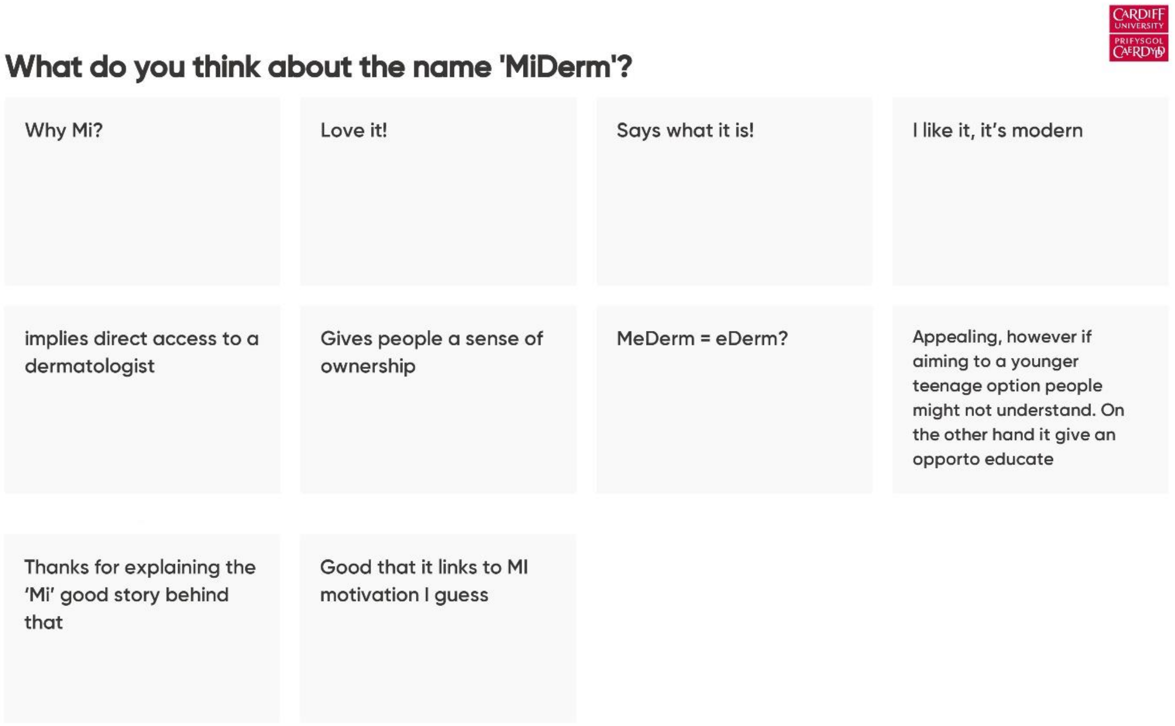
insight timer app
youtube
instagram
tiktok
facebook
met office
im a twitter fiend
tik tok

Name the project/app

confidence
mind the skin
dermablues
skin ease
skinwizz
live
natural
cme
skin smart
skinory
skin clear
free
wise skin
patchwork
dermapp
help

What comes to mind when you think of this project?

23 responses



What do you think about the name 'MiDerm'?

Why Mi?

Love it!

Says what it is!

I like it, it's modern

implies direct access to a dermatologist

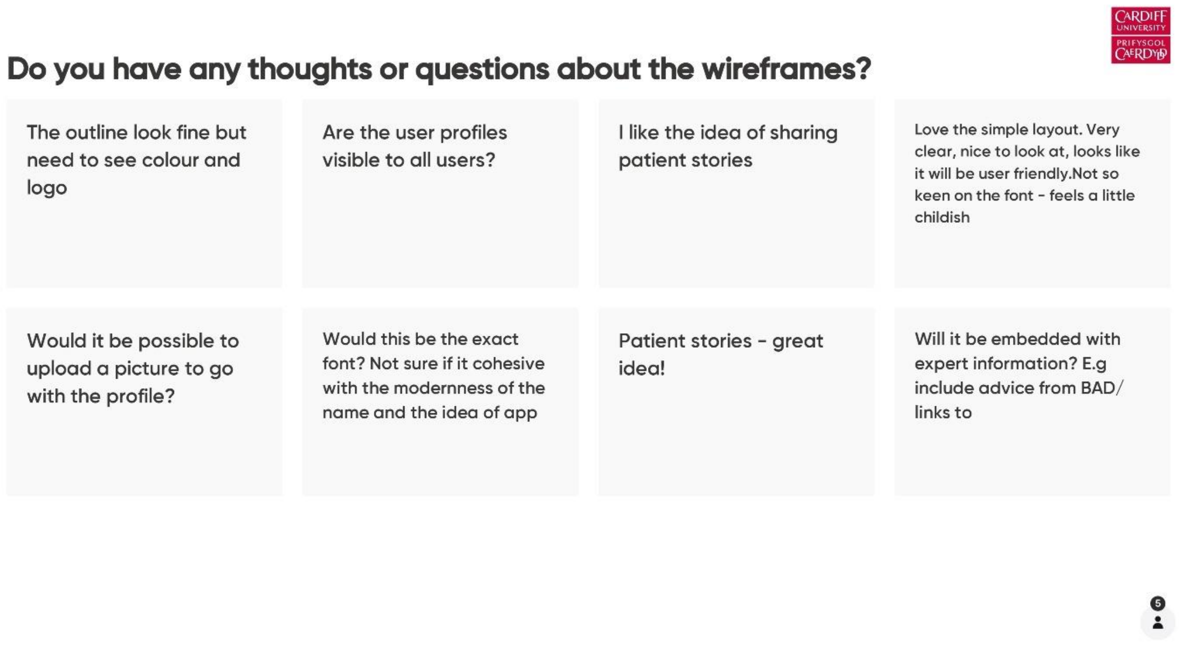
Gives people a sense of ownership

MeDerm = eDerm?

Appealing, however if aiming to a younger teenage option people might not understand. On the other hand it give an opporto educate

Thanks for explaining the 'Mi' good story behind that

Good that it links to MI motivation I guess



Do you have any thoughts or questions about the wireframes?

The outline look fine but need to see colour and logo

Are the user profiles visible to all users?

I like the idea of sharing patient stories

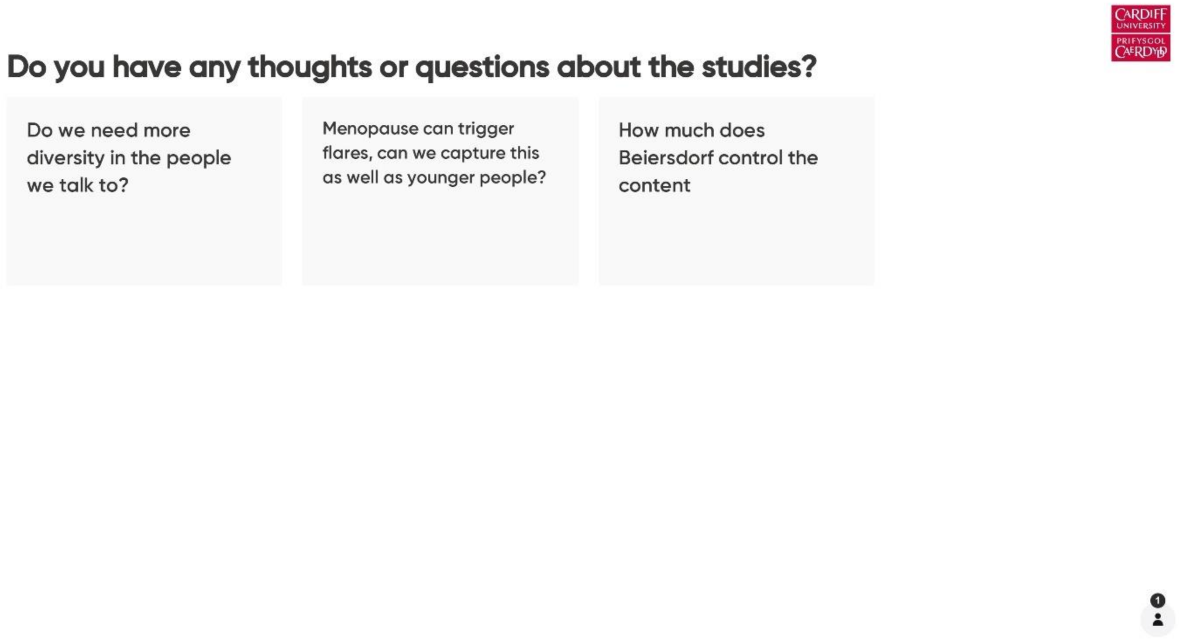
Love the simple layout. Very clear, nice to look at, looks like it will be user friendly.Not so keen on the font - feels a little childish

Would it be possible to upload a picture to go with the profile?

Would this be the exact font? Not sure if it cohesive with the modernness of the name and the idea of app

Patient stories - great idea!

Will it be embedded with expert information? E.g include advice from BAD/ links to



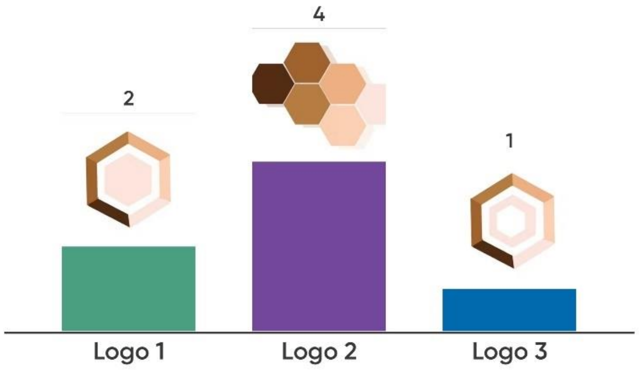
Do you have any thoughts or questions about the studies?

Do we need more diversity in the people we talk to?

Menopause can trigger flares, can we capture this as well as younger people?

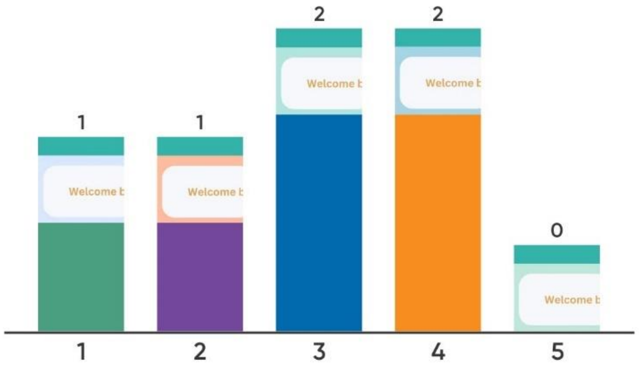
How much does Beiersdorf control the content

Which logo is your favourite?



7

Which colour scheme is your favourite?



6

Appendix 8: Feedback from PPI contributors on topic guide for online group interviews

Comment	Suggested improvements	Change implemented?
The question on impact does not ask if or how impact changes over time.	Include an extra prompt that explores how impact changes across overtime.	Yes, prompt added.
The question about confidence might be interpreted as how confident people feel in themselves (self-esteem) rather than confidence in their ability to self-manage (self-efficacy).	The interviewer should emphasise the focus of the question is on confidence for managing skin conditions and repeat this to the group.	Yes, confidence to self-manage was emphasised.
People are likely to interpret the terms 'self-management' and 'management' differently. Some people in the group perceived these as 'clinical' terms and related them to treating physical symptoms, medication, and skin care.	Prompt people to talk about specific types of impact (e.g., physical, emotional, social etc) or include separate questions on each of the main types of impact. Suggestions for alternative wording were: "I take a holistic approach." "Manging all aspects" /whole condition. "I take a 360 approach to manage my condition." "The changes I make."	Yes, the wording was changed to "managing all aspects of your skin condition."

	“How I deal with it.”	
The phrase ‘reach out to people’ suggests the responsibility and onus is with the individual and this could be a barrier to using the new app.	Rephrase the question to “some people have told us that having access to other people/a community is important.”	Yes, change made.
Questions on the content and features of the app need to be focused. Asking people to think about what apps they use and why could help to direct and focus people’s responses.	Ask people what keeps them coming back to the apps they use already.	Yes, prompt added.
Asking people to rate the different types of impact of skin conditions could be beneficial for benchmarking and prioritising app content.	Ask people to rate different types of impact on a scale from 1 to 10 or state what impacts them most.	Yes, participants were asked to state the biggest impact or the three main impacts.

Appendix 9: Feedback from PPI group members on online survey items

Comment	Suggested improvements	Change implemented?
The survey is too long and 'wordy.' One person said they started reading passively halfway through the list of questions: *"we live in an age now where we are just used to snapshot things really aren't we? [..] er I didn't read it all to be honest, I got a little bit of a way in and just kind of stopped"* (female, acne and scarring).	In part two, include 'managing my skin condition is…' as an opening sentence and remove this wording from each of the individual statements below.	Yes, the wording was removed from individual items and included as the question stem.
One person suggested asking people to state their date of birth, rather than their age, to allow the research team to potentially follow up with people later in the project.	Change the question on age to date of birth.	No, there was a risk that participants could be identified from their date of birth, so this change was not implemented to maintain confidentiality.
There are some conditions, such as ichthyosis, that tend to affect people from birth or a very young age.	Open the survey to carers and parents of people living with skin conditions.	No because the aim of this research is to develop a digital intervention that supports adults to self-manage their skin condition effectively.

There is no need for a 'not relevant' option. Including this option gives people *"a bit of an out"* (female, rosacea).	Remove the 'not relevant' option and any instructions relating to this.	Yes.
Not all questions are applicable to everyone. A male with ichthyosis explained: *"for some types of skin conditions, there won't be medications as such, it will be creams or whatever."*	Include a 'not applicable' response option.	No, this was an oversight on the researcher's part and an earlier version of the survey that did not include the 'not applicable' response option was published.
Wording is important because some words can trigger a bad feeling. For example, some people do not like the word 'illness.'	Change the word 'illness' to 'condition.'	Yes.
The statement 'managing my skin condition is effortful' is vague and not familiar to people. Effortful *"isn't a great word is it really?"* (Male, psoriasis). *"When I saw the word effortful, I know what effortful means, but for me it's probably not a word I would use within my language*" (female, psoriasis).	Replace 'effortful' with 'time consuming' or 'time and effort.'	Yes, the wording was changed to '… takes time and effort.'

The statement 'what I do can determine whether my illness gets better or worse' is difficult to understand. The word control sounds more positive and might be more empowering for people who often feel as though they have had their sense of control has been taken away.	Rephrase as: I control whether my condition gets better or worse.	No, this item was taken from the Brief IPQ (Broadbent et al. 2006) and thus could not be reworded.
Unsure what the term 'patient organisation' means. The individual who made this comment questioned whether patient organisations are related to healthcare and medication.	Give some examples in brackets of existing patient organisations to aid understanding.	No, this question was removed to help reduce the length of the survey.
The word 'rely' is not appropriate, as many people "*receive"* additional support but do not necessarily *rely* on it.	Change the word 'rely' to 'receive' throughout.	Yes.
The type of support people find online is different to that which they might get from a patient organisation. The former relates more to peer support, and it would be	Include an additional statement in part two of the survey: 'I receive support from people online' and include examples of what is meant by online support (i.e., support groups, Facebook pages).	Yes.

interesting to understand how many people receive online support.		
In part two, the statement 'Managing my skin condition impacts how I feel' is vague.	Make this statement specific to physical impact.	Yes, the wording of the item was changed to: *Impacts me physically (e.g., symptoms).* The following item was also included to distinguish between the physical and psychological impacts: *Impacts me psychologically (e.g., my emotions and mood).*
Some of the questions on coping seem repetitive (e.g., two questions about alcohol and drug use, and humour). One individual said people might not read the questions properly and not pay attention to the subtle differences in the questions.	Have one question for each topic to reduce the length of the survey overall. Include a sentence in the introductory paragraph to make people aware that some of the statements are similar and need to be read carefully.	Partly. It was not possible to only include one of the items as these formed part of the Brief COPE (Carver 1997). The following sentence was included in the introductory paragraph: 'Some of the statements below are very similar so please read each statement carefully and tick one box for each statement.'

The statements ‘I’ve been concentrating my efforts on doing something about the situation I’m in’ and ‘I’ve been taking action to try to make the situation better’ are vague and “need to be more direct.”	Suggestions for alternative phrasing: ‘I’ve been concentrating my efforts on doing something about my skin condition.’ ‘I’ve been taking action to try and make my skin condition better.’	No. Unable to make this change because it related to the wording used in the Brief COPE.
The statement ‘I’ve been saying to myself this isn’t real’ seemed strange to a couple of people. The wording was perceived as negative.	Suggestions for alternative phrasing: ‘I’ve been ignoring my skin condition.’ ‘I find it difficult to accept my skin condition.’	No. Unable to make this change because it related to the wording used in the Brief COPE
Unlike the other statements, the statement ‘I’ve been spending time with friends and family’ was not in relation to managing a skin condition.	Add ‘I’ve been spending time with friends and family as a way of coping with my skin condition.’	No, this question was removed because it overlapped with existing items in the Brief COPE and one of the questions in the section on existing support.
Section headings for part two and three are similar, which makes it hard to understand the difference.	Change the wording to make it clearer what each section refers to in order to prompt participants.	Yes.
Not all people join support groups to communicate with others, some people might join a group just to observe what	Change the statement in part five to: ‘… offers the option to *connect* with other people with skin conditions.’	Yes.

others do and share. The word “*connect”* would be more appropriate.		
The question in part five relating to an app that gives people a sense of security did not make sense; it was queried whether an app could make people feel secure.	Consider removing this item.	Yes.

Appendix 10: Mixed methods systematic review of digital psychological interventions in dermatology

A mixed methods systematic review of digital interventions to support the psychological health and well-being of people living with dermatological conditions

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Keywords: systematic review, dermatology, psychology, digital health

Abstract

Background: Dermatological conditions can have a substantial impact on psychological as well as physical health yet dedicated face-to-face psychological support for patients is lacking. Thus, individuals may require additional support to self-manage dermatological conditions effectively.

Digital technology can contribute to long-term condition management, but knowledge of the effectiveness of digital interventions addressing psychological (cognitive, emotional, and behavioural) aspects of dermatological conditions is limited.

Objectives: To identify, determine the effectiveness, and explore people's views and experiences of digital interventions supporting the psychological health of people with dermatological conditions.

Methods: A mixed methods systematic review informed by JBI methodology. The protocol was registered on PROSPERO. Eight electronic databases were searched for papers written between January 2002 and October 2021. Data screening and extraction were conducted in Covidence. The methodological quality of studies were scrutinized against JBI critical appraisal tools. Intervention characteristics were captured using the Template for Intervention Description and Replication checklist and guide. Data were synthesized using a convergent segregated approach. The results were reported in a narrative summary.

Results: Twenty-three papers were identified from 4,883 references, including 15 randomised, controlled trials. Nineteen interventions were condition-specific, 13 were delivered online, 16 involved an educational component, and seven endorsed established, evidence-based therapeutic approaches.

Improvements in knowledge, mood, quality of life, the therapeutic relationship, and reduced disease severity in the short to medium term, were reported, although there was substantial heterogeneity within the literature.

Thirteen studies captured feedback from users, who considered various digital interventions as convenient and helpful for improving knowledge, emotion regulation, and personal control, but technical and individual barriers to use were reported. Use of established qualitative methodologies was limited and, in some cases, poorly reported.

Conclusion: Some web-based digital psychological interventions seem to be acceptable to people living with mainly psoriasis and eczema. Whilst some digital interventions benefitted cognitive and emotional factors, heterogeneity and inconsistencies in the literature meant definitive statements about their effectiveness could not be drawn. Interdisciplinary and patient-centred approaches to research are needed to develop and test quality digital interventions supporting the psychological health of adults living with common and rare dermatological conditions.

Introduction

Dermatological conditions can impact all aspects of life with people commonly reporting psychological, social, financial, occupational, and educational consequences, plus challenges to daily activities, in addition to their physical manifestations (Thompson et al. 2002; Bundy et al. 2014; Johnston et al. 2018; All-Party Parliamentary Group on Skin 2020; Ra et al. 2021; Teasdale et al. 2021; Wheeler et al. 2021). Many individuals living with dermatological conditions consider the psychological impact to be most profound (Ra et al. 2021). In a recent survey of 544 people in the UK with a skin condition, 97.61% revealed that their emotional wellbeing had been negatively affected as a result of the condition (Wheeler et al. 2021). Impaired quality of life (QoL) and a range of mental health issues are recognised in people with dermatological conditions, across the spectrum of psychological conditions, including low mood, anxiety and depression, to suicidality (Ra et al. 2021) psychoses (Cortés et al.). Inter-disciplinary and whole person approaches are, therefore, essential for condition management and improving QoL in people with dermatological conditions (All-Party Parliamentary Group on Skin 2013; British Association of Dermatologists 2013; All-Party Parliamentary Group on Skin 2020).

The 2013 All-Party Parliamentary Group on Skin report called for more integrated and dedicated psychological support within dermatology (All-Party Parliamentary Group on Skin 2013). The most recent iteration showed little positive change over the previous decade, as the provision of specialist psychological support within dermatology settings, and dedicated psychodermatology services, both remain limited (All-Party Parliamentary Group on Skin 2020). In addition, previous research has shown that dermatology staff report lacking confidence in their ability to address the psychological impact of dermatological conditions (Nelson et al. 2014; Nelson et al. 2016) and that some dermatologists still fail to recognize (Chisholm et al. 2016) and manage dermatological conditions as long-term conditions (Hewitt et al. 2022a). Thus, inadequacies in education and training for healthcare professionals on the psychological aspects of dermatological conditions persist (All-Party Parliamentary Group on Skin 2013,2020).

Many people with dermatological conditions report not being able to access psychological services (Wheeler et al. 2021), or being dismissed (Ra et al. 2021) by medical professionals who fail to understand (Wheeler et al. 2021), or even acknowledge (Bundy et al. 2014) the severity of the psychological impact of dermatological conditions. Individuals report dissatisfaction with the quality of care leaving them feeling unsupported and with no choice but to cope with their condition alone (All-Party Parliamentary Group on Skin 2013; Pattinson et al. submitted). Clearly, additional forms of support are needed to help people to live well with dermatological conditions (Manolache and Finlay 2022).

Digital technology has transformed healthcare delivery (van Gemert-Pijnen et al. 2018a), including dermatology (Glines et al. 2020). For example, both asynchronous and synchronous teledermatology is now widely embedded within dermatology service provision (Glines et al. 2020), yet the primary focus has been on the assessment, diagnoses, and monitoring of physical symptoms and treatments (Lee and English 2018; Glines et al. 2020), with little to no consideration given to the psychological impact of that condition on the individual.

Interventions using digital technology using the internet and smartphone applications (apps), have proved to be effective in facilitating the management of other long-term conditions (van Gemert-Pijnen et al. 2018a). For example, people living with type 2 diabetes (Shan et al. 2019) and cancers (Escriva Boulley et al. 2018) consider them a useful and convenient adjunct to standard care that inform, enable and empower individuals to control their health and lifestyle (Kelders and Howard 2018). In the context of dermatology, digital health interventions are limited; some have been developed mainly for skin cancer, focusing on primary prevention (Chuchu et al. 2018b; Ferrante di Ruffano et al. 2018). Digital technology could provide a platform for delivering psychological support to adults with dermatological conditions, but it is not clear what works or what delivery methods are acceptable to this group.

We conducted a mixed methods systematic review to identify existing digital programmes, determine their effectiveness, and explore people's views and experiences of available programmes for supporting the psychological health and well-being of adults living with dermatological conditions.

Methods

The present systematic review was informed by the JBI methodology for conducting mixed method systematic reviews (Stern et al. 2021).

Eligibility criteria

We developed comprehensive inclusion and exclusion criteria to judge the eligibility of papers for inclusion in this systematic review. The criteria were developed a priori based on the results of a preliminary scoping search on the MEDLINE (Ovid) database and were piloted on three papers identified through the initial search. The eligibility criteria were independently applied by RMH and one other reviewer (GHW or OH). The reviewers discussed potential changes and the eligibility criteria were updated prior to application. The full eligibility criteria are outlined below.

Study design

Qualitative, quantitative, and mixed methods studies written in English were included. Systematic reviews, meta-analyses, study and review protocols, commentaries, editorials, grey literature, conference posters, abstracts, and papers on intervention development, were excluded.

Participants

We included studies concerning adults (18+ years) with a clinician- or self- diagnosed dermatological condition, either with or without established comorbidities. Papers focused on children and adolescents, or people with non-dermatological conditions or mental, psychological, psychiatric disorders only, were excluded.

Interventions

Eligible interventions were those designed for patient use, delivered by digital technology, accessed online or offline, and comprised of at least one of the following interactive components:

- Patient-to-patient communication.
- Patient-to-practitioner communication.
- On-demand information services.
- Personal health tracking.
- Targeted communication.

This definition of digital interventions was adapted from an existing definition (Hewitt et al. 2020), which was based on the World Health Organization’s classification (World Health

Organisation 2018a). We extended the existing definition to encompass The Medical Research Council's definition of complex interventions (Craig et al. 2008), see Chapter 8.

Digital interventions for detecting, diagnosing, triaging, or assessing physical symptoms, asynchronous telemedicine, and psychological interventions delivered via telephone or email, were not included in this review.

Comparators

Eligible comparators included none or alternative intervention and standard care.

Outcomes

We prioritised psychological outcomes (cognitive, emotional, and behavioural) and considered other outcomes if they were measured alongside a psychological outcome(s). A non-exhaustive list of examples of eligible outcomes are presented in Table 1.

[Insert Table 1]

Systematic review protocol

The review protocol was registered on PROSPERO in October 2021 (reference number: CRD42021285435).

Search strategy

We ran a preliminary search of MEDLINE (Ovid) on 15th October 2021 to scope the existing literature on the review questions. The scoping exercise helped to ensure there were no current or ongoing reviews on the topic, to refine the aims and eligibility criteria for this systematic review, and to estimate the amount of published work available and, therefore, the resources needed to complete this systematic review. Relevant papers identified from a scoping search of MEDLINE were also used to develop a full search strategy; key words in the titles and abstracts, and the index terms used to describe the papers, these were organised into search strings, with support from a specialist subject librarian (see supplementary material, section 1).

The search period spanned 1st January 2002 to 29th October 2021. We only included papers published from 2002 onwards because this year followed the publication of an influential paper on defining eHealth (Eysenbach 2001), which marked the beginning of a global increase in the implementation of eHealth policy and strategies (World Health Organisation 2016a).

Data sources

We searched the following electronic databases for peer-reviewed material:

- MEDLINE, EMBASE, Emcare, PsycINFO (Ovid).
- CINAHL (EBSCO).
- Scopus.
- Web of Science.

We also conducted a search of the Open Science Framework Preprint Archive for unpublished papers, but no papers relevant to the review questions were retrieved.

Article screening

References were imported into EndNote X9 (Clarivate Analytics USA), and duplicates were removed. References were subsequently imported to Covidence; an online platform designed to support the conduct of systematic reviews. More potential duplicates were identified automatically in Covidence, which were reviewed and later removed by the review team.

A two-step screening process determined the papers included for analysis. Firstly, titles and abstracts of papers were screened against the eligibility criteria. All were screened independently by RMH and one other reviewer (MP, BJ, RP, GHW or OH) using a screening tool developed for the purpose of this systematic review (see supplementary material, section 2). Any conflicts that arose were resolved by a third reviewer (CP, MJR or ART).

The full texts of the remaining papers were screened independently by RMH and another reviewer (MP, BJ, RP, GHW or OH), using the screening tool. The reference lists of full texts were also screened to ensure no potentially relevant papers had been missed. Reasons for exclusion were recorded and one reviewer (RP) was responsible for resolving disagreements at this second stage.

The screening process was reported in the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) 2020 flow diagram (Page et al. 2021).

Data extraction

Data were independently extracted in Covidence by RMH and another reviewer (MP, RP, BJ, GHW or OH). The research team conducted consensus checks and resolved discrepancies through discussion. Intervention characteristics were charted against the Template for Intervention Description and Replication (TIDieR) checklist and guide (Hoffmann et al. 2014), which we adapted to capture for *whom* interventions were intended. Specific intervention features were captured independently by RMH and another reviewer (MP, RP, BJ, GHW or OH) before discrepancies were resolved through team discussion.

Critical appraisal

We assessed the methodological quality of included papers using established JBI critical appraisal tools for the following study designs: Randomised Controlled Trials (RCTs) and quasi-experimental studies (Tufanaru et al. 2020); analytical cross-sectional studies, case reports, and cohort studies (Moola et al. 2020); and qualitative research (Lockwood et al. 2015).

We adopted the method outlined by Edwards and colleagues (Edwards et al. 2016) to judge quality, and included studies were assessed against the pre-determined criteria. Quantitative and qualitative components of mixed methods studies were appraised separately using the appropriate critical appraisal instruments. Each paper received an overall score based on the number of criteria met (13 for RCTs, 10 for qualitative and cohort studies, 9 for quasi-experimental studies, 8 for analytical cross-sectional studies and case reports). Studies scored one for each criterion met and zero for any criterion for which the evidence was unclear. If a criterion was considered not applicable to a particular study, a point was deducted from the overall score; for example, if the total possible score was 10, one was deducted reducing the total possible to 9.

Each paper was assessed independently by RMH and another reviewer (MP, RP, BJ, GHW or OH) and all scores were checked by a third reviewer. For completeness data were extracted from all papers irrespective of their quality score. In addition, each paper was also assigned to a JBI level of evidence for effectiveness (1 = high, 2 = moderate, 3 = low, 4 = very low) or meaningfulness (1 – 5), based on the study design reported (JBI levels of evidence and grades of recommendation working party 2014). The purpose was to support healthcare professionals and others working in this area to form preliminary judgements of the rigour of the evidence presented in this review, and facilitate the implementation of quality evidence based research in clinical and health settings (JBI levels of evidence and grades of recommendation working party 2014).

Data analysis

Papers were imported into NVivo 12 Pro where one reviewer (RMH) conducted a content analysis to synthesise the data. This involved assigning codes to parts of the text which captured study and intervention characteristics and results relating to the main aims. The results of the content analysis were verified by two reviewers (CP and CB). The code book is included as supplementary material (section 3).

One reviewer (RMH) employed a convergent segregated approach to synthesise the data; this involved analysing qualitative and quantitative data separately before integrating the results into a narrative summary (Lizarondo et al. 2020; Lizarondo et al. 2022). The summary was scrutinised by the research team for accuracy.

Results

Study selection and characteristics

We screened 4,883 titles and abstracts and assessed 70 full texts for eligibility. Twenty-three papers met the eligibility criteria and were included in the review (see Figure 1).

[Insert Figure 1]

The characteristics of studies included in this systematic review are presented in Table 2.

[Insert Table 2]

We identified experimental studies, including 15 RCTs (Armstrong et al. 2011; Bundy et al. 2013; Mollerup et al. 2016; van Beugen et al. 2016; Alinia et al. 2017; Hawkins et al. 2017; Lee et al. 2018; Svendsen et al. 2018; Russell et al. 2019; Erdil et al. 2020; Joergensen et al. 2020; Domogalla et al. 2021; Hedman-Lagerlöf et al. 2021; Manne et al. 2021; Zhao et al. 2021), two randomised pilot trials (Balato et al. 2013; Sherman et al. 2019), one quasi-experimental design (Marasca et al. 2020), as well as four observational studies (van Cranenburgh et al. 2015; Koulil et al. 2018; Schuster et al. 2020; Heckman et al. 2021) and one qualitative study (Iliffe and Thompson 2019). The majority of studies were conducted in western countries; 11 in European countries (Balato et al. 2013; van Cranenburgh et al. 2015; Mollerup et al. 2016;

van Beugen et al. 2016; Koulil et al. 2018; Svendsen et al. 2018; Joergensen et al. 2020; Marasca et al. 2020; Schuster et al. 2020; Domogalla et al. 2021; Hedman-Lagerlöf et al. 2021) and six in the USA (Armstrong et al. 2011; Alinia et al. 2017; Hawkins et al. 2017; Lee et al. 2018; Heckman et al. 2021; Manne et al. 2021).

Various sampling approaches were employed. Eleven studies utilized convenience sampling (Armstrong et al. 2011; Balato et al. 2013; van Cranenburgh et al. 2015; van Beugen et al. 2016; Hawkins et al. 2017; Russell et al. 2019; Erdil et al. 2020; Marasca et al. 2020; Domogalla et al. 2021; Manne et al. 2021; Zhao et al. 2021), four studies relied on voluntary sample (Bundy et al. 2013; Joergensen et al. 2020; Schuster et al. 2020; Hedman-Lagerlöf et al. 2021), and one study sampled purposively (Koulil et al. 2018). Six studies used a combination of two sampling approaches (Mollerup et al. 2016; Alinia et al. 2017; Lee et al. 2018; Svendsen et al. 2018; Iliffe and Thompson 2019; Sherman et al. 2019). One study did not clearly state how participants were sampled (Heckman et al. 2021).

Twenty papers stated an eligibility criteria for participants, however, two papers (Iliffe and Thompson 2019; Marasca et al. 2020) did not provide an explicit criteria and one paper noted that the eligibility criteria was reported elsewhere (Manne et al. 2021). Several studies indicated a diagnosis by a clinician as a requirement for inclusion (Bundy et al. 2013; Joergensen et al. 2020; Schuster et al. 2020). Other studies specified people with a 'diagnosis' as an inclusion criterion but failed to clarify whether this was a self- or clinician- diagnosis (van Cranenburgh et al. 2015; Mollerup et al. 2016; van Beugen et al. 2016; Alinia et al. 2017; Hawkins et al. 2017; Koulil et al. 2018; Svendsen et al. 2018; Russell et al. 2019; Sherman et al. 2019; Erdil et al. 2020; Heckman et al. 2021). However, given that research participants were mostly recruited from outpatient dermatology clinics (Armstrong et al. 2011; Balato et al. 2013; van Cranenburgh et al. 2015; Mollerup et al. 2016; Alinia et al. 2017; Hawkins et al. 2017; Erdil et al. 2020; Marasca et al. 2020; Domogalla et al. 2021; Zhao et al. 2021) or using a combination of recruitment methods (van Beugen et al. 2016; Lee et al. 2018; Svendsen et al. 2018; Sherman et al. 2019; Manne et al. 2021), it is reasonable to assume that most studies included people with an established dermatological condition.

Few studies utilised established diagnostic criteria for determining eligibility for inclusion. Two studies relied on criteria for atopic dermatitis; one study (Armstrong et al. 2011) used criteria by Hanifin and Rajka (Hanifin and Rajka 1980) and the other study (Hedman-Lagerlöf et al.

2021) employed The UK Working Party's Diagnostic Criteria for atopic dermatitis (Williams et al. 1994). One study (Lee et al. 2018) determined the eligibility of people with trichotillomania for inclusion using the Diagnostic Statistical Manual of Mental Disorders 5 (DSM-5) criteria (American Psychiatric Association 2013).

A number of studies only included people with determined severity using the following:

- Psoriasis Area Severity Index (PASI) (Fredriksson and Pettersson 1978) score of 5-15 (Balato et al. 2013).
- Mild to moderate psoriasis (Bundy et al. 2013; Svendsen et al. 2018).
- PASI and body surface area scores of >10 (Domogalla et al. 2021) .
- Mild to moderate psoriasis judged as body surface area score of ≤ 10 (Zhao et al. 2021).
- At least moderate severity according to the Patient-Oriented Eczema Measure (POEM) (Charman et al. 2004), defined as scores ≥8 (Hedman-Lagerlöf et al. 2021).

The majority of studies were intended for people with specific dermatological conditions, including:

- Psoriasis (Balato et al. 2013; Bundy et al. 2013; van Beugen et al. 2016; Alinia et al. 2017; Hawkins et al. 2017; Koulil et al. 2018; Svendsen et al. 2018; Schuster et al. 2020; Domogalla et al. 2021; Zhao et al. 2021).
- Atopic dermatitis (Armstrong et al. 2011; Mollerup et al. 2016; Erdil et al. 2020; Joergensen et al. 2020; Hedman-Lagerlöf et al. 2021).
- Melanoma (Russell et al. 2019; Manne et al. 2021).
- Alopecia (Iliffe and Thompson 2019).

One study (Lee et al. 2018) included people with Trichotillomania . Four studies were not condition-specific and were open to people living with different dermatological conditions, including, but not limited to, acne, vitiligo, hidradenitis suppurativa, and lichen-plan-pilaris, plus visible differences such as birthmarks (van Cranenburgh et al. 2015; Sherman et al. 2019; Marasca et al. 2020; Heckman et al. 2021).

One sample included a parent of a person with alopecia (Iliffe and Thompson 2019) and one study recruited dermatologists in addition to patients (van Cranenburgh et al. 2015). Another study described the case of a person with rheumatoid arthritis (Koulil et al. 2018). These data were not included in the paper.

Sample sizes ranged from 2 (Koulil et al. 2018) to 441 (Manne et al. 2021) participants. There were 2,268 participants across the studies and 556 participants were lost to follow-up. The total sample included 933 males and 1,132 females, although two papers did not report gender (van Cranenburgh et al. 2015; Hawkins et al. 2017). An overview of the number of participants and dropouts, as well as the gender and mean age of participants, are presented in supplementary material, section 4.

A wide range of outcomes were studied, and a variety of measurement tools were used. Some psychological outcomes were assessed with established measures. For example, nine studies (Balato et al. 2013; Bundy et al. 2013; Mollerup et al. 2016; Svendsen et al. 2018; Joergensen et al. 2020; Marasca et al. 2020; Schuster et al. 2020; Domogalla et al. 2021; Hedman-Lagerlöf et al. 2021) measured QoL using the Dermatology Life Quality Index (DLQI) (Finlay and Khan 1994). One study (Hedman-Lagerlöf et al. 2021) also used the The Brunnsviken Brief Quality of Life Scale (BBQ) (Lindner et al. 2016), and another study (Lee et al. 2018) employed the Quality of Life Scale (Burckhardt and Anderson 2003). Validated measures of disease severity were also used widely: for example, six studies used the PASI (Fredriksson and Pettersson 1978); three studies (Armstrong et al. 2011; Joergensen et al. 2020; Hedman-Lagerlöf et al. 2021) utilized the POEM (Charman et al. 2004); and four studies (Balato et al. 2013; Bundy et al. 2013; van Beugen et al. 2016; Koulil et al. 2018) collected these data with the Self-Administered Psoriasis Area and Severity Index (SAPASI) (Fleischer Jr. et al. 1999). Several studies used non-validated self-report measures that had been developed for the purpose of the research being undertaken. These measures comprised of Likert (van Cranenburgh et al. 2015; Sherman et al. 2019; Domogalla et al. 2021; Manne et al. 2021), numeric rating (Balato et al. 2013; Mollerup et al. 2016; Alinia et al. 2017; Koulil et al. 2018; Domogalla et al. 2021; Heckman et al. 2021), and visual analogue (Mollerup et al. 2016; Hawkins et al. 2017; Erdil et al. 2020; Hedman-Lagerlöf et al. 2021) scales, as well as multiple choice (Balato et al. 2013; Hawkins et al. 2017; Manne et al. 2021) and true or false questions (Erdil et al. 2020; Manne et al. 2021). Fourteen studies (Armstrong et al. 2011; Bundy et al. 2013; van Cranenburgh et al. 2015; Mollerup et al. 2016; van Beugen et al. 2016; Hawkins et al. 2017; Lee et al. 2018; Svendsen et al. 2018; Iliffe and Thompson 2019; Joergensen et al. 2020; Domogalla et al. 2021;

Heckman et al. 2021; Hedman-Lagerlöf et al. 2021; Manne et al. 2021) specified at least one primary outcome and five studies alluded to a primary outcome (Balato et al. 2013; Alinia et al. 2017; Sherman et al. 2019; Erdil et al. 2020; Marasca et al. 2020; Zhao et al. 2021). The primary outcome could not be inferred for four studies (Koulil et al. 2018; Russell et al. 2019; Erdil et al. 2020; Schuster et al. 2020). All outcome variables studied, and measurement tools used in each study, are presented in supplementary material, section 5.

Eighteen papers (Armstrong et al. 2011; Balato et al. 2013; Bundy et al. 2013; Mollerup et al. 2016; van Beugen et al. 2016; Alinia et al. 2017; Koulil et al. 2018; Lee et al. 2018; Svendsen et al. 2018; Russell et al. 2019; Erdil et al. 2020; Joergensen et al. 2020; Marasca et al. 2020; Domogalla et al. 2021; Heckman et al. 2021; Hedman-Lagerlöf et al. 2021; Manne et al. 2021; Zhao et al. 2021) included baseline measures and follow up periods varied substantially. Three papers conducted follow up immediately post-intervention (Hawkins et al. 2017; Sherman et al. 2019), although one study adopted a cross-sectional design meaning there was no baseline data to compare against (Schuster et al. 2020). Other studies conducted follow up assessments after -four (Joergensen et al. 2020; Marasca et al. 2020; Heckman et al. 2021), six (Russell et al. 2019), eight (van Cranenburgh et al. 2015; Erdil et al. 2020), 12 (Armstrong et al. 2011; Balato et al. 2013; Lee et al. 2018), 24 (Bundy et al. 2013; Mollerup et al. 2016; van Beugen et al. 2016; Koulil et al. 2018), 26 (Svendsen et al. 2018), 48 (Manne et al. 2021), 52 (Alinia et al. 2017; Hedman-Lagerlöf et al. 2021; Zhao et al. 2021), and 60 (Domogalla et al. 2021) weeks post-intervention. Twelve papers assessed key outcomes more than once at the following timepoints:

- 1, 3, 6 and 12 months (Alinia et al. 2017).
- After the 6-week intervention and 12 months (Bundy et al. 2013).
- 12, 24, 36 and 60 weeks (Domogalla et al. 2021).
- 4 and 8 weeks (Erdil et al. 2020).
- 3, 6 and 12 months (Hedman-Lagerlöf et al. 2021).
- 9 weeks and 6 months (Koulil et al. 2018).
- After fifth sessions, immediately post intervention, and 12 weeks following treatment (Lee et al. 2018).
- 8, 24 and 48 weeks (Manne et al. 2021).
- 2 and 4 weeks (Marasca et al. 2020).

- 4, 8, and 26 weeks (Svendsen et al. 2018).
- 6 and 12 months (van Beugen et al. 2016).
- 2, 8, 16, 28, 48, and 52 weeks (Zhao et al. 2021).

Seventeen studies included a comparator (Armstrong et al. 2011; Balato et al. 2013; Bundy et al. 2013; Mollerup et al. 2016; van Beugen et al. 2016; Alinia et al. 2017; Hawkins et al. 2017; Koulil et al. 2018; Lee et al. 2018; Svendsen et al. 2018; Russell et al. 2019; Sherman et al. 2019; Erdil et al. 2020; Joergensen et al. 2020; Domogalla et al. 2021; Hedman-Lagerlöf et al. 2021; Manne et al. 2021; Zhao et al. 2021), mostly standard medical care (van Beugen et al. 2016; Koulil et al. 2018; Russell et al. 2019), including drug treatments (Alinia et al. 2017; Svendsen et al. 2018), physical examinations (Manne et al. 2021), and written information about the condition of interest and treatment (Armstrong et al. 2011; Mollerup et al. 2016; Hedman-Lagerlöf et al. 2021). Other control conditions included:

- A waitlist control group (Bundy et al. 2013; Lee et al. 2018).
- Use of electronic treatment dispensary caps (Svendsen et al. 2018).
- In-person follow-up visits (Domogalla et al. 2021).
- A standard writing activity (Sherman et al. 2019).
- No intervention (Hawkins et al. 2017; Erdil et al. 2020).
- A matched control group (Balato et al. 2013).
- Daivobet® (treatment) plus a mobile app without proactive communication with a doctor (Zhao et al. 2021).

One study included two control groups; use of memory buttons only and no intervention (Joergensen et al. 2020).

Methodological quality

Scores for methodological quality are presented in Table 3 (supplementary material, section 6). Total quality scores ranged from two to 10, indicating that no paper met every criterion for their study design.

Levels of evidence

As for levels of evidence for effectiveness, papers were ranked to levels 1 (n = 16), 2 (n = 2), 3 (n = 1), and 4 (n = 2). Rankings ranged from level 1c (high quality) to 4d (very low quality). The two studies involving established qualitative methodology were both ranked to level 3 for meaningfulness (Mollerup et al. 2016; Iliffe and Thompson 2019). Levels of evidence of effectiveness and meaningfulness are presented in Table 4 (supplementary material, section 7).

Risk of bias

Seven papers (Armstrong et al. 2011; Alinia et al. 2017; Svendsen et al. 2018; Domogalla et al. 2021; Heckman et al. 2021; Hedman-Lagerlöf et al. 2021; Zhao et al. 2021) reported potential conflicts of interest and fourteen papers (Balato et al. 2013; Bundy et al. 2013; van Cranenburgh et al. 2015; Mollerup et al. 2016; van Beugen et al. 2016; Alinia et al. 2017; Koulil et al. 2018; Iliffe and Thompson 2019; Russell et al. 2019; Sherman et al. 2019; Erdil et al. 2020; Joergensen et al. 2020; Marasca et al. 2020; Schuster et al. 2020; Manne et al. 2021) declared none. Two papers provided no information on this (Hawkins et al. 2017; Lee et al. 2018).

Six studies were funded by pharmaceutical companies (van Cranenburgh et al. 2015; Alinia et al. 2017; Joergensen et al. 2020; Domogalla et al. 2021; Heckman et al. 2021; Zhao et al. 2021), seven by public bodies (Balato et al. 2013; Bundy et al. 2013; Mollerup et al. 2016; Iliffe and Thompson 2019; Schuster et al. 2020; Hedman-Lagerlöf et al. 2021; Manne et al. 2021), and three studies were funded by a combination of private and public organisations (van Beugen et al. 2016; Koulil et al. 2018; Svendsen et al. 2018). Seven papers did not provide any funding information (Armstrong et al. 2011; Hawkins et al. 2017; Lee et al. 2018; Russell et al. 2019; Sherman et al. 2019; Erdil et al. 2020; Marasca et al. 2020).

Blinding procedures were often poorly described or absent in reports of RCTs; in total, five papers explicitly described blinding procedures for participants (Armstrong et al. 2011; Sherman et al. 2019; Hedman-Lagerlöf et al. 2021) and treatment providers (Balato et al. 2013; Joergensen et al. 2020), and only one paper covered blinding procedures for outcome assessors (Balato et al. 2013).

Intervention characteristics

Intervention characteristics are presented according to the TIDieR checklist and guide (Hoffmann et al. 2014) in supplementary material, section 8. All interventions but one (Iliffe and Thompson 2019) were intended for individual use. Most interventions were delivered online via the internet (Armstrong et al. 2011; Bundy et al. 2013; van Cranenburgh et al. 2015; van Beugen et al. 2016; Hawkins et al. 2017; Koulil et al. 2018; Russell et al. 2019; Sherman et al. 2019; Heckman et al. 2021; Hedman-Lagerlöf et al. 2021; Manne et al. 2021), including the social media platform Facebook (Iliffe and Thompson 2019; Schuster et al. 2020). Five interventions utilized mobile technologies, including text messaging (Balato et al. 2013; Erdil et al. 2020) and mobile apps (Zhao et al. 2021), or video conferencing software (Lee et al. 2018; Marasca et al. 2020). Five interventions comprised of two modes of delivery:

- Electronic medication canisters for monitoring psoriasis treatment, plus online reporting of disease status (Alinia et al. 2017), or treatment information and reminders sent via a mobile app (Svendsen et al. 2018).
- Memory buttons and a mobile app for monitoring eczema treatment (Joergensen et al. 2020).
- Face-to-face education with an app for monitoring psoriasis (Domogalla et al. 2021).
- Face-to-face counselling and a website providing education, self-monitoring, and asynchronous communication for people with hand eczema (Mollerup et al. 2016).

Most interventions did not require a provider due to the focus on patient self-management. However, where involved, intervention providers included psychologists (van Beugen et al. 2016; Hedman-Lagerlöf et al. 2021), advanced graduate students supervised by a licensed psychologist (Lee et al. 2018), dermatology specialists (Domogalla et al. 2021), and nurses (Mollerup et al. 2016). The digital components of two interventions were not led by a provider (Mollerup et al. 2016; van Beugen et al. 2016) and two papers did not describe the provider (Koulil et al. 2018; Marasca et al. 2020). Only three papers gave sufficient detail about of the background, expertise, and suitability of the people responsible for intervention delivery (van Beugen et al. 2016; Lee et al. 2018; Hedman-Lagerlöf et al. 2021).

Most interventions provided educational content on dermatological conditions and their management (Armstrong et al. 2011; Balato et al. 2013; Bundy et al. 2013; Mollerup et al. 2016; Hawkins et al. 2017; Koulil et al. 2018; Erdil et al. 2020; Domogalla et al. 2021; Hedman-Lagerlöf et al. 2021; Manne et al. 2021; Zhao et al. 2021) or:

- Psychological or social factors and coping (Bundy et al. 2013; van Cranenburgh et al. 2015; van Beugen et al. 2016; Hedman-Lagerlöf et al. 2021).
- Biological, psychological and social factors related to itch (Heckman et al. 2021).
- Psychological factors related to trichotillomania and techniques for changing related cognitions and habits (Lee et al. 2018).
- Mindfulness (Russell et al. 2019).

Other features of digital interventions included:

- Text or email reminders prompting treatment (Balato et al. 2013) (Erdil et al. 2020; Zhao et al. 2021) or intervention use (Mollerup et al. 2016; Russell et al. 2019; Heckman et al. 2021).
- General assignments (Bundy et al. 2013) and activities, for example, meditation (Russell et al. 2019) and writing a self-compassionate letter to oneself (Sherman et al. 2019).
- Contact with intervention providers (Mollerup et al. 2016; Koulil et al. 2018; Lee et al. 2018; Domogalla et al. 2021; Hedman-Lagerlöf et al. 2021; Zhao et al. 2021) or patients (Mollerup et al. 2016; Iliffe and Thompson 2019; Schuster et al. 2020).

Some interventions offered tailored content, including:

- Modules, assignments (Mollerup et al. 2016) and feedback, and goal setting (van Beugen et al. 2016; Koulil et al. 2018).
- Tracking physical (Mollerup et al. 2016; Alinia et al. 2017; Domogalla et al. 2021; Manne et al. 2021) and psychological (Domogalla et al. 2021) symptoms or treatment activity (Svendsen et al. 2018; Joergensen et al. 2020).
- Allowing users a choice of modules to complete (van Cranenburgh et al. 2015) and respecting personal treatment preferences (Joergensen et al. 2020).
- Individual counselling (Mollerup et al. 2016).
- Encouragement to verbalise reasons for performing sun protection behaviours and developing action plans (Manne et al. 2021).

Whilst intervention development was not the focus of this systematic review, we noted any descriptions of the theoretical foundations on which digital interventions were developed.

Seven interventions endorsed established, evidence-based therapeutic approaches, including:

- Cognitive Behavioural Therapy (CBT) for psoriasis (Bundy et al. 2013; van Beugen et al. 2016; Koulil et al. 2018) or eczema (Hedman-Lagerlöf et al. 2021).
- Acceptance and Commitment Therapy (ACT) Enhanced Behavior Therapy for trichotillomania (Lee et al. 2018).
- Self-compassion and written emotional disclosure (Sherman et al. 2019).
- A mindfulness-based programme for melanoma (Russell et al. 2019).
- Habit reversal (Koulil et al. 2018; Lee et al. 2018).

Five of these digital interventions were based on existing protocols for face-to-face interventions (Bundy et al. 2013; van Beugen et al. 2016; Koulil et al. 2018; Lee et al. 2018; Hedman-Lagerlöf et al. 2021). The authors of the written disclosure intervention (Sherman et al. 2019) had adapted it from an existing intervention for breast cancer survivors. The web-based mindfulness programme (Russell et al. 2019) was built on a systematic review and the findings of a survey examining knowledge, attitudes and practices of meditation in people with melanoma.

In addition, parts of a web-based intervention (Heckman et al. 2021) were based on the Biopsychosocial Model of chronic itch (Verhoeven et al. 2008) and offered 'cognitive-behavioural strategies' for coping. One paper referenced using the Preventative Health Model (Myers et al. 1994) as a conceptual framework on which potential mechanisms of intervention effect could be based (Manne et al. 2021).

Other digital interventions were developed from:

- Expert medical knowledge of atopic dermatitis and its management (Armstrong et al. 2011).
- An existing educational intervention for psoriasis (Domogalla et al. 2021).
- A model of a German Tertiary Individual Prevention (TIP) clinical programme (Mollerup et al. 2016).
- 'Previous research conducted by the research team', including prototype testing of the electronic foam dispensers (SmarTop™) and smartphone app (MyPso SmarTop™) (Svendsen et al. 2018).

- An existing dermatology-specific measure of QoL (van Cranenburgh et al. 2015) called Skindex-29 (Chren et al. 1996).

Three studies utilised existing digital technologies as part of their intervention, these included:

- Medication Event Monitoring System (MEMS®) caps (Alinia et al. 2017).
- Memory buttons and a mobile app (Joergensen et al. 2020).
- A commercially available smartphone app (Zhao et al. 2021).

The details of the development of some digital interventions were limited or absent from papers. For example, one text-based intervention delivered generic informational and motivational text messages to people with psoriasis, which were based on frequently asked questions and general recommendations for managing psoriasis, but the authors of the paper (Balato et al. 2013) did not give detail, including whether the motivational messages were underpinned by an existing theory or model of motivation. Another (Joergensen et al. 2020) drew links between their combined digital intervention and the Health Belief Model (Hochbaum et al. 1952), in the discussion section of the paper, but did not expand on this anywhere in the methods section. One study developed an educational video on psoriasis onto an existing educational website for people with dermatological conditions, but no description of the development process was provided (Hawkins et al. 2017). The protocol for one intervention offering individual psychological video consultations was also not described (Marasca et al. 2020).

Results of intervention effectiveness

There were small bodies of evidence supporting the effectiveness of digital interventions for improving some 'psycho-educational' outcomes, particularly knowledge (Armstrong et al. 2011; Hawkins et al. 2017; Erdil et al. 2020), mood (Koulil et al. 2018; Sherman et al. 2019; Heckman et al. 2021), the therapeutic relationship (Balato et al. 2013; Koulil et al. 2018; Lee et al. 2018) to name a few.

The outcome variables studied and the associated findings for each study are presented in supplementary material, section 9. We also recorded results relating to intervention usage, which are reported in supplementary material, section 10.

Knowledge

The three studies (Armstrong et al. 2011; Hawkins et al. 2017; Erdil et al. 2020) that assessed knowledge all reported significant improvements. One study found a significant improvement (*p*=.007) in the average knowledge scores between intervention (11/14) and control (9/14) groups immediately post-intervention (Hawkins et al. 2017).

Similarly, another study (Armstrong et al. 2011) showed significant improvement in knowledge in people who watched an educational video versus those who were given a pamphlet on atopic dermatitis at 12 weeks (3.05 vs 1.85, *p*=.011).

One study (Erdil et al. 2020) reported significant improvements in the knowledge level of people who did (14.8+3.4) and did not (14.6+3.9) receive a text-based intervention from baseline to four week follow up (*p*<.001 for both groups), although there was no significant difference in the change in knowledge levels between the two groups (*p*=.23).

Mood

All three studies (Koulil et al. 2018; Sherman et al. 2019; Heckman et al. 2021) measuring affect detected positive results. One study (Heckman et al. 2021) observed significant improvements in mean scores on the emotion subscale of ItchyQoL in people with atopic dermatitis, psoriasis and chronic itch through an educational website called Interactive Toolbox of Comprehensive Health Resources to Enhance Living with Itch (ITCH RELIEF) from baseline to one month (33.4 vs 31.5, *p*<.01). A case report of an individual with psoriasis who received Internet-based CBT (ICBT) reported an improvement of at least 30% in negative mood from baseline to post-intervention, and at six month follow up (Koulil et al. 2018). Similarly, individuals living with visible skin conditions demonstrated a significant improvement in mean scores for negative (baseline: 24.06+7.90 vs follow up: 22.21+8.20, *p*=.028), but not positive affect, immediately after taking part in an online self-compassion writing activity, compared to those who participated in a standard online writing activity (Sherman et al. 2019).

Therapeutic relationship

Four studies (Balato et al. 2013; van Beugen et al. 2016; Koulil et al. 2018; Lee et al. 2018) addressed the therapeutic relationship between patients and practitioners. Three of these studies indicated that different types of digital interventions can at least maintain (Lee et al. 2018), if not improve (Balato et al. 2013; Koulil et al. 2018), good working relationships between people with skin conditions and practitioners. One study (Lee et al. 2018) found mean scores for agreement on tasks and goals and the emotional ‘bond’ between participants and practitioners before and after treatment were higher than original scores, but no p valued was stated. The second study (Koulil et al. 2018) reported improvements in mean scores pre and post ICBT intervention for agreement on treatment tasks (4.25 vs 4.75) and goals (4.5 vs 4.75) yet no p value was reported. The third study (Balato et al. 2013), however, did not report the statistics or p values used to test this variable. The final study found that positive perceptions of the therapeutic alliance at the outset of ICBT treatment predicted significant improvements in physical (p=.02) and psychological (p<.001) outcomes (van Beugen et al. 2016).

Anxiety

Five studies explored anxiety and reported mixed results. One study (Bundy et al. 2013) observed a significant reduction in mean anxiety scores from baseline (7.6+3.6) to six month follow up (6.1+3.5) in people with psoriasis compared to controls (p<.05), whereas two studies reported no group differences in general anxiety scores (p=.24) (Hedman-Lagerlöf et al. 2021) or anxiety as a composite component of psychological functioning (p≥.20) (van Beugen et al. 2016). One study (Koulil et al. 2018) found improvement of at least 30% in anxiety scores post ICBT treatment but were not maintained long-term follow up, although no significance value was reported. A significant improvements in anxiety scores were found in another study (Domogalla et al. 2021) after 12 (p=.02) and 24 weeks (p=.01) but not after 36 (p=.08) or 60 (p=.06) weeks.

Depression

Similarly, the evidence for depression varied. Significant between-group differences (reductions) in depressive symptoms were reported in people with psoriasis (p<.05) (Domogalla et al. 2021) and atopic dermatitis (p=.008) (Hedman-Lagerlöf et al. 2021) from baseline to 12 weeks post treatment.

Another study (Bundy et al. 2013) found that the proportion of people with psoriasis who were considered to be clinically depressed fell from 15.5% to 2.3% following the eTIPs intervention, yet the difference in depression scores between the intervention and control groups was not statistically significant for either the complete cases (p=.088) or following multiple imputation analysis for missing data (*p*=.34). In addition, no significant differences in depression were found between participants who received ICBT and those who did not from baseline to post treatment or 6 month follow up (*p*≥.20) (van Beugen et al. 2016). One individual with psoriasis showed an improvement in depression of at least 30% from baseline to post treatment assessment, but no significance value was stated (Koulil et al. 2018).

Treatment adherence and compliance

Eight studies measured adherence to treatment (Balato et al. 2013; van Beugen et al. 2016; Alinia et al. 2017; Hawkins et al. 2017; Koulil et al. 2018; Svendsen et al. 2018; Erdil et al. 2020; Zhao et al. 2021). The first study (Alinia et al. 2017) found post-treatment rates of adherence were significantly higher for participants in the internet survey group compared to the control group from the first to the tenth month (*p*=.03), after which adherence rates declined for both groups. The second study (Balato et al. 2013) found that treatment adherence increased in the experimental group only from 3.86 days per week at enrolment to 6.46 days per week following the text message intervention (*p*<.01). Another study (Hawkins et al. 2017) reported that participants were not more likely to report using their medication as prescribed after accessing an educational psoriasis website (no significance value given). The next study (Svendsen et al. 2018) found, according to the main analysis of chip adherence data, more patients in the intervention group were adherent than patients in the non-intervention group (65% vs. 38%, *p*=.004). This study also claimed that patient reported adherence to cutaneous foam was higher in the intervention group (14%) compared to the control (8%) after one month, but the difference was not statistically significant (*p*=.069) (Svendsen et al. 2018). One study (Zhao et al. 2021) found that 13/41 (31.7%) participants who completed a follow up survey at week 12 reported using Daivobet® sometimes or never in the previous four weeks. Three studies (van Beugen et al. 2016; Koulil et al. 2018; Erdil et al. 2020) referred to treatment compliance. One study (Erdil et al. 2020) found no statistically significant difference between the number of participants in the text-based intervention and control groups who forgot to use their medication (52.9% vs 64.7%, *p*=.33). No significant change in the maximal treatment compliance score was observed in an individual with psoriasis from pre to post intervention or follow up (Koulil et al. 2018). Nor did treatment compliance differ significantly between participants who received ICBT or standard care at pre, post or follow up assessment (*p*≥.25) (van Beugen et al. 2016).

Skin protection behaviours

As for skin protection behaviours, one study detected significant improvements in moisturiser use from baseline to weeks 4 (*p*<.001) and 8 (*p*=.020), in the text-based intervention group (Erdil et al. 2020), although the use of moisturiser was significantly higher in the intervention versus control group at week 4 only (*p*=.008). In another study (Mollerup et al. 2016) people with hand eczema who received a combined face-to-face counselling and website intervention reported a significant change in the mean scores for performing habits relating to their condition (e.g., using topical steroids and consulting General Practitioner) compared to participants who did not have access to the website (7.9+2.4 vs 6.6+3.2, *p*=.024). This was the case for people with melanoma who participated in the mySmartSkin intervention, who reported performing significantly more sun protection behaviours on average at 24 weeks (i.e., sunscreen use, wearing hats and long sleeves, and seeking shade) compared to controls (3.54+.74 vs 3.37+.84, *p*=.031) (Manne et al. 2021). Greater knowledge of melanoma and increased self-efficacy both partially mediated the relationship between intervention use and performing sun protection behaviours (Manne et al. 2021). Two studies recorded scratching behaviour using different measures; one study reported significant within-group reductions from baseline to one month follow up in mean scores for scratch intensity (12.3 vs 11.6, *p*<.05) and impact (19.8 vs 17.9, *p*<.001), and sleep-related itch and scratch (37.4 vs 133.3, *p*<.001) (Heckman et al. 2021). The other study (Koulil et al. 2018) reported a reduction in scratching behaviour in a person with psoriasis, but the authors did not specify whether the change reached the threshold for statistical significance.

Physical outcomes

A similar picture was observed for physical outcomes. There was clear evidence for improving disease severity in the short term (1-3 months). One study (Alinia et al. 2017) detected significant improvements in PASI, but not Investigator Global Assessment, scores between the intervention and control group after one (1.61 vs –0.12, *p*=.003), three (2.50 vs 0.79, *p*=.025) and 12 (3.32 vs 0.34, *p*=.038) months. Another study (Svendsen et al. 2018) found a significant improvement in psoriasis severity in the intervention group from baseline to week 4. One study found no significant difference between SAPASI scores of participants who tested the eTIPs intervention and those who did not for either the complete cases (*p*=.67) data or multiple imputation analysis for missing data (*p*=.92) (Bundy et al. 2013). Significant mean reductions in hand eczema severity scores were seen after 8 weeks in participants who received a text message intervention compared to the control group (70.2%+35.2 vs 38.9%+67.7, *p*=.017) (Erdil et al. 2020). At 12 weeks, greater improvements in the severity of atopic dermatitis were observed in people who viewed an educational video online compared to those who read an educational pamphlet (3.30 vs 1.03, *p*=.0043) (Armstrong et al. 2011). Following receipt of a text-based intervention, people with psoriasis also reported significantly reduced (*p*<.05) disease severity (PASI, SAPASI, Physician Global Assessment (PGA), and body surface area) at 12 weeks compared to controls (Balato et al. 2013). Lastly, significantly larger reductions (*p*<.005) in scores of objective measures of disease severity (EASI and SCORAD) were observed in people who received electronic memory buttons plus an app, compared to the two control groups, as was a significant decrease (*p*<.05) in subjective POEM scores at the second consultation approximately one month after participants began using the intervention (Joergensen et al. 2020).

Evidence for effectiveness beyond 6 months was mixed. One study (Alinia et al. 2017) observed a significant improvement in PASI scores in the intervention group at 12 month follow up compared to the control group (3.32 vs. 0.34, *p*=.038) until alcohol use and smoking status were included in the analysis as covariates. Similarly, people with eczema who trialled ICBT showed a significantly greater reduction (*p*<.001) in average weekly symptoms measured by POEM at 12 month follow up compared to the control group (Hedman-Lagerlöf et al. 2021). Another study showed that clinician-assessed disease severity worsened slightly between baseline and 6 month follow up but no significance value was reported (Koulil et al. 2018). One study did not detect a significant difference (*p*=.16) in median HECSI scores of website and non-website users (Mollerup et al. 2016).

Improvements in psoriasis severity were noted in the longer term in two studies; the first study (Domogalla et al. 2021) reported significant reductions (*p*<.001) in PASI scores in all patients from baseline to follow up at week 60, but no group effect was found. The second study (Svendsen et al. 2018) found that the greater improvement in psoriasis severity, measured by the LS-PGA, that was observed in the intervention group in the short term, no longer reached the threshold for statistical significance at week 8 or 26.

Reductions in itch were also seen at 4 weeks (*p*<.001) (Heckman et al. 2021), after 6 months (*p*=.052) (Mollerup et al. 2016) and 12 months in people with atopic dermatitis (*p*=.01)

(Hedman-Lagerlöf et al. 2021). One study (Domogalla et al. 2021) found itch significantly reduced in all participants with psoriasis after 60 weeks, although the difference between the groups was not statistically significant. One study did not control for use of itch medication (Heckman et al. 2021).

Quality of life (QoL)

As for QoL, two studies (Marasca et al. 2020; Heckman et al. 2021) reported significant within-group differences from baseline to four week follow up. The first study was specific to itch-related QoL (78.9, 95%, confidence interval [CI] = 75.9-81.9) to follow up (75.4, CI = 72.4-78.5), *p*=0.007) (Heckman et al. 2021). The second study employed the DLQI (4.4+3.9 vs 1.6+2.5, *p*<.05).

Three studies detected significant between-group differences in QoL favouring the intervention group, from baseline to week six (*p*=.042) (Bundy et al. 2013), week 12 (*p*<.05) (Balato et al. 2013), and after six months (*p*=.014) (Mollerup et al. 2016). One study (Hedman-Lagerlöf et al. 2021) found a significant between-group difference in QoL favouring the ICBT intervention group with the BBQ (*p*=.001) (Lindner et al. 2016), but not the DLQI (*p*=.07) (Finlay and Khan 1994).

Two studies (Lee et al. 2018; Domogalla et al. 2021) reported improvements in QoL that did not reach statistical significance. Another study noted a reduction in DLQI scores in the intervention group compared to controls at weeks four and eight, which relapsed at week 26, yet none of these group differences reached the threshold for statistical significance (Svendsen et al. 2018).

Other psychological outcomes

Various psychological concepts were measured in one study only. The high level of heterogeneity in the outcome variables studied meant evidence was often not sufficient to make general claims about specific outcome variables. Statistically significant reductions were found for the following outcomes:

- Perceived helplessness in one individual living with psoriasis (significance value not reported) (Koulil et al. 2018).

- Fear of cancer recurrence in people who received an online mindfulness-based programme, compared to controls (mean difference: −2.55; 95% CI = – 4.43- −0.67; *p*=.008), but only few of these scores fell below the clinical cut-off (≥ 13) (Russell et al. 2019).
- Perceived stress (B = 5.09; 95% CI – 1.96-8.21; z = 3.19; *p*=.001) and sleep problems (B = 3.38; 95% CI = 1.28-5.48; z = 3.15; *p*=.002) in people who received ICBT versus the control group (Hedman-Lagerlöf et al. 2021).
- Trichotillomania severity from pre to post ACT Enhanced Behavior Therapy via telepsychology (slope estimate = -6.13, SE = 1.30, t(58.48) = -4.72, *p*<.001) (Lee et al. 2018).

One study observed a statistically significant improvement in mean self-compassion scores (*p*=.006) in people with visible skin conditions following an online self-compassion writing activity (3.33+.60), compared to those who participated in a standard online writing activity (2.84+.62) (Sherman et al. 2019).

A number of these papers reported trends towards improvement but were not statistically significant. These outcomes included:

- Self-efficacy for managing eczema in website users versus non-website users (*p*=.093) (Mollerup et al. 2016).
- Rumination in people with melanoma following an online mindfulness programme compared to controls (mean difference: −2.76; 95% CI = − 6.67-1.17; *p*=.169) (Russell et al. 2019).
- Impairment in daily activities following an educational session via a psoriasis management smartphone app, and participants in the control group (*p*=.63) (Domogalla et al. 2021).
- Psychological wellbeing of people with skin conditions following psychological video consultations (baseline: 68.5+15; week 4: 77.1+16; no p value reported) (Marasca et al. 2020).
- Psychological flexibility scores post ACT Enhanced Behavior Therapy via telepsychology (F[1, 18] = 3.790, *p*=.068, ω^2 = .064) (Lee et al. 2018).

There were several psychological outcomes for which no significant between-group differences were reported:

- Perceived stress (*p*=.719) or worry (*p*=.814) in people with melanoma who attempted mindfulness and those in the control group (Russell et al. 2019).
- Anxiety, depression and negative mood (all *p*>.20), or psychological functioning overall (*p*=.32), in people with chronic skin conditions following ICBT and those in the control group (van Beugen et al. 2016).
- The rates of hospital visits in people with psoriasis who received a smartphone app with or without prompted communication from doctors (5.2–15.7% vs 7.5–17.0%, *p*>0.05), although older age (50 to 60 years: *P* = .02) and greater body surface area (scores 7 to 10: *p*=.02), were associated with more hospital visits (Zhao et al. 2021).

One case study tracked changes in psychological and social outcomes overtime in someone with psoriasis who received ICBT and found that high and low levels of social support and stigma (respectively), and maximal impact of psoriasis on daily life, remained unchanged from baseline through to follow up (Koulil et al. 2018).

Individual studies also produced mixed findings for specific outcomes. For example, a study of ACT Enhanced Behavior Therapy delivered via video conferencing showed decreases in shame scores that did not differ significantly when comparing the intervention and control groups. However, when the groups were entered into a combined analysis, a significant change in shame scores was observed from post-treatment to follow up only (*p*=.002) (Lee et al. 2018).

Another study used a composite measure of impact on daily life, which was comprised of physical and psychological functioning and role limitations due to physical and emotional health problems, as a measure of impact on daily activities (van Beugen et al. 2016). After 6 months, significant improvements were observed for role limitations due to emotional and physical health problems (both *p*=.04) in individuals receiving ICBT, compared to other participants who received care as usual. The improvement in role limitations due to emotional problems was further enhanced at follow up (*p*=.047). However, no significant difference (*p*≥0.17) in role limitations was found between the groups when baseline values of the dependent variable were included in a secondary analysis.

One study reported that the significant between-group difference in PASI scores favouring the intervention group (*p*=.038) at 12 months no longer reached statistical significance when alcohol consumption and smoking status were controlled (*p*=.07) (Alinia et al. 2017).

Other independent studies included measures of psychological outcomes but were limited for different reasons. Firstly, one study found that higher levels of Facebook envy were associated with lower levels of life satisfaction (standardized coefficient [β] = –0.38, CI = –0.58- –0.16) and happiness (β = –0.36, CI = –0.57- –0.14) in people with psoriasis. This study was cross-sectional and thus Facebook envy and potentially relevant factors could only be measured at one timepoint.

One study measured the average number of minutes that people with melanoma reported meditating per week across a 6-week online mindfulness programme (Russell et al. 2019). This varied greatly from 64 minutes in week 2 to 129 minutes in week 5, but the authors did not test for statistically meaningful differences in the average meditation times at different timepoints.

Lastly, two papers reported measuring psychological outcomes, specifically participants' beliefs about psoriasis (Bundy et al. 2013) and self-efficacy to interact with clinicians (Heckman et al. 2021), but the results for these outcomes were not reported.

User views and experiences

In total, 13 studies explored people's views and experiences of digital psychological interventions (Armstrong et al. 2011; Balato et al. 2013; van Cranenburgh et al. 2015; Mollerup et al. 2016; van Beugen et al. 2016; Hawkins et al. 2017; Koulil et al. 2018; Lee et al. 2018; Svendsen et al. 2018; Iliffe and Thompson 2019; Russell et al. 2019; Hedman-Lagerlöf et al. 2021; Manne et al. 2021). Of these studies, only one adopted a purely qualitative design, (Iliffe and Thompson 2019) and others:

- Included a qualitative component, but only referred to the study as a mixed-methods study in the discussion section (Mollerup et al. 2016).
- Described a qualitative content analysis, but did not label the analysis as such (Russell et al. 2019).
- Did not describe how qualitative data were analysed (Hawkins et al. 2017).

The synthesis is reported in relation to acceptability and feasibility, satisfaction, positive feedback, perceived benefits, and barriers to digital intervention use.

In terms of the acceptability and feasibility of digital psychological intervention, two studies (van Cranenburgh et al. 2015; Russell et al. 2019) explicitly aimed to explore intervention acceptability and feasibility. The first study (Russell et al. 2019) found that an online mindfulness intervention was acceptable to people with melanoma, as 23/32 (72%) respondents deemed the intervention to be helpful. Furthermore, 70% of participants completed the end-of-study questionnaire and most participants noted that the intervention was simple to use, demonstrating intervention feasibility (Russell et al. 2019). The second study (van Cranenburgh et al. 2015) reported that people with visible skin conditions considered an online educational website appealing and convenient, but overall acceptability was lower than expected because users did not think the website content was relevant to them. It was concluded that this intervention was not feasible overall because users either somewhat or totally agreed that their daily activities prevented regular use (van Cranenburgh et al. 2015).

Seven studies measured how satisfied people living with psoriasis (Balato et al. 2013; van Beugen et al. 2016; Hawkins et al. 2017; Koulil et al. 2018), atopic dermatitis (Armstrong et al. 2011; Hedman-Lagerlöf et al. 2021), and trichotillomania (Lee et al. 2018) were with the interventions they received. These studies indicate high levels of user satisfaction, and that users would recommend, continue using (Balato et al. 2013; Hawkins et al. 2017), and might prefer online interventions in future (van Beugen et al. 2016; Koulil et al. 2018).

Six studies (Armstrong et al. 2011; Balato et al. 2013; van Beugen et al. 2016; Hawkins et al. 2017; Koulil et al. 2018; Lee et al. 2018) captured positive feedback from users, which lends further support to the acceptability and feasibility of digital psychological interventions. Users remarked on the user-friendliness (van Beugen et al. 2016; Koulil et al. 2018), appeal (Armstrong et al. 2011), convenience (Koulil et al. 2018; Lee et al. 2018), and usefulness (Balato et al. 2013) of digital psychological interventions, particularly for understanding dermatological conditions (Hawkins et al. 2017).

A range of perceived benefits of using digital psychological interventions were reported by users across five studies (Mollerup et al. 2016; Koulil et al. 2018; Iliffe and Thompson 2019;

Russell et al. 2019; Manne et al. 2021). People reported that interventions of this kind improved their knowledge of their condition and sense of personal control (Mollerup et al. 2016; Manne et al. 2021).

In addition, these interventions were seen to facilitate positive psychological well-being by helping individuals to accept (Russell et al. 2019) and regulate their feelings (e.g., helplessness, depression) (Koulil et al. 2018; Iliffe and Thompson 2019; Manne et al. 2021) and behaviour (e.g., itch), and identify coping strategies (Koulil et al. 2018). The benefits of online peer support included facilitating emotional expression, self-confidence and acceptance, and exchanging knowledge, experiences and tips for coping and management (Iliffe and Thompson 2019).

Four studies identified barriers to digital intervention use. These barriers included technical problems (e.g., difficulty accessing and navigating intervention) and individual factors (e.g., personal priorities, preferences and schedules, physical symptoms, geographical location, and a lack of time) (van Cranenburgh et al. 2015; Mollerup et al. 2016; Russell et al. 2019; Manne et al. 2021). One study (Mollerup et al. 2016) found that certain features, specifically digital reminders and interactive activities, facilitated the use of digital interventions.

Integration of qualitative and quantitative results

We identified some overlap between qualitative and quantitative data for some outcomes. Firstly, knowledge of skin conditions and their management. Quantitative data revealed significant improvements in participants' knowledge following the use of digital psychological interventions, including an online educational video on eczema (Armstrong et al. 2011), and a text message intervention (Erdil et al. 2020) and an online educational website (Hawkins et al. 2017) for psoriasis. Two studies (Hawkins et al. 2017; Manne et al. 2021) involving patient evaluations also found participants felt more informed about their conditions and how to manage them following intervention use, and a group intervention enabled members to share knowledge and learn from each other (Iliffe and Thompson 2019).

Secondly, we identified some parallels between the quantitative and qualitative data relating to emotions. The former indicated that use of digital interventions, including ICBT (Koulil et al. 2018), online self-compassion writing (Sherman et al. 2019), and an educational website (Heckman et al. 2021) improved negative mood in particular. One qualitative study (Iliffe and

Thompson 2019) similarly found that an online support group enabled people to express how they felt about alopecia. In addition, feedback from people with melanoma suggested that they felt calmer, at peace and more at ease after taking part in online mindfulness (Russell et al. 2019).

Another outcome for which there was congruence was stress. One study (Hedman-Lagerlöf et al. 2021) found significant reductions in perceived stress among the ICBT intervention group versus controls. This was supported by one study (Russell et al. 2019) in which eight reports from five participants suggested an online mindfulness intervention helped individuals to manage their stress.

We did not identify any contradictory evidence. Many of the outcome variables measured in quantitative studies were not addressed in the few qualitative studies that were included in this review.

Discussion

As digital technology becomes further embedded in health care generally, this mixed methods systematic review offers valuable insight into the potential effectiveness of digital platforms and content for improving some psychological and physical outcomes in people with dermatological conditions, mainly psoriasis and eczema. There is some support for web-based digital interventions to improve people's knowledge of their skin conditions and its management, and emotional functioning, particularly negative affect. Use of digital interventions also seemed to benefit aspects of disease severity in the short to medium term. These insights align with some of the findings of an earlier meta-analysis of effectiveness of psychological interventions for adults with skin conditions, which detected medium effect sizes for psychological outcomes and skin severity (Lavda et al. 2012).

We identified several digital interventions that focused on treatment non-adherence, a significant problem within dermatology (Feldman et al. 2017). However, most of these interventions did not lead to significant improvements in treatment adherence and therefore a new approach is needed.

Some digital interventions showed improvement in QoL and offers some confidence that digital interventions requiring active involvement from a provider (e.g., ICBT) are at least as good as those delivered in person in terms of facilitating rapport between the people receiving and delivering the intervention. This is a useful finding given that previous research with people with psoriasis (Hewitt et al. 2022e) and hidradenitis suppurativa (Patel 2021) have indicated that other forms of digital interventions, including remote consultations via video, and telephone consultations especially, are not conducive to discussing the broader psychological impact of skin conditions or building rapport between patients and clinicians.

Overall, considerable heterogeneity in study designs, measures and outcomes meant there was a lack of sufficient and consistent evidence for many psychological outcomes preventing us making definitive conclusions about intervention effectiveness. The level of diversity within this systematic review mirrors that found in a previous systematic review of psychological therapies in psoriasis management (Qureshi et al. 2019). Several papers indicated any suggested improvements did not reach the threshold for statistical significance; it is plausible that some of the studies reviewed were not sufficiently powered, as also suggested by another previous systematic review and meta-analysis of psychological and education interventions for atopic dermatitis specifically (Hashimoto et al. 2017).

As for people's views and experiences, we found poor reporting of qualitative methodology in some studies that sought patient evaluations. Some, mostly web-based interventions, may be acceptable to people living with different dermatological conditions but personal factors could also present as barriers to intervention use. The main benefits of digital interventions included improved emotional control (Ariens et al. 2017) and confidence to socially interact (Williamson et al. 2019), which echo similar findings of previous research (Ariens et al. 2017; Williamson et al. 2019). A better understanding of dermatological conditions and approaches to management were also a key benefit of digital interventions. Importantly, some of these key qualitative findings lend support to the positive quantitative results showing improved knowledge and emotional functioning. Furthermore, the qualitative and quantitative insights on user knowledge that we have identified arguably builds on previous research, which was unable to determine the efficacy of educational and psychological approaches for adults with atopic dermatitis (Hashimoto et al. 2017). The present review gives us some confidence that digital interventions including educational material are likely to be of some benefit to people with dermatological conditions, the next step is to find out what benefit and for whom.

Strengths and limitations

To our knowledge, this is the first mixed methods systematic review investigating *digitally delivered* interventions supporting the psychological health of people with dermatological conditions. The TIDieR checklist and guide (Hoffmann et al. 2014) provided a comprehensive framework for charting key characteristics of the digital interventions clearly, and identifying gaps in reporting. This review was conducted by a multi-disciplinary team of health and clinical psychologists and a general practitioner, most of whom specialize in dermatology research and practice. It was supported by experts from a JBI Centre of Excellence and followed JBI methodology; JBI is renowned for the conduct of highly rigorous evidence syntheses to promote and implement evidenced-based decisions to improve health and healthcare globally (Jordan et al. 2019). The use of JBI critical appraisal tools allowed for a detailed and nuanced assessment of different study designs. In addition, it has been noted by experts in JBI methodology that the step of corroborating and refuting findings is often lacking or missing entirely from mixed methods systematic reviews (Lizarondo et al. 2022). We adopted a convergent segregated approach to data synthesis and as a result were able to triangulate some of the key findings relating to cognitions and emotions specifically, further strengthening the present review.

However, our decision to review all eligible studies regardless of quality meant three short reports (Balato et al. 2013; Marasca et al. 2020; Heckman et al. 2021) and one research letter (Hawkins et al. 2017) were included, arguably weakening the overall quality of this review. We also opted to include a paper specific to trichotillomania; a complex psychiatric disorder (Torales et al. 2021). Whilst this inclusion constitutes as a deviation from the protocol, people with trichotillomania often present to dermatology staff, psychiatrists and psychologists (Sah et al. 2008), reiterating the complex interplay between dermatological and psychological factors. Thus, we argue that the contents of this paper on trichotillomania are likely to be of relevance to the dermatology community, justifying its inclusion in this systematic review. Furthermore, we identified several papers at the full text screening stage which were of some relevance to this review, but these were excluded on the basis that they involved people as young as 12 (Boker et al. 2012), 14 (Pena-Robichaux et al. 2010; Fabbrocini et al. 2014; Liu et al. 2020) and 16 (Heapy et al. 2020; Hudson et al. 2020) years old and pooled the results (Bessell et al. 2012; van Os-Medendorp et al. 2012; Donnarumma et al. 2019; Parks et al. 2020), preventing us from extrapolating the results specific to our population of interest. It is possible that we missed information related to the review questions by excluding these papers. Lastly, two of the papers included in this review were authored by CB (Bundy et al. 2013) and ART (Iliffe and Thompson 2019), potentially introducing bias. However, we attempted to counter this bias by ensuring that neither author was responsible for reviewing their respective papers at any point in the review process.

Future research

Further work to design and test digital psychological interventions is needed, as is qualitative research, to ensure future interventions are feasible, appropriate, meaningful and effective (Jordan et al. 2019) for people with a broad range of common and rare dermatological conditions (Hewitt and Bundy 2021). The TIDieR checklist and guide (Hoffmann et al. 2014) is likely to be a useful tool for intervention developers to consider when planning, developing, and particularly when reporting, complex digital interventions.

This review highlights that many existing studies lack quality, despite the level of evidence they were assigned to. In the context of RCTs, for example, these studies were ranked to level 1, the highest level of evidence for effectiveness, but most were missing detailed information about standard trial procedures, such as blinding. This criticism aligns with earlier research calling for a higher quality and better reporting of RCTs (Lavda et al. 2012). Underreporting of blinding procedures in RCTs of psychological interventions is not a new finding, but it is paramount that researchers explore all possible avenues for blinding, adequately report blinding attempts, and acknowledge potential pitfalls where blinding is not possible (Juul et al. 2021). Greater transparency in the reporting of these procedures could facilitate the development of more robust RCTs in the future, and support healthcare professionals and policy makers to make more informed, evidence-based decisions relating to the care of people with dermatological conditions.

Furthermore, it seems that larger samples might be required for future studies of digital interventions to determine whether their use can significantly improve psychological outcomes (e.g., self-efficacy, well-being, etc.) in people with dermatological conditions, and to establish the magnitude of the effect where one exists.

We also emphasize the need for more qualitative research to further explore intervention barriers and facilitators to using digital psychological interventions and outcomes that are meaningful to patients. Addressing these issues directly with people living with a range of dermatological conditions, as well as ways of overcoming barriers to use, could help to maximize the appropriateness, practicability, and usability of new digital psychological interventions for this population (Craig et al. 2008). The qualitative data offers some insight into psychological factors (e.g., personal control and acceptance) which might help to explain the mechanisms through which digital interventions work, as does qualitative and quantitative data on self-efficacy and knowledge. It is important to investigate these factors further to determine whether they are indeed mechanisms for change. However, qualitative methodologies were sometimes not acknowledged or described sufficiently by authors. Thus, more explicit and comprehensive reporting of qualitative methodologies is required.

Practical implications

Several studies focused on treatment behaviours. Whilst treatment adherence and skin protection are important for managing dermatological conditions (Feldman et al. 2017), other modifiable dietary and health behaviours, such as smoking, alcohol consumption, and poor sleep are associated with some, mostly inflammatory, dermatological conditions (Sawada et al. 2021), and increased risk of cardiovascular disease (Marshall et al. 2016; Ingram 2018; Masson et al. 2020). Digital interventions addressing a variety of health behaviours are, therefore, needed to support a holistic and effective approach to patient self-management.

While many studies in this review included an educational component, the provision of information alone is not always sufficient for eliciting behaviour change; other factors, including personal capabilities, opportunities and levels of motivation, are established drivers of behaviour (Michie et al. 2011b). In the context of treatment adherence, for example, other psychological factors, such as illness and treatment beliefs and concerns, are known to influence behaviour (Feldman et al. 2017). Dermatologists involved in developing digital interventions should address the psychological factors which underpin adherence to dermatological treatments (Feldman et al. 2017), as well as target other related health behaviours.

Whilst intervention development in the usual way was not the focus of this systematic review, it was not always clear from the papers included if or how theoretical frameworks contributed to intervention development, or if the perspectives and needs of the target user were considered throughout this process. Digital behaviour change interventions, like face to face interventions, should be informed by theory in order to determine and test mechanisms for change (Michie et al. 2017). The Behaviour Change Wheel (BCW) is an example of an established and evidence-based framework for designing behaviour change interventions (Michie et al. 2011b). At the heart of the BCW sits the COM-B Model, which encapsulates three key drivers of behaviour: Capability, Opportunity and Motivation (Michie et al. 2011b). The BCW also specifies nine intervention types and seven policy categories that could aid the design and implementation of new interventions (Michie et al. 2011b). Specialists in dermatology should adopt behavioural science principles, including recognised theories of behaviour change, such as the COM-B Model (Michie et al. 2011b), and a person-based approach from the outset, to ensure digital interventions meet the needs and preferences of people living with dermatological conditions (Michie et al. 2017). We also advocate for interdisciplinary collaborations between experts in dermatology, technology, and particularly behaviour change, to facilitate better understanding, development and testing of future complex digital interventions (Michie et al. 2017).

Conclusion

This mixed-methods systematic review shines light on a diverse range of existing digital psychological interventions for some dermatology conditions, as well as substantial heterogeneity and varying quality in the literature. A lack of sufficient and consistent evidence allowed for, at best, tentative conclusions on intervention effectiveness. Whilst digital interventions of this kind are, to some extent, acceptable to patients, there are barriers to their use, and these must be addressed to maximise future use. Collectively, existing evidence underscores the need for quality and interdisciplinary research to develop and test complex digital psychological interventions targeting a broader range of psychological factors, specifically health behaviours, with input from people living with dermatological conditions.

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Conflict of Interest

RMH has received financial support for research from Beiersdorf AG. ART is a Topic Editor of the special article collection title Psychosocial Aspects of Skin Conditions and Diseases in Frontiers in Medicine (Dermatology). He has received workshop and consultancy fees from a number of pharmaceutical companies including UCB (nonspecific); He is also receiving research support from Pfizer. He is a scientific advisor for the Vitiligo Society, and a trustee of Changing Faces; and has been psychological advisor to the All-Party Parliamentary Group on Skin. CB has over the last 3 years received funds for research, honoraria or consultancy from the following pharmaceutical companies: Abbvie, Almirall, Amgen (was Celgene), Beiersdorf AG, Janssen, Novartis, Pfizer, UCB. The remaining authors (MP, CP, RP, BJ, GHW, OH and MJR) have no conflicts of interest to report.

Author Contributions

RMH: Supported conceptualization, lead for methodology, material development, database searching, article screening, data extraction, curation, critical appraisal, data synthesis, writing – original draft, writing – review and editing, and project administration. MP: Supported database searching, article screening, data extraction, critical appraisal, and writing – review and editing. CP: Supported conceptualization, methodology, consensus checks and discrepancy resolution for article screening, data extraction and critical appraisal, and writing – review and editing, and supervision. RP: Supported conceptualization, methodology, article screening, data extraction, critical appraisal, discrepancy resolution, consensus checking, and writing – review and editing. BJ: Supported methodology, material development, article screening, data extraction, critical appraisal, consensus checking, and writing – review and editing. GHW: Supported material development, article screening, data extraction, critical appraisal, consensus checking, and writing – review and editing. OH: Supported material development, article screening, data extraction, critical appraisal, consensus checking, and writing – review and editing. MJR: Supported consensus checking and discrepancy resolution for article screening, data extraction and critical appraisal, and writing – review and editing. ART: Supported consensus checking and discrepancy resolution for article screening and data extraction, and writing – review and editing. CB: Lead for conceptualization and supervision, supported methodology and writing – review and editing.

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Data Availability Statement

The original contributions presented in the study are included in the article and supplemental file. Please direct any further enquiries to the corresponding author.

Appendix 11: Examples of primary and secondary outcomes

Category	**Examples**
Primary outcomes	
Cognitive	Beliefs about illness, beliefs about treatment, knowledge
Emotional	Fear, stress
Behavioural/behaviour change	Diet and weight management, physical activity or exercise, smoking, alcohol consumption, sleep, medication adherence
Other psychological	Adjustment, self-efficacy, self-compassion, motivation, QoL, health-related QoL, depression, anxiety
Secondary Outcomes*	
Physical	Pain, severity, duration, skin coverage
Usage data metrics	Number of log ins, modules accessed, time spent on/using intervention
Other	Intervention feasibility, acceptability or usability, user satisfaction or engagement

QoL, quality of life

*Only included if measured in addition to at least one psychological outcome.

Appendix 12: Search strategy for MEDLINE (Ovid)

exp Skin Diseases/

exp Skin Neoplasms/

exp Dermatology/

((Skin or dermatolog* or cutaneous or visible) adj2 (condition* or disease* or disorder* or manifestation* or difference*)).ti,ab.

1 or 2 or 3 or 4

exp Mobile Applications/

exp Cell Phone/

exp Internet-Based Intervention/

exp Telemedicine/

((mobile* or cell* or smart* or text* or tablet) adj3 (phone* or device* or app or apps or application* or message* or comput*)).ti,ab.

(iPhone* or i-Phone* or iPad* or i-Pad* or email or e-mail).ti,ab.

((internet* or web* or online* or comput*) adj3 (device* or app or apps or application* or program* or intervention*)).ti,ab.

(ehealth or e-health or "electronic health" or mhealth or m-health or "mobile health" or etool* or e-tool* or e-diar* or elearning or e-education).ti,ab.

(digital adj3 (health or intervention* or technolo* or program* or device* or app or apps or application*)).ti,ab.

((remote or virtual or tele) adj3 (health* or intervention* or program* or consultation* or counsell* or therap*)).ti,ab.

("social media" or facebook or Instagram or twitter or whatsapp or tiktok or instant messag*).ti,ab.

6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16

exp "Quality of Life"/

exp Health Behavior/

exp Illness Behavior/

exp Social Behavior/

exp Self-Management/

exp Self Care/

exp Stress, Psychological/

(quality adj4 (health-related or life or adjusted Life Years)).ti,ab.

((cognitive or psycholog* or psychosocial or emotion* or mental* or behavio?r or social or daily) adj3 (adjustment* or function or support or health or well-being or wellbeing)).ti,ab.

(emotion* or mood or distress or motivation* or depression or anxi*).ti,ab.

((illness or treatment) adj3 belief*).mp.

((behaviour* or behavior*) adj3 (health or change or illness or coping)).ti,ab.

(self* adj2 (manage* or help or care or efficacy or esteem or compassion)).ti,ab.

(alcohol or smoking or smoking cessation or exercise or physical activity or diet or healthy eating or eating behavio?r or weight loss or weight maintenance or weight management or sleep or adherence or treatment adherence or meditat* or mindfulness or yoga).ti,ab.

(daily adj2 (living or function or activit*)).ti,ab.

(social adj2 (support or adjustment or connect* or interaction* or function or activit*)).ti,ab.

18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33

5 and 17 and 34

limit 35 to (english language and yr="2002 -Current")

Appendix 13: Screening tool

Section A

Author(s): ID:

Year: Country:

Reviewer: Date reviewed:

Instructions: Assess the article against the criteria below and tick one box for each statement. Please state your final decision in Section G and provide a brief explanation.

Section B

The study…

Is written in English ☐ Yes (continue screening) ☐ No (exclude)

Was written/published in or after 2002 ☐ Yes (continue screening) ☐ No (exclude)

Section C

The participants…

Are aged 18+ years ☐ Yes (continue screening) ☐ No (exclude)

Have a dermatological condition ☐ Yes (continue screening) ☐ No (exclude)

If yes, state name of condition(s):

Section D

A digital intervention for patients that includes at least one of the following functions:

q Yes (tick all functions below that apply and continue) q No (exclude)

Delivered by digital technology q
Can be accessed online or offline q
Patient-to-patient communication q
Patient-to-practitioner communication q
On-demand information services q
Personal health tracking q
Targeted patient communication q

A digital health intervention(s) for symptom detection, diagnosis, examination or assessment q Yes (exclude)

Intervention delivered via telephone only q Yes (exclude)

Asynchronous telemedicine (e.g., Store and Forward) only q Yes (exclude)

Section E

This study concerns the following outcomes (tick all that apply) …

Cognitive (e.g., beliefs about illness or treatment) q Yes q No

Emotional (e.g., depression, anxiety, stress)	☐ Yes	☐ No
Behavioural and behaviour change (e.g., diet and weight management, physical activity or exercise, smoking, alcohol consumption, sleep, medication adherence).	☐ Yes	☐ No
Other psychological outcomes (e.g., self-efficacy, self-compassion, motivation, quality of life, and adjustment).	☐ Yes	☐ No
Other outcomes (e.g., intervention feasibility, acceptability or usability, and user satisfaction or engagement) ***in addition to*** one or more psychological outcome.	☐ Yes	☐ No
Physical outcome (e.g., pain severity, duration, skin coverage) ***in addition to*** one or more psychological outcome.	☐ Yes	☐ No
Usage data metrics (e.g., number of log ins, modules accessed, time spent on/ using digital intervention) ***in addition to*** one or more psychological outcome.	☐ Yes	☐ No
Physical outcome only	☐ Yes (exclude)	

Section F

This paper reports on a…

Quantitative study	q Yes (continue screening)
Qualitative study	q Yes (continue screening)
Mixed methods study	q Yes (continue screening)
Research/review protocol	q Yes (exclude)
Systematic review and/or meta-analysis	q Yes (exclude)
Conference poster or abstract	q Yes (exclude)
Commentary or editorial	q Yes (exclude)
Grey literature (i.e., dissertation/ thesis)	q Yes (exclude)

Section G

Tick one of the following:

Include q

Exclude q

Unsure q

Comments/reasons:

Appendix 14: Code book for systematic review

Name of node (code)	Description
Outcomes and measures	
Primary outcome	Code assigned to papers which specified a primary outcome.
Behaviours	
Alcohol consumption	Relates to the frequency or duration of alcohol consumption, or the type of alcohol consumed.
Daily activities	Activities that are performed regularly as part of everyday life (e.g., chores or shopping).
Role limitations	The inability of an individual to perform their actual or perceived role in society due to physical or emotional problems.
Hair pulling	
Meditation	An activity whereby people attempt to increase their awareness of the present moment by focusing their attention, usually on the breath, resulting in a more relaxed physical and psychological state.
Mindfulness	A state in which an individual attempts to remain present in the moment, acknowledging thoughts and feelings in a non-judgemental manner, which usually results in a more relaxed physical and psychological state.
Protective behaviours	Behaviours which can help to prevent condition onset or flare ups (e.g., hand washing, moisturiser use, wearing a hat).
Scratching	The behavioural response to itchy.
Sleep	Factors related to sleep hygiene (e.g., sleep quality, problems sleeping).

Smoking status	
Treatment-related behaviours	Behaviours related to taking medication (i.e., treatment adherence or compliance).
Visit adherence	The rate of hospital visits.
Cognitions	
Beliefs	Thoughts, views or opinions.
Cognitions	General cognitive processes that help people to make sense of their situation or surroundings.
Itch-related cognitions	Cognitive processes specifically related to the itch caused by a skin condition.
Concerns	A matter of interest or worry.
Knowledge	Improving knowledge.
Rumination	Repetitive and/or consistent thoughts about something.
Self-efficacy	The belief or confidence in one's own ability to perform a behaviour or task.
Emotions	
Affect	Feelings or emotions, which can be positive or negative.
Anxiety	Physical and/or psychological response to a stressor, which typically manifests as feelings of unease, worry or fear.
Depression	A state of low mood which lasts over time, which often results in a loss of pleasure in life or activities, feelings of hopelessness and in some more severe cases, suicidal ideation.
Distress	Typically, negative thoughts, feelings and behaviours that surmount to a person feeling overwhelmed and impact functioning.
Fear of cancer recurrence	Feeling afraid of cancer returning.

Shame	The feeling of humiliation or embarrassment in oneself.
Stress	A physical and psychological response to a perceived threat, which often occurs when an individual does not believe that they have the personal resources to overcome the perceived threat.
Worry	A state of feeling anxious or uneasy that results from thinking about a problem or challenge.
Other psychological factors	
Psychological functioning	Composite measure of negative mood, depression and anxiety
Psychological inflexibility	One's ability to adapt how they think and feel towards something, someone or a situation.
Psychological symptoms	A general term used to refer to symptoms relating to how we think and feel (e.g., feeling confused or sad).
Psychological well-being	A personal sense of satisfaction, contentment and potentially fulfilment with oneself or life.
Self-compassion	The ability to express compassion, kindness and understanding towards oneself.
Quality of life (QoL)	Personal perceptions of one's position in life in relation to other factors such as social and cultural norms, personal goals, values and interests, health, economics, and the environment.
Improvement in QoL	
Itch-related QoL	
No improvement in QoL	
Therapeutic relationship	Relationship between patients and practitioners
Social	This relates to societal issues, such as stigmatization, and social factors, including social support.
Physical	Physical aspects associated with having a skin condition (e.g., symptoms).
Body surface area	

Disease severity	
Fatigue	
Itch	
Physical functioning	
Symptoms/severity worse	
Symptoms/severity improved	
No change in symptoms/severity	
Change in symptoms/severity but not significant	
Study characteristics	
Conflict of Interest (COI)	A situation in which financial interests or other personal circumstances could influence a person’s professional judgement in conducting or reporting research.
No information provided	
No COI declared	
COI stated elsewhere	
Eligibility criteria	Key requirements of participants for participation in a study.
Exclusion criteria	
Inclusion criteria	
Sampling approaches	The ways in which researchers select their study sample from the target population.

Convenience	Researchers approach individuals in a setting or location that is convenient and easy to reach the target population.
Multiple methods	Combination or two or more sampling approaches were used.
Purposive	A sample is selected based on the personal judgement of the researcher.
Unclear	Insufficient information to be able to decipher the sampling approach used.
Voluntary	Individuals from the target population volunteer to participate in research (e.g., an individual responds to a study advertisement they saw online).
Baseline measure	
Follow up period	Points in time at which key outcomes were assessed.
Immediately after intervention	
1 month/4 weeks	
2 months/8 weeks	
3 months/12 weeks	
6 weeks	
6 months/24 weeks	
26 weeks	
11 months/48 weeks	
12 months/52 weeks	
60 weeks	
Intervention characteristics	

Assignments/homework	Tasks set for users to complete as part of the intervention.
Contact with patients	Users can communicate with other users via the intervention.
Contact with practitioner	Users can communicate with healthcare professionals via the intervention.
Provision of education/information	The intervention includes an educational component.
Reminders	Digital messages sent to prompt people to engage with the intervention.
Symptom tracking	The intervention allows users to monitor their symptoms (physical or psychological).
Treatment tracking	The intervention allows users to monitor treatment types and frequency/duration of use.
Tailored intervention	The intervention is fully or in part personalised to the individual user.
Medium of delivery	The type of digital technology used to deliver the intervention.
Combination of mediums	More than one type of digital technology used to deliver the intervention.
Mobile – text message	Text or SMS.
Mobile – application (app)	
Online	Delivered via the internet.
Pre-recorded video	
Social media	
Website	
Video conferencing platform/software	Synchronous (live) video technologies.
Nodes (Codes) for Qualitative Research	
Acceptability	How appropriate the intervention is perceived to be by the target audience.
Perceived effectiveness	Perceptions of how well the intervention achieves meets its purpose/achieves its goal.

Helpfulness	Perceptions relating to how helpful the intervention is.
Relevance	How suitable the intervention and its content is for the individual or group using it.
Design	How the intervention is presented and looks to the user.
Satisfaction	How satisfied people are with the intervention they receive.
Feasibility	How practical the intervention is perceived to be by the people receiving it.
Facilitators	Factors that are perceived to support intervention access or use.
Interactive activities	The intervention offers or requires users to complete tasks that require active engagement.
Reminders	Digital messages sent to prompt people to engage with the intervention.
Barriers	Factors that limit or prevent intervention use.
Individual factors	Factors that limit or prevent intervention use which are relevant to the individual user.
Daily routine/ activities	Other daily activities limit or prevent use of intervention.
Physical symptoms	Physical symptoms associated with a skin condition (e.g., fatigue, pain)
Not a personal priority	This relates to how important individuals perceive the intervention to be in comparison to other aspects of their life and what individuals are willing to make time for.
IT proficiency	Personal ability to use/navigate digital technology.
Lack of time	Individuals do not feel that they have time to use the intervention.
Personal preferences	Individual likes and dislikes relating to the design, content and function of the intervention.
Technical issues	Problems with the intervention technology (e.g., unable to log on or navigate the intervention, technology failures)
Benefits/advantages	Positives perceptions of the intervention and its use.

Facilitates acceptance	Individuals feel they are more accepting of themselves (e.g., body image) and/or their condition as a result of using the intervention.
Convenient	The intervention is easy to access, requires little effort and fits with the user's personal needs or circumstances.
Facilitates emotional expression	Helps individuals to confront and convey their emotions.
Improves coping	Helps people to overcome challenges.
Improves well-being	Facilitates a sense of satisfaction, contentment and potentially fulfilment with one's self or life.
Reduces isolation	Helps people to feel less isolated or alone.
Increases self-confidence	Trust in one's own abilities or qualities.
Knowledge exchange	The intervention allows users to share knowledge of skin conditions and how to manage them.
Self-monitoring	Intervention users can track their own symptoms, feelings or treatment activities.

Appendix 15: Characteristics of studies included in systematic review

Study	Country	Condition	Study Design	Sampling approach	Recruitment method	Primary outcome	Duration of follow up
Alinia et al. (2017)	USA	Psoriasis	RCT	Convenience, purposive	Outpatient clinic	Treatment adherence*	12 months
Armstrong et al. (2011)	USA	AD	RCT	Convenience	Outpatient clinic	Disease severity	3 months
Balato et al. (2013)	Italy	Psoriasis	Randomised pilot trial	Convenience	Outpatient clinic	Treatment adherence*	3 months
Bundy et al. (2013)	UK	Psoriasis	RCT	Voluntary	Advertisement	Anxiety and depression	6 months
Domogalla et al. (2021)	Germany	Psoriasis	RCT	Convenience	Outpatient clinic	Anxiety and depression	60 weeks
Erdil et al. (2020)	Turkey	AD (hand)	RCT	Convenience	Outpatient clinic	Unclear	2 months
(Hawkins et al.)	USA	Psoriasis	RCT	Convenience	Outpatient clinic	Knowledge	Immediately post intervention

Heckman et al. (2021)	USA	AD, psoriasis, chronic itch	Cohort study	Unclear	Market research company	Itch-related QoL	1 month
Hedman-Lagerlöf et al. (2021)	Sweden	AD	RCT	Voluntary	Online application	Disease severity	12 months
Iliffe and Thompson (2019)	UK	Alopecia	Qualitative	Voluntary, purposive	Social media	Patient experiences	No follow up
Joergensen et al. (2020)	Denmark	AD	RCT	Voluntary	Social media	Disease severity, QoL	1 month
Koulil et al. (2018)	The Netherlands	Psoriasis**	Case report	Purposive	Unclear	Unclear	6 months
Lee et al. (2018)	USA	Trichotillomania	RCT	Convenience, voluntary	University campus, mental health providers, online advertisement	Symptom severity, QoL	3 months
Manne et al. (2021)	USA	Melanoma	RCT	Convenience	Cancer registry, dermatology	Skin self-examinations,	11 months

					clinics, medical centre	sun protection behaviours	
Marasca et al. (2020)	Italy	Acne, alopecia, HS, lichen-plan-pilaris, psoriasis	Quasi-experimental study	Convenience	Outpatient clinic	QoL*	1 month
Mollerup et al. (2016)	Denmark	AD (hand)	RCT	Convenience, voluntary	Outpatient clinic	Disease severity	6 months
Schuster et al. (2020)	Germany	Psoriasis	Analytical cross-sectional study	Convenience, voluntary	Psoriasis	Unclear	No follow up
Sherman et al. (2019)	Australia	Visible skin conditions (i.e., acne, birthmark, eczema, psoriasis, other)	Randomised pilot trial	Convenience, voluntary	University campus, outpatient clinics, social media (Facebook)	Self-compassion*	Immediately post-intervention
Svendsen et al. (2018)	Denmark	Psoriasis	RCT	Convenience, voluntary	Outpatient clinic, advertisement	Treatment adherence	26 weeks

Russell et al. (2019)	Australia	Melanoma	RCT	Convenience	Cancer centre	Unclear	6 weeks
van Beugen et al. (2016)	The Netherlands	Psoriasis	RCT	Convenience	Outpatient clinic, advertisement	Impact on daily life	6 months
van Cranenburgh et al. (2015)	The Netherlands	Acne, HS, psoriasis, vitiligo***	Observational pilot study	Convenience	Outpatient clinic	Acceptability, feasibility	2 months
Zhao et al. (2021)	China	Psoriasis	RCT	Convenience	Outpatient clinic	Visit adherence*	12 months

AD, Atopic Dermatitis; HS, Hidradenitis Suppurativa; RCT, Randomised Controlled Trial; QoL, Quality of Life.

*Primary outcome not explicitly stated by authors.

**This study also included one person with Rheumatoid Arthritis, but data were not included.

***Dermatologists were also recruited but data were not included.

Appendix 16: Sample sizes, attrition and participant demographics (gender and mean age) of studies reviewed

Study (First author, year)	Number of participants	Number of dropouts	Females	Males	Mean age (SD)
Alinia et al. (2017)	40	20	23	17	58.6
Armstrong et al. (2011)	80	3	36	44	48 (15)
Balato et al. (2013)	40	0	18	22	38.8 (9.8)
Bundy et al. (2013)	126	41	59	67	45.0 (12.6)
Domogalla et al. (2021)	107	30	42	65	49.1 (12.1)
Erdil et al. (2020)	81	41	37	44	37.1 (11.8)
Hawkins et al. (2017)	50	28	Not stated	Not stated	Not stated
Heckman et al. (2021)	137	30	56	44	40.9
Hedman-Lagerlöf et al. (2021)	102	11	83	19	37 (11)
Iliffe and Thompson (2019)	12	N/A	12	0	Not stated
Joergensen et al. (2020)	83	Unclear	59	24	Not stated

Koulil et al. (2018)	2	N/A	1	1	45
Lee et al. (2018)	22	10	19	3	Group 1 (n = 12) 34.2 (9.4). Group 2 (n = 10) 30.4 (6.8)
Manne et al. (2021)	441	59	216	225	61.4 (13.3)
Marasca et al. (2020)	23	N/A	13	10	35.4
Mollerup et al. (2016)	140	N/A	90	50	38.1 (13.7)
Russell et al. (2019)	69	37	37	32	IG (n = 46) 53.5 (12.1) CG (n = 23) 53.1 (15.2)
Schuster et al. (2020)	101	N/A	73	28	47.4 (15.4)
Sherman et al. (2019)	50	0	35	15	27.1 (10.8)
Svendsen et al. (2018)	134	12	82	52	48
van Beugen et al. (2016)	131	49	64	67	53.1 (12.3)
van Cranenburgh et al. (2015)	11 dermatologists, 105 patients	35 patients	UC		Not provided
Zhao et al. (2021)	221	180	100	121	34.1 (10.6)
TOTAL	2,268	556	1,132	933	-

N/A, not applicable.

Appendix 17: Outcome variables and measurement tools reported in the studies reviewed

Study	Category	Outcome	Measure	Additional Information
Alinia et al. (2017)				
	Behavioural	Alcohol consumption	Unclear	
	Behavioural	Smoking status	Unclear	Included in analysis as a covariate
	Behavioural	Treatment adherence	MEMS® caps	Electronic Monitoring System
	Physical	Disease severity	PASI	
	Physical	Disease severity	IGA	
Armstrong et al. (2011)				
	Cognitive	Knowledge of condition	14-item questionnaire	Questions based on intervention content
	Physical	Disease severity	POEM	
	Satisfaction	Satisfaction with intervention (appeal and usefulness)	10-point rating scale	
Balato et al. (2013)				
	Other psychological	Quality of life	DLQI	

	Behavioural	Treatment adherence (number of days per week medication forgotten)	One item	MCQ
	Behavioural	Treatment adherence (number of days medication taken)	Seven-day calendar	
	Physical	Disease severity	PASI	
	Physical	Disease severity	SAPASI	
	Physical	Disease severity	PGA	
	Physical	Disease severity	BSA	
	Therapeutic relationship	Patient-physician relationship	Questionnaire including a 10-point rating scale	
Bundy et al. (2013)				
	Cognitive	Beliefs about condition	IPQ-R	
	Other psychological	Anxiety	HADS	
	Other psychological	Depression	HADS	
	Other psychological	Quality of life	DLQI	
	Behavioural	Alcohol consumption	Unclear	

	Behavioural	Smoking status	Unclear	Included in analysis as a predictor variable
	Physical	Disease severity	SAPASI	
Domogalla et al. (2021)				
	Emotional	Mood	Likert scale	
	Other psychological	Quality of life	DLQI	
	Other psychological	Anxiety	HADS	
	Other psychological	Depression	HADS	
	Behavioural	Alcohol consumption (number of days alcohol consumed per week)	One item	
	Behavioural	Smoking status	Unclear	Measured for demographic purposes only
	Behavioural	Daily activities	Likert scale	
	Physical	Itch	Numeric rating scale	
	Physical	Disease severity	PASI	
Erdil et al. (2020)				

	Cognitive	Knowledge of condition	Eczema assessment questionnaire	20 true/false items on preventative measures
	Behavioural	Protective behaviours (Hand washing and use of moisturizer, gloves, liquid soap, cologne, wet wipes)	Scores were based on the irritation exposure score developed by Jungbauer.	Use of cologne, wet wipes, moisturizers, and gloves, were added to the scoring system.
	Behavioural	Treatment compliance (frequency of medication use)	Unclear	
	Physical	Disease severity	HECSI	
	Physical	Disease severity	5-point scale VAS	
Hawkins et al. (2017)				
	Cognitive	Knowledge of condition	Unclear	
	Cognitive	Treatment concerns (extent to which the clinician addressed patient concerns)	VAS	
	Behavioural	Treatment adherence	One item	MCQ
	Satisfaction	Satisfaction with intervention	Unclear	
Heckman et al. (2021)				

	Cognitive	Itch cognitions	Itch cognitions questionnaire	
		Perceived Efficacy in Patient-Physician Interactions	PEPPI-5	
	Emotional	Stress	PSS	
	Other psychological	Itch-related quality of life	ItchyQoL questionnaire	
	Behavioural	Scratch	Sleep-Related Itch and Scratch	
	Behavioural	Scratch	Scratch Intensity and Impact Scale	
	Behavioural	Risk of treatment non-adherence	MMAS-8-IS	8-item scale
	Physical	Itch	5-D Pruritus Scale	
	Physical	Itch severity and scratching pleasure	10-point numeric rating scale	
	Intervention usage	Frequency and duration of intervention use		
	Intervention usage	Completion rate		
Hedman-Lagerlöf et al. (2021)				
	Emotional	Stress	PSS	
	Other psychological	Anxiety	Beck Anxiety Inventory	
	Other psychological	Depression	PHQ-9	

	Other psychological	Quality of life	DLQI
	Other psychological	Quality of life	BBQ
	Behavioural	Sleep problems	ISI
	Physical	Itch	5-D Pruritus Scale
	Physical	itch intensity (past 48 hours)	VAS
	Physical	Disease severity	POEM
	General health	Health status	One item
	Satisfaction	Satisfaction with intervention	CSQ
Iliffe and Thompson (2019)			
	Qualitative	Personal experiences of an online support group for people living with alopecia	Semi-structured interviews
Joergensen et al. (2020)			
	Other psychological	Quality of life	DLQI
	Behavioural	Treatment adherence	Clicks of memory button
	Behavioural	Treatment adherence	Manual tracking via a mobile app
	Physical	Disease severity	POEM

	Physical	Disease severity	EASI	
	Physical	Disease severity	SCORAD	
Koulil et al. (2018)				
	Cognitive	Illness cognitions	Illness cognitions questionnaire	Helplessness and acceptance subscales only
	Emotional	Worry	PSWQ	
	Other psychological	Anxiety	ISDL	
	Other psychological	Depression	Beck Depression Inventory	
	Behavioural	Sleep hygiene	A sleep schedule	
	Behavioural	Scratch	ISDL	Conscious and automatic scratching sub-scales
	Behavioural	Treatment compliance (frequency of medication use)	Questionnaire	5-point Likert scale
	Physical	Disease severity	PASI	
	Physical	Disease severity	SAPASI	
	Therapeutic relationship	Patient-physician relationship	WAI-S	

	Therapeutic relationship	Patient-physician relationship	ITRQ	
	Therapeutic relationship	How useful/motivating patient found contact with the therapist	Numeric rating scale	6-point
	Satisfaction	Satisfaction with intervention	Unclear	
	Impact on daily life	Role limitations due to physical and emotional problems	RAND-36 Health Status Inventory	
	Social	Perceived social support	ISDL	
	Social	Stigmatization	ISDL	
Lee et al. (2018)				
	Emotional	Shame	ESS	
	Other psychological	Quality of life	QOLS	
	Other psychological	Psychological inflexibility	AAQ-TTM	
	Other psychological	Psychological symptoms	MINI	
	Behavioural	Hair pulling	MGH-HPS	
	Therapeutic relationship	Patient-physician relationship	WAI-SR	
	Satisfaction	Satisfaction with intervention	CSQ-8	
Manne et al. (2021)				

Cognitive	Knowledge of condition	13-item questionnaire	True/false questions on melanoma
Cognitive	Knowledge of condition	6-item questionnaire	MCQ on characteristics of abnormal lesions
Cognitive	Self-efficacy for performing a skin self-examination	12-item questionnaire	
Cognitive	Self-efficacy for performing sun protection behaviours	Four Likert scale items	
Behavioural	Self-management issues (use of gloves, topical steroids, consulting General Practitioner)	10-item questionnaire	Questionnaire developed for the study.
Behavioural	Frequency of sun protection behaviours (use of sunscreen, hats, long-sleeves, and staying in the shade).	Four items comprised of 5-point Likert scales	
Behavioural	Performance of a skin self-examination	One item	Yes/no response
Intervention usage	Number of page visits		
Intervention usage	Completion rate		

	Acceptability	Barriers (technological, personal and general barriers to use, and intervention-specific barriers)	22-item questionnaire
	Acceptability	Perceived effectiveness of intervention	20-item Impact and Effectiveness measure
	Acceptability	Programme characteristics (usefulness, convenience, ease of use and navigation, worry about privacy, and satisfaction)	15-item Evaluation and Utility survey based on 5-point Likert scales
Marasca et al. (2020)			
	Other psychological	Quality of life	DLQI
	Other psychological	Psychological well-being	PGWB
Mollerup et al. (2016)			
	Cognitive	Self-efficacy	10-point numeric rating scale
	Other psychological	Quality of life	DLQI
	Behavioural	Treatment adherence	DMARS-4
	Physical	Itch (in the past 4 weeks)	VAS
	Physical	Disease severity	HECSI
	Physical	Disease severity	10-point VAS
	Intervention usage	Number of page visits	

Schuster et al. (2020)				
	Emotional	Affect	Scale of Positive and Negative Experience	
	Emotional	Happiness	One item	Taken from European Social Survey
	Emotional	Facebook envy	6-item scale	
	Other psychological	Quality of life	DLQI	
	Satisfaction	Life satisfaction	Satisfaction with Life Scale	
	Intervention usage	Frequency and duration of intervention use		
Sherman et al. (2019)				
	Emotional	Affect	PANAS	
	Emotional	Body image related distress	Body Image Disturbance Questionnaire	
	Other psychological	Self-compassion	SCS-SF	
	Physical	Disease severity	One item (5-point Likert scale)	
Svendsen et al. (2018)				
	Other psychological	Quality of life	DLQI	

	Behavioural	Smoking status	Unclear	Included as a covariate
	Behavioural	Treatment adherence (PO)	Electronic medication dispensers	
	Behavioural	Treatment adherence (PO)	Weight of medication canisters	Weighed before/after use
	Physical	Disease severity	PASI	
	Physical	Disease severity	LS-PGA	
Russell et al. (2019)				
	Cognitive	Rumination	Rumination and Reflection questionnaire	Rumination subscale
	Emotional	Stress	PSS	
	Emotional	Worry	PSQW-A	
	Emotional	Fear of cancer recurrence	FCRI	
	Other psychological	Experience of mindfulness	CAMS-R	
	Behavioural	Frequency of informal meditation practice	3-item questionnaire	
	Acceptability	Relevance of intervention content (benefits and participant preferences)	Three open-ended items	Completed each week

	Acceptability	Perceived helpfulness of intervention	Three items	Completed post-intervention.
van Beugen et al. (2016)				
	Behavioural	Treatment compliance	Unclear	
	Other psychological	Psychological functioning (depression)	Beck Depression Inventory	Composite measure of psychological functioning including measures of negative mood, depression, and anxiety
	Other psychological	Psychological functioning (negative mood and anxiety)	ISDL	
	Physical	Disease severity	PASI	
	Physical	Disease severity	SAPASI	
	Physical	Physical functioning (itch)	ISDL	Composite measure of physical functioning including itch and fatigue. 4-item subscale for itch
	Impact on daily life	Role limitations	RAND-36 Health Status Inventory	

van Cranenburgh et al. (2015)			
	Intervention usage	Frequency and duration of use	
	Intervention usage	Number of page visits	
	Feasibility	Factors preventing intervention use	2 Likert scale items
	Acceptability	Relevance of intervention	10 items based on 5-point Likert scale
	Acceptability	Convenience of intervention	4 items based on 5-point Likert scale
	Acceptability	Intervention design (layout and attractiveness)	5 items based on 5-point Likert scale
	Acceptability	Intervention design (font size and text length)	2 items based on 5-point Likert scale
Zhao et al. (2021)			
	Behavioural	Treatment adherence	Questionnaire
	Behavioural	Visit adherence	Rate of patient hospital visits

MEMS, Medication Event Monitoring System; PASI, Psoriasis Area and Severity Index; IGA, Investigator's Global Assessment; POEM, Patient Oriented Eczema Measure; DLQI, Dermatology Life Quality Index; SAPASI, Self-Administered Psoriasis Area and Severity Index; PGA, Physician's Global Assessment; LS-PGA, Lattice System Physician's Global Assessment; BSA, Body Surface Area; IPQ-R, Illness Perception

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Questionnaire Revised; HADS, Hospital Anxiety Depression Scale; HECSI, Hand Eczema Clinical Severity Index; PEPPI-5, Perceived Efficacy in Patient-Physician Interactions; PSS, Perceived Stress Scale; MMAS-8-IS, Morisky Medication Adherence Scale Itch Specific; PHQ-9, Patient Health Questionnaire 9; BBQ, Brunnsviken Brief Quality of Life Scale; ISI, Insomnia Severity Index; CSQ, Client Satisfaction Questionnaire; CSQ-8, Client Satisfaction Questionnaire–8; EASI, Eczema Area and Severity Index; SCORAD, SCORing Atopic Dermatitis; PSWQ, Penn State Worry Questionnaire; PSQW-A, Penn State Worry Questionnaire-Abbreviated; ISDL, Impact of Chronic Skin Disease on Daily Life; ITRQ, Internet-Specific Therapeutic Relationship Questionnaire; ESS, Experience of Shame Scale; QOLS, Quality of Life Scale; AAQ-TTM, Acceptance and Action Questionnaire for Trichotillomania; MINI, The Miniature International Neuropsychiatric Interview; MGH-HPS, Massachusetts General Hospital Hair Pulling Scale; WAI-SR, Working Alliance Inventory – Short Revised; PGWB, Psychological-General-Well-Being-Index; DMARS-4, Danish Medication Adherence Report Scale; PANAS, Positive and Negative Affect Schedule; SCS-SF, 12-item Self-Compassion Scale Short Form; FCRI, Fear of cancer recurrence Inventory; CAMS-R, Cognitive and Affective Mindfulness Scale-Revised;

Appendix 18: Critical appraisal of methodological quality of studies reviewed

Table 8: Critical appraisal of methodological quality of studies reviewed

Study (first author, year)	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Total Score
RCTs[1]														
Alinia et al. (2017)	UC	UC	Y	UC	UC	UC	Y	Y	Y	Y	Y	Y	Y	8/13
Armstrong et al. (2011)	Y	Y	Y	Y	UC	N	N	N	Y	Y	UC	Y	Y	8/13
Balato et al. (2013)	Y	Y	Y	N	Y	Y	Y	UC	Y	N/A	Y	Y	Y	10/12
Bundy et al. (2013)	Y	UC	Y	N	N/A	N/A	Y	Y	Y	Y	Y	Y	Y	9/11
Domogalla et al. (2021)	UC	Y	Y	N	N	UC	Y	Y	UC	Y	N	UC	Y	6/13
Erdil et al. (2020)	Y	N	Y	N	N	N	Y	Y	Y	Y	UC	Y	Y	8/13
Hawkins et al. (2017)	Y	UC	UC	UC	N	UC	UC	N	Y	UC	UC	Y	Y	4/13
Hedman-Lagerlöf et al. (2021)	Y	Y	Y	Y	UC	UC	Y	N	Y	Y	Y	Y	Y	10/13
Joergensen et al. (2020)	Y	UC	Y	N	Y	UC	UC	UC	Y	Y	Y	Y	Y	8/13
Lee et al. (2018)	Y	UC	Y	N	N	N	Y	N	Y	Y	Y	Y	Y	8/13
Manne et al. (2021)	Y	UC	Y	N	N	N	Y	Y	Y	Y	Y	UC	Y	8/13
Mollerup et al. (2016)	UC	UC	Y	UC	UC	UC	N	N	Y	Y	Y	UC	UC	4/13
Russell et al. (2019)	Y	Y	Y	N	N/A	UC	Y	Y	Y	Y	Y	Y	Y	10/12

Sherman et al. (2019)	Y	UC	N	Y	N/A	UC	Y	Y	N	Y	UC	UC	Y	6/12
Svendsen et al. (2018)	Y	Y	Y	N	N	N	Y	N	Y	Y	Y	Y	Y	9/13
van Beugen et al. (2016)	Y	Y	UC	N	N	N	Y	Y	Y	Y	UC	Y	Y	8/13
Zhao et al. (2021)	Y	UC	N	UC	N	UC	Y	N	UC	Y	UC	Y	Y	5/13
Quasi-experimental studies[2]														
Marasca et al. (2020)	Y	N/A	N/A	N	Y	N/A	N/A	N/A	N	-	-	-	-	2/4
Analytical cross-sectional studies[3]														
Schuster et al. (2020)	N	Y	Y	UC	UC	N	Y	UC	-	-	-	-	-	3/8
van Cranenburgh et al. (2015)	Y	Y	UC	N/A	UC	N	Y	Y	-	-	-	-	-	4/7
Case reports[4]														
Koulil et al. (2018)	N	N	N	Y	Y	Y	N	Y	-	-	-	-	-	4/8
Cohort studies[5]														
Heckman et al. (2021)	N/A	N/A	Y	Y	Y	Y	Y	Y	N	N	Y	-	-	7/9
Qualitative research[6]														
Iliffe and Thompson (2019)	Y	Y	Y	Y	Y	N	N	Y	Y	Y	-	-	-	8/10
Mollerup et al. (2016)	UC	Y	Y	Y	Y	N	N	UC	Y	Y	-	-	-	6/10

RCTs, Randomised Controlled Trials; N, no; Y, yes; UC, unclear; N/A, not applicable

[1] JBI checklist questions for RCTs (Tufanaru et al. 2020): 1) Was true randomization used for assignment of participants to treatment groups?; 2) Was allocation to treatment groups concealed?; 3) Were treatment groups similar at the baseline?; 4) Were participants blind to treatment assignment?; 5) Were those delivering treatment blind to treatment assignment?; 6) Were outcomes assessors blind to treatment assignment?; 7) Were treatment groups treated identically other than the intervention of interest?; 8) Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?; 9) Were participants analyzed in the groups to which they were randomized?; 10) Were outcomes measured in the same way for treatment groups?; 11) Were outcomes measured in a reliable way?; 12) Was appropriate statistical analysis used?; 13) Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?

[2] JBI checklist questions for quasi-experimental studies (Tufanaru et al. 2020): 1) Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?; 2) Were the participants included in any comparisons similar?; 3) Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?; 4) Was there a control group?; 5) Were there multiple measurements of the outcome both pre and post the intervention/exposure?; 6) Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?; 7) Were the outcomes of participants included in any comparisons measured in the same way?; 8) Were outcomes measured in a reliable way?; 9) Was appropriate statistical analysis used?

[3] JBI checklist questions for analytical cross-sectional studies (Moola et al. 2020): 1) Were the criteria for inclusion in the sample clearly defined?; 2) Were the study subjects and the setting described in detail?; 3) Was the exposure measured in a valid and reliable way?; 4) Were objective, standard criteria used for measurement of the condition?; 5) Were confounding factors identified?; 6) Were strategies to deal with confounding factors stated?; 7) Were the outcomes measured in a valid and reliable way?; 8) Was appropriate statistical analysis used?

[4] JBI checklist questions for case reports (Moola et al. 2020): 1) Were patient's demographic characteristics clearly described?; 2) Was the patient's history clearly described and presented as a timeline?; 3) Was the current clinical condition of the patient on presentation clearly described?; 4) Were diagnostic tests or assessment methods and the results clearly described?; 5) Was the intervention(s) or treatment procedure(s) clearly described?; 6) Was the post-intervention clinical condition clearly described?; 7) Were adverse events (harms) or unanticipated events identified and described?; 8) Does the case report provide takeaway lessons?

[5] JBI checklist questions for cohort studies (Moola et al. 2020): 1) Were the two groups similar and recruited from the same population?; 2) Were the exposures measured similarly to assign people to both exposed and unexposed groups?; 3) Was the exposure measured in a valid and reliable way?; 4) Were confounding factors identified?; 5) Were strategies to deal with confounding factors stated?; 6) Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?; 7) Were the outcomes measured in a valid and reliable way?; 8) Was the follow up time reported and sufficient to be long enough for outcomes to occur?; 9) Was follow up complete, and if not, were the reasons to loss to follow up described and explored?; 10) Were strategies to address incomplete follow up utilized?; 11) Was appropriate statistical analysis used?

[6] JBI checklist questions for qualitative research (Lockwood et al. 2015): 1) Is there congruity between the stated philosophical perspective and the research methodology?; 2) Is there congruity between the research methodology and the research question or objectives?; 3) Is there congruity between the research methodology and the methods used to collect data?; 4) Is there congruity between the research methodology and the representation and analysis of data?; 5) Is there congruity between the research methodology and the interpretation of results?; 6) Is there a statement locating the researcher culturally or theoretically?; 7) Is the influence of the researcher on the research, and vice- versa, addressed? 8) Are participants, and their voices, adequately represented?; 9) Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?; 10) Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

Appendix 19: Rankings of the effectiveness and meaningfulness of evidence reviewed according to the JBI levels of evidence and grades of recommendation working party (2014)

Level of evidence	Study design		*n*	Study (first author, year)
	Effectiveness			
1: Experimental designs	1a	Systematic review of RCTs	N/A	-
	1b	Systematic review of RCTs and other study designs	N/A	-
	1c	RCT	12	Armstrong et al. (2011) Balato et al. (2013) Bundy et al. (2013) Domogalla et al. (2021) Erdil et al. (2020) Hedman-Lagerlöf et al. (2021) Manne et al. (2021) Russell et al. (2019) Sherman et al. (2019) Svendsen et al. (2018) van Beugen et al. (2016) Zhao et al. (2021)

	1d	Pseudo-RCTs	3	Lee et al. (2018) Hawkins et al. (2017) Joergensen et al. (2020)
	1 unclear*	Unable to assign to a specific level due to limited information		Alinia et al. (2017) Mollerup et al. (2016)
2: Quasi-experimental designs	2a	Systematic review of quasi-experimental studies	N/A	-
	2b	Systematic review of quasi-experimental studies and other lower study designs	N/A	-
	2c	Quasi-experimental studies prospectively controlled study	0	-
	2d	Pre-test – post-test or historic/retrospective control group study	2	Heckman et al. (2021) Marasca et al. (2020)
3: Observational – analytical designs	3a	Systematic review of comparable cohort studies	N/A	-
	3b	Systematic review of comparable cohort studies and other lower study designs	N/A	-
	3c	Cohort study with control group	0	-
	3d	Case-controlled study	0	-

	3e	Observational study without a control group.	1	van Cranenburgh et al. (2015)
4: Observational – descriptive studies	4a	Systematic review of descriptive studies	N/A	-
	4b	Cross-sectional study	1	Schuster et al. (2020)
	4c	Case series	0	-
	4d	Case study	1	Koulil et al. (2018)
5: Expert opinion and bench research	5a	Systematic review of expert opinion	N/A	-
	5b	Expert consensus	N/A	-
	5c	Bench research, single expert opinion	N/A	-
		Meaningfulness		
1		Qualitative or mixed-methods systematic review	N/A	-
2		Qualitative or mixed-methods synthesis	N/A	-
3		Single qualitative study	2	Iliffe and Thompson (2019) Mollerup et al. (2016)
4		Systematic review of expert opinion	N/A	-
5		Expert opinion	N/A	-

RCTs, Randomised Controlled Trial; N/A, not applicable (to this systematic review)

*We added this category for papers with limited or contradictory information, which prevented assignment to a specific level.

Appendix 20: Characteristics of interventions reviewed according to the TIDieR checklist and guide adapted from Hoffman et al. (2014)

TIDieR item	Relevant information
Alinia et al. (2017)	
1	Online psoriasis symptom questionnaire.
2	Aimed to investigate the effectiveness of weekly online symptom reporting for maintaining treatment adherence.
3 & 4	Participants were prescribed Fluocinonide (0.05%) (topical medication) with an electronic cap that tracked medication use. They were given a treatment protocol at the initial study visit and were instructed to refill their medication canister when empty. Clinic visits were scheduled for 1, 3, 6 and 12 months after initial appointments. Participants reported their symptoms online on a weekly basis, but no detail on the questionnaire provided.
5	The intervention was for people living with psoriasis and was provided by study staff. No mention of staff training.
6	The intervention was designed for individual use. No information provided on the online questionnaire for symptom tracking. Medication Event Monitoring System (MEMS) recorded the number of times participants opened their medication.
7	No information provided on location of visits after recruitment from Wake Forrest Medical Centre, (Winston-Salem, USA).

8	Participants were prescribed Fluocinonide twice daily and recorded psoriasis symptoms weekly online. One initial visit plus four follow up visits scheduled over 12-month study period.
9	Participants had the ability to track their own symptoms.
10	None described.
11 & 12	11) 20/40 participants completed the study. Half withdrew early due to worsening psoriasis (need for change of treatment) (n = 3), starting a concomitant medication (n = 3), not liking the medication (n = 4), burning side-effects (n = 1), loss to follow-up (n = 8) and fungal infection (n = 1). One cap did not record any data. 12) No data on questionnaire completion rates.
Armstrong et al. (2011)	
1	Online educational video.
2	Aimed to improve knowledge of atopic dermatitis and skin care for atopic dermatitis, plus disease severity.
3 & 4	The online video contained information on the clinical manifestations of atopic dermatitis, contributing environmental factors, bathing and hand washing techniques, moisturizer vehicles, and common treatment modalities. Participants received instructions for video access and use and were asked to demonstrate how to locate and view the video during the initial clinic visit.
5	The intervention was for people with atopic dermatitis. It was not clear who created the video content. Intervention provider training was not applicable.
6	The intervention was designed for individual use. Participants accessed the video online using the instructions provided.
7	Participants attended an initial visit to a dermatology clinic but the intervention was delivered online.

8	Participants were instructed to view the educational material at least once during the 12-week study period. Patients could review the material as often as they desired after the initial viewing.
9	This intervention was not tailored to individual users. The video included generic information on atopic dermatitis and care.
10	None described.
11 & 12	11) The Flesch-Kincaid readability score of the pamphlet was assessed to be 46.06 with a reading level closest to 13- to 15-year-olds, but participants health literacy level was not assessed. 12) The number of participants in both arms of the trial that were lost to follow up were reported, but reasons for drop out were not.
Balato et al. (2013)	
1	The following names were used to refer to the intervention: educational and motivational support service; mobile-phone-based intervention; and text message intervention.
2	Aimed to evaluate the use of text messaging in improving treatment adherence and several patient outcomes such as quality of life, disease severity, patient-perceived disease severity and the patient–physician relationship.
3 & 4	Treatment reminders and educational messages were sent to participants via text message. Text messages were written using simple language, considering frequently asked questions about psoriatic drugs (e.g., adverse effects, administration) and general recommendations for overall health. Patients also received a 7-day calendar to track adherence. Intervention provider training was not applicable.

5	The study investigators were physicians and were responsible for sending the text messages to people with psoriasis.
6	Treatment reminders and educational messages were sent to participants s’ mobile phones via text message.
7	Patients were required to have access to a cellular phone that was capable of receiving text messages.
8	Participants received seven text messages per week (1 per day) for a period of 12 weeks in a randomly selected order (reminders three times weekly and educational tools four times weekly).
9	Text messages were not tailored to individual users.
10	None described.
11 & 12	Not described or reported on.
Bundy et al. (2013)	
1	Electronic Targeted Intervention for Psoriasis (eTIPs) treatment programme.
2	Aimed to determine if eTIPs would reduce distress, improve quality of life and clinical severity in patients with psoriasis.
3 & 4	A programme comprised of six modules of Cognitive Behavioural Therapy plus information on: management of self-esteem; thinking styles; low mood and depression; stress and tension; enhancing coping; and information about psoriasis its general management. After login, patients read module material, listened to simulated patients (actors) talk about common experiences and completed brief assignments designed to test and reinforce understanding of core concepts. Intervention provider training was not applicable.

5	The intervention was intended for people with psoriasis. It was developed by the research team, but no information on the expertise or background of the individual team members was provided.
6	The intervention was designed for individual use.
7	Participants accessed the intervention online.
8	Participants could choose when to complete the modules but were encouraged to complete at least 1 module per week.
9	The educational content was specific to psoriasis but was not tailored for individual users.
10	None described.
11 & 12	The CBT modules that formed part of the eTIPs programme followed gold-standard CBT protocols for face-to-face delivery in other health conditions. The rate of attrition rate was recorded. All patients completed at least one course module. In total, 76–85% (depending on the outcome) provided usable post-treatment data. At follow-up, five people withdrew from the treatment group. Attrition rate: 41 participants (32%) did not complete the study, including 26 people (43%) from the intervention group and 15 people (23%) from the control group.
Domogalla et al. (2021)	
1	Educational programme plus a disease management eHealth smartphone app/ psoriasis monitoring app called DermaScope Mobile.
2	Rationale: eHealth devices have shown positive effects on common chronic diseases, including diabetes, hypertension, chronic heart failure, and asthma, yet data are limited in psoriasis. An educational programme

	developed by Bubak et al. (2019) improved knowledge in psoriasis and general health, but not mental health. This study aimed to improve the mental health of patients with psoriasis.
3 & 4	A 2-hour educational programme on psoriasis pathogenesis, therapy options, and comorbidities. Participants attended baseline visits. The intervention group attended the educational programme and after received a personal anonymized access code and an introduction to the psoriasis monitoring app, which allowed for regular photodocumentation of the skin. Participants tracked their quality of life, mood, activity, pain, and pruritus by completing health questionnaires within the app, and could freely contact specialized dermatologists unrestrictedly via a chat feature in the app.
5	The intervention is intended for people with psoriasis. Dermatology specialists delivered the educational program.
6	The intervention was designed for individual use. A combination of in-person and remote delivery methods were used; the educational program was held in person in a group setting before individuals could access the smartphone app.
7	The group education session was delivered at an outpatient dermatology clinic within the Department of Dermatology, Venereology, and Allergology at the University Medical Center Mannheim, Germany. Participants accessed the app via their personal smartphone using their own anonymized access code.
8	Participants were asked to photo-document their skin condition for 60 weeks and input other health data to the app once per week.
9	Participants monitored their condition, quality of life, mood, activity, pain, and pruritus via the app. They were able to contact a dermatologist via the app, suggesting participants could receive tailored advice.

10	None described.
11 & 12	The authors assessed and reported the frequency of app use, as well as the rate of and reasons for dropouts. 20% (10/49) of participants in the control group and 19% (9/47) of participants in the intervention group discontinued use by week 60. Reported reasons for withdrawal included: a lack of time (12/107, 11.2%); unavailability or nonappearance (10/107, 9.3%); distance to the outpatient clinic or relocating (4/107, 3.7%); poor health status (2/107, 1.9%); and other reasons (3/107, 2.8%).
Erdil et al. (2020)	
1	The following names were used to refer to the intervention: short message service (SMS) and text messaging (TM).
2	Aimed to determine whether regular SMS reminder and information messages improve the medication adherence and knowledge of patients with hand eczema.
3 & 4	A new module was created on the dermatology patient education website, DermPatientEd.com, to display an educational video about psoriasis, text-based information, and graphics about side effects. A research fellow recruited clinic patients to the study. Participants received a paper card with a link to the intervention (module and survey) or control (survey only) conditions. Patients viewed the educational content and completed the survey online.
5	Research fellow was responsible for recruiting people with psoriasis to join the study. Participants were examined by doctors at their baseline visit and that this same doctor provided the information session.
6	The intervention was delivered via the internet. Each patient could access the intervention using the unique link on the paper card that was handed to them during their initial visit to the clinic.

7	The intervention was designed for individual use. Participant recruitment and 4 and 8 week follow up appointments took place at Istanbul Training and Research Hospital Dermatology Department.
8	Participants were recommended to use topical corticosteroids twice per day for 4 weeks, and moisturizers at least twice per day for 8 weeks. Informational and reminder text messages were sent twice daily for 4 weeks.
9	The intervention was not tailored to individual users. Text messages were taken from a list of standard prompts (e.g., use soap bars that do not contain colour or perfume').
10	None described.
11 & 12	Compliance with treatment was assessed as the frequency of medication use (at baseline and after 4 and 8 weeks). Compliance to treatment and preventive behaviours were reported: at week 4, 52.9% of the patients in the SMS group and 64.7% of the non-SMS group stated that they forgotten to take, or did not use the treatment, at least once.
Hawkins et al. (2017)	
1	Web application (app) based education.
2	Aimed to educate people with psoriasis using videos, digital graphics, and textual information
3 & 4	A new module was created on the dermatology patient education website, DermPatientEd.com, to display an educational video about psoriasis, text-based information, and graphics about side effects. Each patient received a paper card with a unique link to either the online module and survey (intervention), or just the survey only (control). A research fellow recruited clinic patients to the study. Participants viewed the educational content and completed the survey online.

5	The intervention is intended for people with psoriasis. No information was provided on the people responsible for creating the website content. Training for intervention providers may not have been applicable as this intervention was delivered online.
6	The educational intervention was designed for individual use and was delivered remotely via a website.
7	Participants were recruited from the Wake Forest Baptist Health Dermatology clinic from January 2016 to May 2016. Access to the internet was essential for intervention access.
8	Participants were asked to browse the information on the website and then complete the survey.
9	The intervention was not tailored to individual users, only generic information was provided.
10	No modifications were reported.
11 & 12	The authors intended to contact participants via telephone who did not complete the survey within 72 hours. They reported distributing 50 paper cards with links to the website or survey (25 per group), and 23 surveys were completed, although one contained an unrecognizable numeric study identifier, leaving 22 valid responses in total. The overall response rate to the survey was 46%.
Heckman et al. (2021)	
1	An educational website called ITCH-RELIEF (Interactive Toolbox of Comprehensive Health Resources to Enhance Living with Itch – Educational Facilitation).
2	Aimed to improve itch-related quality of life in adults with atopic dermatitis, psoriasis and chronic itch.
3 & 4	Participants completed an online baseline survey online before they accessed ITCH-RELIEF, which comprised of five modules addressing the components of the Biopsychosocial Model of Chronic Itch. Intervention

	providers sent patients reminders via and/or SMS text to use the materials and to rate their scratching pleasure and itch. Patients completed a follow up survey after 4 weeks.
5	The intervention is intended for people with psoriasis, atopic dermatitis and chronic itch (itch lasting longer than six weeks). No information on the people responsible for creating or delivering the content for the website was provided. Training for intervention providers may not have been applicable because the intervention is delivered online.
6	The educational intervention was designed for individual use and was delivered remotely via a website.
7	Access to the internet was a requirement for intervention use.
8	Participants tested the website over a four-week period. Email and text messages were sent to remind participants to use the materials weekly for 3 weeks and to rate their scratching pleasure and itch.
9	The intervention content was not tailored to individual users.
10	No modifications were reported.
11 & 12	The intervention providers planned to send text or email reminders to patients who had not accessed the website to encourage patients to use the materials and rate their itch and scratching. Website usage was also a secondary outcome. The authors reported 248 individuals completed the screening questionnaire and 173 (69.8%) people were eligible for inclusion. 164 (94.8%) people consented to take part, 137 (83.5%) completed the baseline survey, and 107 (78.1%) completed the follow-up survey and had total length of website visit data recorded. People with atopic dermatitis and psoriasis visited 56.5% of the pages of the website on average. People with atopic dermatitis spent an average of 21.01 (95% CI = 12.6, 29.5) minutes

	on the 16-page eczema-oriented website. Patients with psoriasis averaged approximately 20.9 (CI = 7.0, 34.7) minutes on the 14-page psoriasis-oriented website.
Hedman-Lagerlöf et al. (2021)	
1	Internet-delivered Cognitive Behavior Therapy (ICBT).
2	Rationale: symptoms and distress associated with atopic dermatitis are influenced by learned aversive conditioning, and thus avoidant coping strategies can exacerbate symptoms. Scratching behavior forms part of a vicious cycle in which itch leads to scratching and subsequent skin damage and inflammation. ICBT posits that changing avoidant behaviours is key to reducing symptoms. The aim of the intervention was to reduce symptoms (itch, bleeding, and cracked skin) and improve quality of life, and psychological outcomes (perceived stress, anxiety and insomnia).
3 & 4	Ten modules covering the following topics: introduction and mindfulness training; CBT model for understanding eczema; protecting the skin barrier; issues with control and avoidance behaviors; conditioned eczema symptoms and exposure; exposure and function of behaviors; exposure to social stigma; continued exposure and value-based action; continued exposure and handling sleep problems (optional); treatment summary; and relapse prevention. Contact between participants and the therapist was made through asynchronous text messages.
5	The intervention is intended for adults (18+) with atopic dermatitis. Therapists in the study were four licensed psychologists who specialized in CBT.

6	Therapists delivered ICBT to individuals. The primary role of the therapist was to provide feedback on homework.
7	The treatment was delivered through a secure and encrypted internet-based treatment platform.
8	A 12-week programmer including 10 modules to which participants were granted gradual access.
9	Therapists provided tailored feedback on the participant’s weekly homework assignments and directed the general treatment model to suit the participant’s goals and problems.
10	No modifications were reported.
11 & 12	No plans to measure intervention fidelity/adherence outlined, although the number of hours spent using the online intervention and treating patients were reported: Participants receiving ICBT spent on average 10.8 hours reading the text material and 23.6 hours conducting treatment exercises over 12 weeks. ICBT therapists spent on average 39.7 minutes with each participant.
Iliffe and Thompson (2019)	
1	A closed Facebook peer support group provided by the charity Alopecia UK.
2	Rationale: Facebook groups can provide opportunities to share and gain knowledge, emotional support, as well as achieve goals. Online support platforms might offer protection from social stigma and better opportunities for self-expression and facilitate feelings of empowerment. This study aimed to understand the experiences of online support in people living with alopecia.
3 & 4	A closed group on Facebook for people in the UK with experience of Alopecia. Participants are expected to follow a clear set of rules once accepted into the group. Individuals can post in the group and reply to posts

	by others. All posts must be approved by charity administration staff before they are published to ensure the culture remains welcoming and friendly. Individuals who break the rules are removed from the group and unsuitable posts are deleted.
5	The Facebook group is exclusive to people in the UK who have Alopecia and the family members of patients. The group was created by staff from Alopecia UK who also monitor group membership and activity.
6	A group intervention. Participants require access to the internet and a Facebook account to join the group. Prospective group members are required to answer a set of questions before being allowed to join the group.
7	The group is delivered via the social media platform Facebook. In addition to internet access, group facilitators are needed to moderate group admissions and activity.
8	Members of the support group are free to post to the group whenever they wish, providing their post is appropriate and approved by the group monitors.
9	Tailoring is not applicable to this intervention. Groups members are free to share their personal views and experiences of alopecia, providing the content they share is appropriate and approved by the group monitors.
10	Group membership and content can be modified by administrative staff from Alopecia UK.
11 & 12	Group posts are monitored by staff from Alopecia UK to ensure individuals adhere to the rules of the group, to ensure the culture remains welcoming and friendly. Actual intervention adherence/fidelity was not assessed.
Joergensen et al. (2020)	

1	Electronic memory button and a supportive application (app).
2	Aimed to determine whether the combination of an electronic memory button and a supportive application (app) would affect the quality of life and subjective and objective severity measures among people with atopic dermatitis over one month following the patient’s normal schedules of treatment.
3 & 4	The memory button is CE-marked (developed by The HabLab Aps, KlikKit, Copenhagen, Denmark) and connected via Bluetooth to a mobile phone and the corresponding app. Participants tracked treatment use by clicking the button or manually inputting data into the app. The memory button also saves the clicks, which can be added to the app later. Participants attended two consultations with the same doctor 28 ± 3 days apart. Key outcomes were assessed at both consultations. Participants received care and education on medication application based on their preferred topical treatment and were introduced to the button and/or app at the first consultation.
5	The intervention was designed for people (18+ years) with atopic dermatitis who could read Danish. Doctors were responsible for introducing the button and app, and assessed SCORAD, EASI, POEM, and DLQI at both consultations.
6	The intervention is designed for individuals and was delivered via a digital memory button and a mobile app. The memory button connects to the mobile app via Bluetooth.
7	The intervention was tested by researchers in Denmark. The paper does not state where the two consultations were conducted. The memory button/app was used by patients at home or during daily life by people who had an Android phone or an iPhone.

8	Participants were asked to track their treatment activities, but no further information was provided. It is assumed that participants were required to click a button or register on the app whenever they applied treatment.
9	Patients were able to choose their preferred topical treatment.
10	No modifications were reported.
11 & 12	The authors did not outline plans for assessment of intervention adherence/fidelity. They reported that 84/96 patients completed both consultations, but no additional information was given on those who withdrew from the study.
Koulil et al. (2018)	
1	Tailored Therapist-guided Internet-based Cognitive Behavioural Treatment (ICBT).
2	Aimed to provide an in-depth illustration of the course and content of the tailored therapist-guided ICBT, through 2 case reports differing in symptomatology and treatment goals, including challenges and obstacles that might be encountered. Also aimed to investigate the development of the therapeutic alliance in the online treatment.
3 & 4	ICBT comprised of an introductory module, five treatment modules (pain, itch, fatigue and physical limitations, negative mood, and social relationships), and a closing module. The treatment protocol was based on techniques from standardized protocols for face-to-face treatment of various chronic somatic conditions. One individual with psoriasis attended one or two face-to-face intake sessions with the therapist. A flexible protocol was used for each module and the therapist selected suitable activities and assignments for the person’s goals and clinical profile. Introductory module - treatment goals were set relating to

	decreasing itch-scratching problems and improving mood. Itch module – psycho-education texts and activities (including habit reversal) plus self-monitoring diary. Negative mood module – stress management (e.g., relaxation exercises, distraction, problem-solving, and reappraising the situation); audio relaxation exercises (progressive muscle relaxation, cued relaxation, and visualization exercise); and relaxation/distraction activities (e.g., reading, gardening, cycling, and walking). Closing module - relapse prevention and further goal attainment.
5	ICBT was for people with Psoriasis, Psoriatic Arthritis or Rheumatoid Arthritis experiencing anxiety or negative mood. No details given on the therapist who delivered the intervention.
6	The intervention was delivered to individuals via an online treatment portal.
7	The intervention was delivered online and access to a computer and the internet were a requirement for participation.
8	Up to two modules were selected for each patient based on their treatment targets. Duration of modules varied based on participants' progress through. Activities included goal setting, education, relaxation exercises (once per day), self-monitoring, valued activities, relapse prevention, activity management, sleep hygiene. Feedback on assignments was given once per week.
9	The ICBT was designed as a tailored, personalized treatment. The therapist selected assignments and online texts that were most suitable to patients' individual problems, treatment goals, and perpetuating cognitive-behavioural factors, and gave individualized feedback on assignments approximately once a week.
10	No modifications were reported.

11 & 12	No plans for assessing intervention adherence/fidelity were outlined. The patients use of the ICBT intervention was reported, including the number of logins, assignments completed, as well as the number of messages sent, and phone calls made to the therapist. The participant logged in 47 times, completed 37 assignments (95% of the total given assignments), received 13 messages from the therapist, and sent 11 messages within a period of 5 months (1-week introduction module, 8-week itch module, 9-week negative mood module, 2-week closing module). One phone call was made by the therapist during the online treatment to clarify a given assignment.
Lee et al. (2018)	
1	Acceptance and Commitment Therapy Enhanced Behavior Therapy delivered by way of telepsychology.
2	Aimed to conduct a randomized controlled trial to examine the feasibility of delivering ACT-enhanced behavior therapy as a treatment for trichotillomania by way of telepsychology.
3 & 4	The intervention protocol closely followed an empirically supported acceptance and commitment therapy-enhanced behavior therapy treatment manual (Woods & Twohig, 2008), which includes traditional habit reversal training techniques and contemporary behavior therapy elements from ACT that employ techniques to change the function of the urges to pull as well as the associated cognitions. The intervention group completed a pre-treatment assessment and tracked their baseline hair pulling for one week before starting the 12-week treatment. All treatment sessions utilised telepsychology procedures, meaning participants received all treatment in their homes while therapists were located in a private room in a university clinic. A HIPAA approved video conferencing software (VSee) was utilized. All sessions were

	video and audio recorded and saved to a HIPAA compliant server. All assessments were completed using online survey software (Qualtrics).
5	The intervention was intended for people with trichotillomania. Advanced graduate students provided treatment under the supervision of a licensed psychologist who co-authored the manual on which the treatment protocol was based.
6	Intervention is designed for individual users and was delivered via a video conferencing system called VSee.
7	Participants were based in Utah, USA but received treatment remotely via telepsychology service. Although not stated explicitly, participants required a computer to access the video conferencing software and the internet to complete the required assessments via an online survey software platform called Qualtrics.
8	Individuals attended 10 one-hour treatment sessions in total, ideally one per week.
9	The overall length of the intervention was flexible to accommodate the personal schedules of participants.
10	The paper states that the protocol ‘closely’ followed an empirically supported acceptance and commitment therapy-enhanced behavior therapy treatment manual (Woods & Twohig, 2008), suggesting some modifications may have been made, although it is not clear from the paper if any modifications were made.
11 & 12	All sessions were video and audio recorded using the built-in recording function in VSee. Twenty percent of all sessions were viewed and scored for the quantity and quality of the coverage of each treatment component using a standardized treatment integrity scoring system used in previous ACT research (Crosby & Twohig, 2016; Twohig & Crosby, 2010). Two sessions from each 10-session treatment were systematically chosen such that each session number was reviewed approximately five times. An independent reviewer scored each of the 48 selected sessions. For every coded session, HRT consistent (i.e., awareness training,

	competing response training, and contingency management), ACT consistent (i.e., acceptance, defusion, self as context, present moment awareness, values clarification, and committed action), and ACT inconsistent (i.e., cognitive challenging, experiential avoidant change strategies, and thoughts and feelings cause action) behaviors were rated on a five-point Likert-type scale (1 = the variable was never explicitly covered to 5 = the variable occurred with high frequency and was covered in a very in-depth manner). Therapist adherence to the treatment model and therapist competency were rated on the same scale. Treatment adherence and therapist competency were highly rated. Each process was thoroughly covered in at least one session. On average, the therapists covered acceptance, defusion, and committed action more than other processes, but changes observed in participants from pre to post intervention did not differ significantly between therapists.
Manne et al. (2021)	
1	MySmartSkin (MSS) web-based intervention.
2	Aimed to promote skin self-examination and sun protection behaviours. The conceptual framework guiding MSS was the Preventive Health Model (PHM) and prior work evaluating factors associated with skin cancer surveillance and sun protection behaviors among melanoma survivors.
3 & 4	MSS consisted of an orientation section, a body mole map, and three core sections. Core 1: goals of the intervention, information about melanoma and risks of recurrence, skin cancer risk factors, performing a thorough skin self-examination (SSE); and an overview of sun protection behaviors. Core 2 assessed prior experience with SSE, benefits and barriers to SSE, confidence in conducting skin self-check, and strategies for doing a skin self-check. Core 3 assessed participants’ current sun-safe behaviors guided them to set sun-

	safety goals and provided a sun-safety action plan. Users could access printable documents from each core section and a summary of the most recent SSE and sun-safe action plan. An online body mole map was provided to record and track moles and other skin growths over time. Participants could log in to use the program to help them complete their monthly SSE. Additional elements: features to promote user engagement and interest (i.e., automated email reminders; tailored content; brief physician videos; quizzes; and interactive game-like activities. Participants were emailed a unique username and password. They completed an orientation to MSS before gaining access to the core sections. Core sections were accessed sequentially providing the previous section was completed.
5	The intervention is designed for individuals diagnosed with stage 0–III melanoma who were 3–24 months post-surgery, had not completed a thorough SSE in the past 2 months, and/or were not adherent to sun protection recommendations, were ≥18 years of age, able to speak and read English, and had access to a computer connected to the Internet. There was no intervention provider.
6	The intervention is delivered to individuals via the internet. Individuals are emailed a unique username and password to access the online intervention.
7	The online app intervention was tested by people living in New Jersey, USA but was delivered remotely.
8	No information on the frequency and duration of the intervention was provided, but the study lasted for 48 weeks.

9	Tailored activities included selecting reasons why conducting SSE (and engaging in sun protection) is important to the participant, assessing barriers to engaging in SSE (and engaging in sun protection), and completing action plans for SSE and sun protection.
10	No modifications were reported.
11 & 12	The intervention was evaluated using three surveys: (a) a 20-item Impact and Effectiveness measure assessing the degree to which MSS helped the participant learn how to be prepared to conduct SSE and engage in sun protection behaviors as well as feel in control of his/her health and feel less worried about melanoma (1 = not at all, 5 = very); (b) a 22-item intervention barriers measure, which evaluated technological barriers (4 items), personal barriers to use (6 items), general barriers to use (6 items), and intervention specific barriers (5 items; 0 = not a problem, 1 = a little problem, and 2 = a major problem); and (c) a 15-item Evaluation and Utility survey, which assessed program characteristics, including usefulness, convenience, ease of use, worry about privacy, ease of navigation, and satisfaction with the program (1 = not at all, 5 = very). Participant response rate was reported (40.9%). One hundred forty-eight of the 224 participants (66.1%) completed the orientation and all three cores, 25 (11.2%) completed the orientation and two cores, 10 (4.5%) completed the orientation and one core, 19 (8.5%) only completed the orientation core, and 22 (9.8%) did not complete any of the intervention. Almost 38% of participants did not use the Skin Self-check Program to complete SSE, 26.8% used it once, 15.2% used it twice, 7.1% used it three times, and the remaining 12.8% used it between 4 and 12 times over the follow-up. There was less use of the online Sun Safe Action Plan program, with almost 88% not using it and only 4.5% using it more than once. The average

	number of views that did not involve completing a core module, sun-safe action plan, or skin self-check mole map program was 5.2 (SD = 4.2).
Marasca et al. (2020)	
1	Psychological video consultations.
2	Aimed to improve quality of life and psychological well-being.
3 & 4	The intervention elements and materials were not described, nor were the activities or procedures.
5	The intervention was intended for people with chronic skin diseases, although no information was provided on the intervention provider.
6	Individuals attended psychological video consultations.
7	The psychological video consultations were implemented at the dermatology clinic at the University of Naples Federico II in Italy via the clinic's teledermatology service.
8	Each person attended 3 consultations in total. Consultations were held on a bi-weekly basis (every 2 weeks).
9	No information about tailoring provided.
10	No modifications were reported.
11 & 12	The authors did not state any plans for assessing intervention fidelity/adherence and the short report does not provide any information on actual fidelity or adherence to the intervention.
Mollerup et al. (2016)	
1	Healthy Skin Clinic; a complex nurse-led counselling and website intervention.

2	The aim of the intervention was to support patient self-management of hand eczema. The aim of the study was to qualitatively evaluate the intervention by exploring the participants’ views of the programme, and quantitatively evaluate intervention usage using data capture from a transaction log.
3 & 4	The intervention combined face-to-face nurse-led counselling with access to a website that was designed to facilitate self-management. The paper states the intervention was delivered by ‘four trained nurses’ but does not describe the training nurses received. 4) Face-to-face counselling sessions were delivered immediately following medical consultations. The first counselling session involved a tailored discussion on skin care and an introduction to the website. The second counselling session was tailored to the needs of participants based on their personal website profile. Login to the website was restricted. Each time participants used the intervention, they were required to use two-factor authentication solution, which then prompted a single-use six-digit number. The website had two interfaces: one where patients could communicate and another where patients could communicate asynchronously with the intervention team. It comprised of five menus: (1) patient profile; (2) electronic log for self-monitoring disease; (3) education material and videos; (4) quizzes; (5) patient forum. As for the electronic self-monitoring log, participants registered the date and rated their disease severity on a scale from 0 to 10. They could note their symptom and reflect on influencing factors/triggers, as well as tick the extent of their eczema on a set of displayed hands in an interactive programme to which photographs could be attached. Participants could refer to the data they input, as could the intervention team. Although users were not monitored or contacted regularly by the intervention team. Biweekly emails were sent to participants to prompt use of the website and to contact the team if needed.

5	The intervention was intended for Danish-speaking adults (18+ years) with hand eczema. The intervention team comprised of four trained nurses and one academic researcher.
6	The intervention was intended for individuals, although participants who had access to the website could communicate with other patients via a forum.
7	Counselling sessions were delivered in-person in the dermatology departments of Gentofte, a metropolitan university hospital, and at a large private dermatology clinic in Aalborg in the northern region of Denmark. Participants needed internet access to use the website.
8	Two face-to-face counselling sessions; the first at the beginning of the study and the second after individuals had registered on the website. It is not clear how often patients were required to use the online modules. Reminder emails were sent every two weeks.
9	Counselling sessions were tailored, as participants received personalized recommendations for skin care to suit their lifestyle and the second counselling session was based on information individuals provided in their website profile.
10	Patients who do not use the internet were given a folder with the same information on pamphlets and additional prints designed for a self-monitoring offline version.
11 & 12	The intervention team planned to send bi-weekly emails to remind participants to use the website and contact the team if they desired. This relates to attempts to improve intervention adherence. Website use (login frequency) was reported: 37% (52/140) of registered users did not login within the 6-month follow-up. Average login frequency among the 88 people who used the website at least once was 5.1, with a minimum of one visit and a maximum of 20 unique logins.

Russell et al. (2019)	
1	Online mindfulness-based intervention.
2	The development of the intervention was informed be a systematic review of mindfulness-based interventions, a survey to understand the knowledge, attitudes and practices associated with meditation among people with melanoma and followed recommendations for adapting mindfulness-based programs. The intervention was aimed to help people with melanoma to understand the potential benefits of using mindfulness in their day-to-day life and to support daily meditation practice.
3 & 4	A 6-week online mindfulness-based program delivered via a website composed of three main components: (1) an educational component delivered through short videos, (2) formal meditation practices (MP3 audio files) and (3) an informal practice encouraging mindfulness behaviours in daily activities (e.g., “During next week, notice when you are stressed. How is your body responding? What happens to your breathing? What sort of thought activate your stress?”). Each week of the program explored a different topic and built on topics explored in previous weeks. Email reminders encouraging participants to meditate were sent twice daily. including embedded short videos and a downloadable PDF transcript of the videos
5	The program was designed to be self-managed without any staff or teacher interactions with participants, and allowed for flexible navigation of the website where the content could be accessed according to the user’s preferred order.
6	The intervention was delivered to individuals online via a website.
7	Online. Patients were required to have regular access to a digital device (laptop, tablet, smartphone) and received a unique identification number to access the website.

8	The expected weekly meditation time was 70 min for weeks 1 and 2, and 140 min for weeks 3 to 6.
9	The content of the intervention was not tailored to individual users, but users were free to navigate the online content in their preferred order.
10	No modifications were reported.
11 & 12	Content relevance of the program was recorded weekly through three open-ended questions inquiring about the benefits experienced and aspects of the program liked and disliked. Meditation practice was recorded weekly through self-reported questionnaires capturing the use of any other type of meditation unrelated to the intervention, the frequency and duration of the practice, and, if applicable, reasons for not meditating as recommended.
Schuster et al. (2020)	
1	Facebook.
2	Rationale: Some people consider Facebook as an attractive health care tool from which they can retrieve disease-related information and share experiences with similar others, which might support coping.
3 & 4	Intervention was self-selected access to Facebook. Participants accessed and engaged to suit their needs and preferences. No procedure or protocol for using Facebook was outlined. The aim of this study was to explore the relevance and suitability of Facebook as a source of disease-related information for people with psoriasis.
5	Facebook is open to the public and so this study did not require an intervention provider, it sought to evaluate an existing platform as a source of disease-related information for people with psoriasis.

6	Facebook is intended for individual users but provides an opportunity to connect with other users and groups.
7	Online - Facebook can be accessed through any device that support the internet, or via the existing mobile app. Access to the internet and a user profile is necessary to access Facebook.
8	The frequency of use was at the discretion of individual users. Facebook use ranged from no access to use several times a day.
9	Facebook users can create a tailored profile if they wish.
10	Not applicable to this study.
11 & 12	Frequency and duration of Facebook use were measured. Frequency: never or less than once per month (n = 25, 25%); at least once per month (n = 5, 5%); at least once per week (n = 12, 12%); Daily (n = 25, 25%); several times daily (n = 34, 34%). Daily average duration: less than 5 min (n = 4, 5%); 5–30 min (n = 43, 57%); 30–60 min (n = 18, 24%); more than 60 min (n = 11, 14%).
Sherman et al. (2019)	
1	My Changed Body, a web-based self-compassion focused therapeutic writing approach.
2	Rationale: The intervention has proved efficacious in addressing body image concerns of women in the breast cancer context. (Przezdziecki et al., 2016; Sherman et al., 2018) developed for use with breast cancer survivors. The intervention was adapted for people with visible skin conditions. Aimed to enhance self-compassion and modify emotions, including a decrease in negative affect and increase in positive affect.
3 & 4	Participants were provided with five specific self-compassion focused prompts to structure their writing based on the concept of self-compassion (Neff & Dahm, 2015), including treating one’s body with kindness,

	giving kind advice to the self, having connection with others who also experience body image difficulties, awareness of one’s circumstances and reactions in a broader context, and writing a self-compassionate letter to oneself. Participants were instructed to briefly introduce and describe in writing their deepest thoughts and emotions regarding a negative event they had experienced in relation to their condition.
5	The intervention was intended for people aged 18 years and over experiencing a currently symptomatic and visible skin condition (e.g., eczema, psoriasis, acne) and who had experienced at least one negative event related to their condition (e.g., feelings of failure, humiliation, rejection). No intervention provider.
6	Intervention was intended for individual users and was delivered via the internet.
7	Access to the internet was required as the intervention was advertised and delivered online.
8	Patients were allowed up a maximum of 30 minutes writing time.
9	The intervention was not tailored to individual users.
10	No modifications were reported.
11 & 12	The paper did not outline any strategies for assessing intervention adherence/fidelity. All participants assigned to the intervention (and control) completed the study.
Svendsen et al. (2018)	
1	‘MyPso SmarTop’ smartphone app.
2	Rationale: Topical treatment adherence in psoriasis is often low, which can lead to symptoms worsening. Applications for patient support exist but their role in improving adherence has not been evaluated. Aimed to support adherence to daily application of calcipotriol/ betamethasone dipropionate.

3 & 4	From week 4 to 26 all patients were provided with Cal/BD cutaneous foam to be used once daily. Participants were asked to replace the canister when empty and were told to bring their medication canisters and dispensers for destruction at the week 4 return visit. They were not told in advance about the use of the data obtained by the electronic monitor or that each medication canister was weighed before/after use until the final week 26. The app provided reminders and information on number of applications/ amounts of foam prescribed. Information was collected from a monitor chip synchronized to the app via Bluetooth. The app ceased to collect data after 28 days. Participants could contact the laboratory assistant via telephone regarding use of the supporting app and electronic monitor.
5	Intended for people diagnosed with mild to moderate psoriasis. Delivered by investigator and laboratory assistant.
6	Participants received a canister of Cal/BD cutaneous foam which contained an electronic monitor with a chip registering the day/time used.
7	The study was carried out at a dermatology outpatient clinic at Odense University Hospital. Patients had to own a smartphone, or skills for using a smartphone provided by investigator (if app not supported by patient’s smartphone operating system).
8	The app provided once-daily reminders for daily foam application during a 28-day treatment period. Return visits were scheduled for weeks 4, 8 and 26.
9	Dosage of Cal/Bd cutaneous foam were prescribed for each patient; the appropriate quantity for each application on diseased skin was calculated by determining the involved area expressed as body surface area (BSA) and multiplying by 0.5 g foam per 1% BSA.

10	If a participant's smartphone operating system did not support the app, they were provided with a smartphone by the investigator, providing they had the skills to use it.
11 & 12	Participants could replace the medication canister whenever empty and telephone the laboratory assistant with questions regarding use of the supporting app and electronic monitor. Plans to measure medication adherence involved weighing containers of the topical Cal/Bd cutaneous foam before and after the intervention period. Adherence to medication was reported. Not data on usability of app.
van Beugen et al. (2016)	
1	Internet-based Cognitive behavioural therapy (ICBT).
2	Rationale: People with psoriasis frequently experience a high burden of disease in daily life. Systematic reviews show favourable effects of ICBT for chronic somatic conditions, but research in dermatological conditions is scarce. Aimed to improve physical and psychological functioning and reduce the impact of psoriasis on daily activities.
3 & 4	The intervention comprised of five flexible treatment modules containing a broad variety of cognitive and behavioural techniques focused on themes that patients often experience problems with: itch, pain, fatigue, negative mood, and social relationships. Participants had face-to-face sessions with a therapist (a psychologist) and discussed personal goals. Researchers informed participants on how to use the website via telephone. Participants had to log in to a secure website which hosted the intervention. Treatment modules/ individual assignments were based on individual goals, therapist's judgment, and screening procedures. Participants received written feedback on assignments.

5	The intervention was intended for people with psoriasis aged over 18 years, with a positive psychological risk profile (e.g., impact of chronic skin disease on daily life ISDL score of >5 for anxiety and/or >21 for negative mood). Face-to-face sessions were delivered by a therapist (psychologist). There were six female therapists (mean age =29.67,8.76) who had at least an MSc in Clinical/ Health psychology, previous experience of therapy ranging from 0-7 years (mean=2.17,2.79). Three therapists completed studies as healthcare psychologists. All therapists were supervised by a senior clinical psychologist trained in CBT.
6	The ICBT intervention was intended for individuals with psoriasis who accessed the intervention via the internet, by logging on to the secure intervention website.
7	This intervention was tested on people with psoriasis from outpatient dermatology departments in Dutch hospitals and through the Dutch Psoriasis Association. Participants underwent two initial face-to-face intake sessions with therapist and then logged in to the secure intervention website.
8	Intervention duration and content varied between participants, depending on treatment goals, with a mean duration of 25 ± 12 weeks (range 1–57 weeks). During the intervention, there was a period of >4 weeks of no contact with the therapist in 20% of patients (N=13) and IBCT was paused for 34% of patients (N=22) because of personal circumstances. IBCT length was calculated excluding the mutually agreed upon weeks of non-intervention.
9	Participants were given a choice of treatment modules. The assignments within these modules were based on the individual’s goals, therapist’s judgment, and screening procedures. Therapists provided participants with personalized written feedback on their assignments once a week.
10	No modifications were reported.

11 & 12	The research team planned to measure adherence to ICBT. Patient satisfaction with ICBT/evaluation of user-friendliness was assessed on a 10-point Likert scale with greater scores indicating greater satisfaction and user-friendliness. Patients were asked to rate to what extent they felt the intervention had a sustained positive effect, and whether they would recommend the intervention to a friend on a 4-point Likert scale ranging from 'no' to 'certainly.' Intervention attrition was assessed: The ICBT intervention dropout rate was 26.2%: 10 patients did not start treatment (non-starters, 15.4%), 6 patients dropped out during treatment (non-completers, 9.2%), and 1 patient (1.5%) died during treatment.
van Cranenburgh et al. (2015)	
1	E-learning quality of life (EQoL): a Web-based, Educational, Quality-of-life Intervention.
2	Aimed to improve patients' knowledge and skills to cope with their skin disease more effectively and improve their Health-Related Quality of Life. Intervention components were based on Skindex-29 and content was matched against the stages of change as described in the Transtheoretical Model.
3 & 4	The website www.kwaliteitvanleven.nl consists of 6 components: itch, worries, anger, depression, social contacts and leisure time, which are derived from Skindex-29. After a consultation at the outpatient clinic, participants completed a questionnaire on background characteristics and signed an informed consent form. At the same time, the health care provider completed a questionnaire about the patient. Subsequently, the researcher sent the patient an e-mail with a personal password to log into the website. Patients who had not visited the website during the first 2 weeks, received a reminder by e-mail. If needed, patients could contact a help desk. Eight weeks after inclusion, patients received a questionnaire by postal mail. Patients

	who did not return the questionnaire within 2 weeks received reminders by e-mail and/or telephone. During participation in the study, patients’ control visits at the dermatology outpatient clinic were planned following routine clinical practice. At the end of the study, health care providers received a questionnaire by postal mail and a reminder by e-mail, if necessary.
5	The intervention was intended for outpatients (18+) with chronic skin conditions who were recruited by dermatology staff in dermatology clinic. No information about the expertise, background, or training of the people responsible for creating or delivering the content for the website, although researchers were based in dermatology and medical psychology departments.
6	Individuals accessed the website independently via the internet.
7	Participants needed access to a computer with internet connection to access the website.
8	Participants had access to the website for eight weeks, but no information was provided on the required frequency or duration of use. Individuals who did not visit the website during the first two weeks received an email reminder.
9	Participants were able to choose parts of the intervention that were relevant to them but the website was not tailored to individual users, nor were e-mails personalised. This was recognised as a limitation and potential improvements.
10	No modifications were reported.
11 & 12	Researchers planned to analyse dropouts and participants who were lost to follow-up using independent t-tests, Mann Whitney, and χ2 analyses. Dropouts were reported, plus reasons: 107 eligible and provided consent. One patient did not complete the informed consent form and one patient completed less than 50%

	of the baseline questionnaire. 105 patients received a website login. Ten patients (9.5%) withdrew before the end of the study (drop-outs), of whom 7 completed the follow-up questionnaire prematurely. Thirty-two patients (31%) did not return the follow-up questionnaires despite reminders. Characteristics of dropouts vs non-dropouts were compared, as were those of people lost to follow up.
Zhao et al. (2021)	
1	Xingshulin mobile phone patient-to-practitioner system.
2	Aimed to increase adherence to hospital visits and medication The goal of the study was to investigate the effectiveness of using a mobile phone-based messaging app to allow patients to access on demand information about their psoriasis diagnoses and their medications and receive reminders to attend regular clinic check-ins.
3 & 4	The intervention comprised of a commercially available mobile app called Xingshulin. The app provided medical information, including frequently asked-for information, as well as reminders for application of the drug, reminders for regular visits, and self-assessment forms written in Chinese. The app allowed for communication between participants and certified dermatologists. People with psoriasis and dermatologists participating in the study were required to install the app. Dermatologists received electronic reminders to communicate with patients and were required to respond to patients within 24 hours.
5	Intended for adults (18+) living with mild to moderate plaque psoriasis who were prescribed Daivobet®. The app provided a remote platform through which patients could communicate with certified dermatologists asynchronously, and so the app was also intended to be used by health professionals specialized in dermatology.

6	The app was designed for individual users and treatment information and reminders were delivered remotely via the app. Participants received a prescription for Daivobet® in person and were expected to attend clinic appointments at weeks 2, 8, 16, 28, 48, and 52 of the study.
7	The mobile-based intervention was tested with people attending twelve hospitals in China. The content of the app was written in Chinese. Access to a smartphone was needed to download and use the app, although this was not stated in the eligibility criteria. It was unclear if participants used their personal smartphones or were given one to use for the duration of the study.
8	People with psoriasis received a 1-year treatment protocol for Daivobet®. Participants were prescribed Daivobet® once daily use for 2–4 weeks to flatten their skin lesions, after which they were to use Daivobet® once every other day until the colour of their lesions faded. Daivobet® was then prescribed for use twice per week, or Devonex® once daily for at least eight weeks, for skin maintenance before individuals switched to ’treat-as-needed’ until week 52. The app sent automatic messages to dermatologists reminding them to inquire with patients (twice in the first 4 weeks, and once in 4 weeks after the second month). It is unclear how often people with psoriasis were required to use the app.
9	People with psoriasis were able to use the treatment as needed for part of the study. It was not clear whether the messages sent to patients were generic or tailored.
10	No modifications were reported.
11 & 12	In terms of medication adherence, 41/221 participants returned their medication adherence questionnaire in week 12. Visit rates in the intervention and control group were reported. The investigators stated that

they were not able to track the reasons why participants did not complete the study, nor could they record the frequency or duration of app use.

1: Brief name – name or phrase used to define the intervention.

2: Why – rationale, theory or goal of the intervention.

3: What (materials) – description of the elements of the intervention, including materials, and (if applicable) training for intervention providers.

4: What (procedures) – description of intervention activities and delivery procedure(s).

5: Who – information about the intervention provider (title, expertise, background and if training was given) and target audience.

6: How – mode of intervention delivery, including whether the intervention is delivered to individuals or a group.

7: Where – name location or setting where the intervention was delivered and infrastructure required to facilitate its delivery.

8: When/how much – intervention frequency and duration of the intervention, including sessions/activities that form part of the intervention.

9: Tailoring – information about how the intervention was personalized (what, why, when and how).

10: Modifications – description of any changes made to the intervention during the study (what, why, when and how).

11: How well (planned) – plan for assessing and/ or improve intervention adherence/ fidelity.

12: How well (actual) – degree to which the intervention was delivered as intended (only if intervention adherence/fidelity was assessed).

Appendix 21: Results for effectiveness of digital psychological interventions by outcome

Outcome	Results
Alinia et al. (2017)	
Alcohol consumption/ smoking status	When these covariates were included in the analyses, the significant between-group difference in PASI scores at month 12 no longer reached statistical significance.
Treatment adherence	Significantly higher in the intervention group relative to controls from month one to ten, but rates declined over time.
Disease severity	Significant improvement in PASI scores at months one and three. No significant change in IGA at month 1, 3 or 12.
Armstrong et al. (2011)	
Knowledge of condition	Significant improvement after 12 weeks.
Disease severity	Significant improvement in POEM scores in the intervention group at 3 months, compared to controls.
Satisfaction with intervention	(appeal and usefulness)
Balato et al. (2013)	
Quality of life	Significant between-group difference favouring the intervention group after 12 weeks.
Treatment adherence	No significant between-group difference in the number of days per week participants forgot to take their medication.
Disease severity	Significant improvement in PASI, SAPASI, BSA, GPA scores at three months.

Patient-physician relationship	The intervention group reported an improvement after 12 weeks. This change was not observed in the control group.
Bundy et al. (2013)	
Beliefs about condition	Results not reported.
Anxiety	Significant improvement observed for the intervention group from baseline to six month follow up, compared to controls (complete case analysis).
Depression	No significant difference.
Quality of life	Significant between-group difference favouring the intervention group after six weeks.
Alcohol consumption	Results not reported.
Smoking status	Predicted missing outcomes.
Disease severity	No significant between-group difference in self-reported psoriasis severity at 6 months.
Domogalla et al. (2021)	
Mood	Significant improvement observed in the intervention and control group. Group membership had no significant effect.
Quality of life	Improvement in QoL but change not statistically significant.
Anxiety	Improvements seen in all patients at weeks 12 and 24. The difference in group anxiety scores at week 60 did not reach the threshold of statistical significance. Lower levels of anxiety remained stable at weeks 36 and 60 in people who used the app less than 20% (once every 5 weeks).
Depression	Significant reduction observed in all patients from baseline to week 60. The intervention group showed a significantly greater reduction in depression scores at weeks 12 and 24.

Alcohol consumption/smoking status	Reported for demographic purposes only.
Daily activities	Reduction in impairment on daily activities in all participants, but the difference between the intervention and control group was not significant.
Disease severity, itch and pain	Reductions in PASI, itch and pain were seen in both groups at week 60. Differences between groups were not significant.
Erdil et al. (2020)	
Knowledge of condition	Significant improvement after 8 weeks.
Protective behaviours	The intervention group showed a significant increase in moisturiser use from baseline to week 4 compared to controls. No differences in hand washing or the use of gloves, liquid soap, cologne, or wet wipes were observed.
Treatment compliance	The difference in the percentage of people in the intervention (52.9%) and control (64.7%) groups who forgot to take, or did not use their medication, was not significant.
Disease severity	Significant reduction in HECSI scores after two months.
Hawkins et al. (2017)	
Knowledge of condition	Significant and immediate improvement.
Concerns	Seven participants reported not all their concerns were addressed by their clinician.
Treatment adherence	Participants were not more likely to take their medication as prescribed post-intervention.
Satisfaction with intervention	
Heckman et al. (2021)	
Itch cognitions	Significant reduction in catastrophising.

Perceived Efficacy in Patient-Physician Interactions	Result not reported.
Stress	Result not reported.
Itch-related quality of life	Significant within-group differences in QoL after four weeks, also for the emotion subscale.
Scratch	A significant reduction in scratch intensity and especially scratch impact was observed after one month relative to baseline scores. Significant difference between baseline and follow up scores on the sleep-related itch and scratch scale, suggesting the intervention group experienced a reduction in scratching during the night.
Risk of treatment non-adherence	Result not reported.
Itch	Significant improvement in itch severity at 1 month.
Frequency and duration of intervention use	
Completion rate	
Hedman-Lagerlöf et al. (2021)	
Stress	Significantly larger reduction in perceived stress in intervention group compared to control group.
Anxiety	No significant between-group difference.
Depression	Significantly larger reduction in depression scores in the intervention group compared to controls.
Quality of life	Significant between-group difference in QoL when using the BBQ scale, but not the Dermatology Life Quality Index.

Sleep problems	Compared to the control group, participants in the intervention group reported a significant reduction in sleep problems from baseline to six month follow up, which remained stable after 12 months.
Itch	Result not reported.
itch intensity (past 48 hours)	Result not reported.
Disease severity	Moderate to large reduction in symptoms (POEM), which was sustained at 12 month follow up.
Health status	No significant between-group difference.
Satisfaction with intervention	
Iliffe and Thompson (2019)	
Personal experiences of an online support group for people living with alopecia	
Joergensen et al. (2020)	
Quality of life	No significant between-group difference.
Treatment adherence	Result not reported.
Disease severity	Significant improvement in POEM, EASI and SCORAD scores observed in the intervention group compared to controls.
Koulil et al. (2018)	
Illness cognitions	Significant improvement in helplessness but not acceptance.
Worry	No large differences found.

Anxiety	Improvement of at least 30% post-intervention that was not sustained at follow up; slight increase in anxiety scores after six months.
Depression and negative mood	Improvements of at least 30% post-intervention and after six months.
Sleep hygiene	Result not reported.
Scratch	Significant reduction observed.
Treatment compliance (frequency of medication use)	No change in maximal compliance throughout the study.
Disease severity	Despite patient-reported improvements, clinician-assessed disease severity worsened slightly from baseline and six month follow up.
Patient-physician relationship	Scores obtained for face-to-face sessions were either maintained or improved following the online intervention, but it is not clear whether any of the changes observed were statistically significant.
How useful/motivating patient found contact with the therapist	
Satisfaction with intervention	
Daily activities (role limitations)	The individual with psoriasis reported maximal impact at the beginning of the study. No change from baseline to post-treatment or follow up.
Perceived social support and stigmatization	High levels of social support and low levels of stigma at baseline were maintained over the study period.
Lee et al. (2018)	

Shame	Scores reduced from pre to post treatment for all participants, but the difference between groups was not significant. The combined analysis showed a significant reduction (18.2%) in scores from pre-treatment to follow up.
Quality of life	Improvement in QoL but change not statistically significant.
Psychological inflexibility	Scores decreased in the intervention (19.6%) and control (3.4%) groups pre to post intervention, but the difference was not significant, nor were the combined scores from post intervention to follow up.
Psychological symptoms	Result not reported.
Hair pulling	Significant difference between intervention (reduced by 42.2%) and control (increased by 17.7%) group. The combined analysis revealed a significant reduction (39.4%) from pre to post treatment. Scores decreased (26.3%) from post treatment to three month follow up, but the change was not statistically significant.
Patient-physician relationship	Participants reported high average scores.
Satisfaction with intervention	
Manne et al. (2021)	
Knowledge of condition	Partially mediated (22%) the relationship between intervention use and performing sun protection behaviours.
Self-efficacy for performing a skin self-examination	T-tests indicate that skin self-examination self-efficacy was higher in the intervention compared to the control group.

Self-efficacy for performing sun protection behaviours	Partially mediated (29%) the relationship between intervention use and sun protection behaviours.
Self-management issues (use of gloves, topical steroids, consulting General Practitioner)	
Frequency of sun protection behaviours (use of sunscreen, hats, long-sleeves, and staying in the shade).	Intervention group reported performing more sun protection behaviours at 24 weeks compared to the control group, although the effect was small. This effect was also evident at 48 week follow up when covariates were included in the analysis.
Performance of a skin self-examination	
Number of page visits	
Completion rate	
Barriers (technological, personal and general barriers to use, and intervention-specific barriers)	
Perceived effectiveness of intervention	
Programme characteristics (usefulness, convenience, ease of use and navigation, worry about privacy, and satisfaction)	
Marasca et al. (2020)	

Quality of life	Significant within-group differences in QoL after four weeks.
Psychological well-being	Improvements were observed from baseline to weeks two and four, but the changes were not statistically significant.
Mollerup et al. (2016)	
Self-efficacy	Intervention group showed a greater improvement in confidence for self-managing eczema compared to controls, but the difference was not statistically significant.
Quality of life	Significant between-group difference favouring the intervention group after 6 months.
Treatment adherence	Result not reported.
Itch (in the past 4 weeks)	Significant improvement at 6 month for intervention group.
Disease severity	No significant difference in hand eczema severity (HECSI) at 6 months.
Number of page visits	
Protective behaviours	Significant improvement in performing protective habits (e.g., use of topical steroids and consulting GP) observed in the intervention group compared to controls.
Schuster et al. (2020)	
Affect	There were no significant differences between Facebook and non-Facebook users for affect.
Happiness	There were no significant differences between Facebook and non-Facebook users for happiness.
Facebook envy	Higher levels of Facebook envy tended to report lower levels of subjective well-being and happiness.
Quality of life	Higher DLQI was associated with more frequent searching for disease-related information on Facebook.

Life satisfaction	There were no significant differences between Facebook and non-Facebook users for life satisfaction.
Frequency and duration of intervention use	
Sherman et al. (2019)	
Affect	Significant and immediate improvement in negative, but not positive affect, compared to controls.
Body image related distress	No significant effect on self-compassion or positive or negative affect when analysed as a covariate.
Self-compassion	A significant and immediate improvement was observed in the intervention group, compared to the control group.
Disease severity	Results not reported.
Svendsen et al. (2018)	
Quality of life	Significant between-group difference favouring the intervention group after eight weeks. QoL scores decreased 26 weeks.
Smoking status	Included as a covariate but result not reported.
Treatment adherence	Self-reported adherence was higher than that as measured by the weight of medication canisters, and the intervention group indicated greater adherence to the cutaneous foam compared to the control group, but the differences were not statistically significant. Significant between-group difference in treatment adherence as measured by electronic medication dispenser.

Disease severity	The intervention group showed a significantly greater reduction in LS-PGA compared to the control group at week 4. Similar effects were seen at weeks 8 and 26, although these were not statistically significant.
Patient-physician relationship	Positive perceptions of the therapeutic alliance pre-intervention were correlated with greater improvements in psoriasis outcomes post-intervention.
Russell et al. (2019)	
Rumination	Reduced rumination related to melanoma, but not statistically significant.
Stress and worry	No significant between-group difference.
Fear of cancer recurrence	Significant reduction in the severity of fear of cancer recurrence at follow up compared to controls, but few scores fell below the clinical cut-off (≥ 13).
Experience of mindfulness	Nineteen participants reported having had some experience with meditation.
Frequency of informal meditation practice	The average time spent meditating per week varied from 64 minutes in week 2 to 129 minutes in week 5.
Relevance of intervention content (benefits and participant preferences)	
Perceived helpfulness of intervention	
van Beugen et al. (2016)	
Treatment compliance	No significant between-group difference.
Psychological functioning (depression, negative mood and anxiety)	No significant between-group differences were found for anxiety, depression, negative mood, or psychological functioning overall.

Disease severity	No significant between-group difference.
Physical functioning	After six months, the intervention group showed significantly larger improvements compared to the control group. Significant effects were found for fatigue but not for itch.
	After six months, a significant improvement was observed for role limitations due to emotional and physical health problems in the intervention group compared to the control group. The improvement in role limitations due to emotional problems was further enhanced at follow up.
	The secondary analysis, which included baseline values of the dependent variable, showed no significant between-group difference.
van Cranenburgh et al. (2015)	
Frequency and duration of use	
Number of page visits	
Factors preventing intervention use	
Relevance of intervention	
Convenience of intervention	
Intervention design (layout and attractiveness)	
Intervention design (font size and text length)	
Zhao et al. (2021)	

Treatment adherence	Thirteen (31.7%) out of 41 participants who completed the 12-week follow up questionnaire reported using the drug ‘sometimes’ or ‘never.’
Visit adherence	No significant between-group difference.

PASI, Psoriasis Area and Severity Index; IGA, Investigators Global Assessment; POEM, Patient Orientated Eczema Measure; SAPASI, Self-Administered Psoriasis Area and Severity Index; BSA, Body Surface Area; PGA, Physicians Global Assessment; QoL, Quality of Life; HECSI, Hand Eczema Clinical Severity Index; BBQ, Brunnsviken Brief Quality of Life Scale; EASI, Eczema Area and Severity Index; SCORAD, SCORing Atopic Dermatitis; GP, General Practitioner; DLQI, Dermatology Life Quality Index; LS-PGA, Lattice System Physicians Global Assessment.

Appendix 22: Characteristics of intervention studies published since the systematic review

Author and Country	Skin condition	Intervention	Study design	Outcomes of interest	Key findings
Gernart et al. (2017) Germany.	Chronic Pruritis.	Itch App: Smartphone App containing questions on itch severity and quality of life.	Randomised Control Trial, feasibility study.	Itch intensity, QoL.	Excellent test-retest, inter-item validity and convergent validity Majority were able to use the smartphone app for data entry without problem. Those who had technical difficulties were generally older. 97.5% agreed that the app fulfils its purpose. QoL was correlated with itch severity.

Garzorz-Stark et al. (2021) Germany.	Psoriasis.	Smartphone application called IMPROVE 1.0. Prompts users to complete biweekly questionnaires assessing QoL, stress, lifestyle factors and psoriasis severity levels.	Before and after design (48-week intervention period).	QoL, stress, lifestyle factors (drinking alcohol, smoking cigarettes, diet, exercise, body weight, and sleep) and psoriasis severity levels.	Psoriasis severity was correlated with QoL, BMI, stress, and lifestyle factors. 80% considered app to have positive effect.
Trettin et al. (2021a) Denmark.	Psoriasis.	Smartphone app containing a ‘knowledge database’ with information, videos, and a podcast of educational information. The app also contained the DLQI and a questionnaire to prepare for consultations, and the option for video consultations.	Semi-structured qualitative interview study.	Insight into experiences of using the mHealth app.	For both patients and HCPs, using the app was seen as a new approach that required training. The structural analysis revealed 3 main themes: (1) preparation increases reflexivity, (2) video consultations increase the much-appreciated

					attentiveness, and (3) a new approach requires new competencies.
Brandl et al. (2022) Germany.	Psoriasis.	Smartphone application that allows participants to record symptoms, such as itch, and suggests measures to alleviate.	Before and after design (21-day intervention period).	QoL using the DLQI.	No clinically relevant influence on quality of life.
Fortune et al. (2022) Ireland.	Psoriasis.	Smartphone application called Allay that includes CBT-type activities, such as awareness activities, gratitude activities, and forgiveness activities.	Before and after design (12-week intervention period).	QoL, resilience, beliefs about psoriasis, mental heath	Significant changes at end of intervention to perceived impact of psoriasis on emotions, resilience, depression, symptoms, and quality of life. No significant change to mental health. Significant reductions in depression, no

					significant reduction for anxiety. Significant reduction in physical symptoms.
Gudmundsdóttir et al. (2022) Iceland.	Eczema.	Smartphone app which prompts users to complete daily missions themed around nutrition, exercise, mindfulness, disease-specific educational content, and general health.	Before and after design (6-week intervention period).	AD severity, QoL and treatment adherence.	Symptom severity decreased over time. QoL was less affected by AD following intervention. Treatment adherence improved following intervention
Zelihić et al. (2022) Norway and the Netherlands.	Visible Differences.	Young-persons Face IT. Web-based intervention with 7 weekly sessions in a variety of formats, providing guidance on topics such as managing	Randomised Control Trial.	Body esteem, social anxiety, perceived stigmatization, life disengagement.	No significant main effect on body esteem post intervention. Significant reduction in social anxiety post intervention in intervention group.

		staring, bullying, and anxiety.			No significant effects on self-stigmatisation. Non-signification main effect (reduction) on life disengagement.
Greenwell et al. (2022) England.	Eczema.	Eczema Care Online, a web-based application containing educational content on topics such as trigger management, emollient use, emotional management and scratching.	Qualitative think-aloud interviews.	Perceptions of web-based application to support eczema self - management.	Participants valued ECO providing advice on living well with eczema, rather than focusing solely on medical treatments. They particularly valued quotes from others with Eczema.
Norman et al. (2022) United Kingdom.	Visible differences.	Face IT@Home, an eight session programme; with content aimed at addressing distress caused by visible differences.	Qualitative semi-structured and think-aloud interviews.	Usability, Acceptability and Accessibility.	The majority found the app to be acceptable and easy to use, and most found the content to be accessible, bar two

					participants who found it to be too burdensome.
Weigandt et al. (2023) Germany.	Hand and foot eczema.	Smartphone app called DermaScope Mobile, on which patients were able to take pictures of their hands and feet, use a chat function to ask questions that were answered by their treating dermatologists, and complete questionnaires on quality of life (DLQI) and current symptoms (NRS for itch and pain).	Randomised Control Trial.	QoL, pain, eczema severity.	No significant differences between groups in QoL, pain, or symptom severity.
Andrade et al. (2023) USA.	Eczema.	The educational intervention consisted of a weeklong module on a WhatsApp group chat led	Before and after study (1 month intervention period).	Health knowledge.	There was a significant increase in health knowledge following the in intervention

		by a study moderator with daily educational modules consisting of educational text, audio messages, visual aids, and a summary video.			that was retained at one-month follow up.
Kishimoto et al. (2023) Japan.	Eczema.	Self-Compassion and Mindfulness Integrated Online Program for People Living With Eczema (SMiLE), eight 90-minute weekly group sessions of online mindfulness and self-compassion training, and an optional silent, 5.5-hour meditation retreat.	Randomised Control Trial.	QoL, Eczema severity, itchiness, mindfulness Inventory, self-compassion, anxiety, depression, shame and dermatologic treatment adherence.	All outcome measures were significantly improved in the treatment compared to the control group.
Kern et al. (2023b) Sweden.	Eczema.	Web based application containing educational (such as physical and psychological factors	Before and after design (6-week intervention period).	Intervention credibility and usability., QoL, depression, stress,	Credibility was rated above the ‘acceptable’ cutoff point of 70, but usability was rated as

		related to AD) and CBT based content.		pruritis, symptom improvement.	below the acceptable cutoff of 70. Following the intervention, all outcomes showed significant improvements except pruritis. At 3-month follow-up, all outcomes were significant.
Yasuda et al. (2023) Japan.	Eczema.	Smartphone app with three functions: display HA scores of scratch bouts and sleep status; record outcomes and record use of medications and moisturizers.	Two clinical trials were conducted. The first was to develop algorithms to detect scratch and sleep and to discriminate between scratch and non-scratch hand movements using a	QoL, sleep quality and itch.	All outcome measures were improved in the intervention group compared to the control group following the intervention period.

			device called a hand actigraph (HA). The second was a randomized trial.		
Zvulunov et al. (2023) Global.	Eczema.	Smartphone app called the Atopic App. Users complete POEM questionnaire, take clinical photographs, rate itch, transcribe treatment plans, record triggers, and access patient education.	Before and after design (11-month intervention period).	AD severity, AI accessed severity of clinical photographs, feasibility of intervention.	POEM scores significantly improved following the intervention. POEM scores were significantly correlated with AI severity scores and rating of itch.

QoL, Quality of Life; DLQI, Dermatology Life Quality Index; BMI, Body Mass Index; CBT, Cognitive Behavioural Therapy; POEM, Patient Oriented Eczema Measure; AI, Artificial Intelligence.

Appendix 23: Online group interview questions mapped against theoretical concepts

Theoretical Model or Framework	Theoretical Concept	Question	Prompts/Instructions
CSM	Identity, Timeline, Consequences.	We know that having a skin condition can affect people in many ways. How does your skin condition affect you? We know that having a skin condition can affect people in many ways. In the chat box, please tell me what the biggest impact of living with a skin condition is for you?	Show visual prompt depicting types of impact. What impacts you the most? Type the three main impacts in the chat box. What about impact over time? Show visual prompt depicting types of impact. Please explain your answer, if you wish.
CSM	Illness beliefs	I'm interested to find out how you manage *all* aspects of your skin condition day to day, we talk about self-management but… What does the term 'self-management' mean to you?	None.

		When it comes to looking after yourself and your skin, people often talk about self-management… What does the term ‘self-management’ mean to you?	None.
COM-B	Capability, Self-efficacy	I want to know how confident you feel in relation to managing *all* aspects of your skin condition. On a scale from 0-10 (0 = not confident, 10 = completely confident), how confident do you feel in *your* ability to manage *all* aspects of your condition? On a scale from 0-10 (0 = not confident, 10 = completely confident), how confident do you feel in *your* ability to manage *all* aspects of your condition? Type and explain your answer in the chat box.	Type and explain your answer in the chat box. Type and explain your answer in the chat box
CSM	Controllability, Coping	What kinds of things do you have to do day to day to manage your skin condition? Question was revised and re-worded as a set of instructions for participants to follow.	What do you find easy? What do you find challenging? Can you say why? Think about the kinds of things do you have to do day to day to manage *all* aspects of your skin condition. In the chat

			box, please type which aspect of managing your conditions you find easiest, followed by what you find most challenging. Briefly explain why, if you wish.
CSM	Controllability, Coping	Which aspects of your condition, if any, do you feel you need additional support with? Question was removed.	None. N/A.
CSM	Controllability, Coping	What might help to improve how you manage your skin condition? Same question. New prompts were introduced.	None. Some people have said finding a routine is helpful, what do you think about this?
CSM	Controllability	What would help you to feel more in control over the management of your skin condition? Many people have told us that they want to feel more in control of their condition. How do you think we can help you and others to feel more in control of managing a skin condition?	None. Some people have told me that learning to accept their skin condition helped them to manage it better. What do you think about this?
CSM	Coping,	I want to understand what types of psychological/emotional support, if any, are	Tell me about the support you received.

	Social context (services)	currently available to you, in addition to your medical care, to help you to manage your skin condition. Has anyone sought psychological/emotional support because of their skin condition? If so, what was your experience?	How did you access the support? barriers/facilitators) What did it involve? What about lifestyle? Who provided the support? How was support delivered to you? Was there a cost involved? What were the advantages/disadvantages? What was missing?
		Have you ever been offered psychological/emotional support in relation to your skin condition? Have you sought psychological/emotional support because of their skin condition?	In the chat box, please answer yes or no to the following questions: Those of you who said yes, please can you briefly tell me about your experience. For those of you who haven't can you, type in the chat what types of psychological or emotional support would be helpful for you, if anything at all?
TFA	Affective attitude, Ethicality	We are developing a new smartphone application to support people to manage their skin condition	Can you tell me why?

		and live well in their own skin. What do you think about this? Same as above.	Same as above.
CSM	Coping	How do you think we can we support people psychologically/emotionally through an app? How do you think we can we support people to live healthily through an app?	Provision of information, practical tips, goal setting and action planning. What about living healthily? Provision of information, practical tips, goal setting and action planning.
TFA	Affective attitude	Some people have told us that having access to other people with skin conditions is important to them. How do you feel about that? People have told us that social support is important. Some people have expressed a preference for support from others with the same condition, others said social interactions with people living with any skin condition would be helpful. If social support via an app is important to you, can you type in the chat box whether you'd prefer general or condition-specific support?	Can you tell me why? How do you think can we support people to be socially active through an app? If social support via an app is important to you, can you type in the chat box whether you'd prefer general or condition-specific support?

TFA	Affective attitude, Ethicality	People often tell us that trust is a big issue with using apps, help us to understand how we can develop a new app that people trust? People often tell us that trust is a big issue with using apps that are endorsed by industry partners or companies. What do you think about this?	Endorsement by health professionals or patient organisations. Consistent with national guidelines for managing skin conditions. How can we develop a new app that people trust? Endorsement by health professionals or patient organisations. Consistent with national guidelines for managing skin conditions.
TFA	Ethicality, Intervention coherence	If you had the opportunity to design a new app and you could choose one thing to focus the app on to help people with a skin condition to live better with their condition, what would that one thing be? Same as above.	Please put your answer in the chat box and we will discuss. Can you tell me why? Same as above.
COM-B	Opportunity	We want to ensure that people with skin conditions can access the app. How can we make the app accessible to people with skin conditions? Same as above.	Barriers and facilitators. Same as above.

COM-B	Motivation	We also want to ensure that people who access the app continue to do so. Think about the apps you use regularly – what makes you keep coming back to the app? How can we ensure that people who access the app continue to do so?	None. Think about apps you use regularly and what makes you keep coming back to these. Think about cost, personalisation, reminders or alerts, visual feedback, virtual points or rewards; content including images and videos.
N/A	N/A	Some people may be less inclined to use an app that required them to input personal data, for example, their age, weight, and information about their health. How can we overcome this issue? Some people have told us they would be less inclined to use an app that required them to input personal data (e.g., their age, weight, and health information). How can we overcome this issue?	None. None.
TFA	Intervention coherence.	Throughout our discussion, you may or may not have been forming ideas in your mind about how	Think about the colour scheme, content (information, images and videos,

		the new app might look on a screen. Take a few seconds to imagine the new app. Please describe what you see in the chat box. Same as above.	interactive activities) option communicate with other people with skin conditions. If you are struggling, think about other apps – what do you like/dislike about those? Same as above.
N/A	N/A	We need to pick a name for the new app, and we have some ideas already. We are interested to hear your ideas for names for the app. Think for a moment and share your ideas in the chat box. Same as above.	Show visual prompt including potential names for app. Show visual prompt including potential names for app.

CSM, Common-Sense Model of Self-Regulation (Leventhal et al. 1984); COM-B, Capability Opportunity Motivation – Behaviour Model (Michie et al. 2011b); TFA, Theoretical Framework of Acceptability (Sekhon et al. 2017); N/A, Not applicable.

Appendix 24: Visual prompt of common domains of impact

Physical

Psychological

Social

Educational

Daily activities

Financial

Occupational

Appendix 25: Visual prompt of potential names for the app

Dermablues

eSKIN

Skin Ease

SkinWell

Skinory

Wise Skin

Live

Sakina

Free

Patchwork

Dermapp

Mind the skin

Cme

Skin Smart

Skin Wizz

Appendix 26: Field notes template

Interview details
Date:
Time:
Number of people confirmed:
Number of people attended:
Length of interview:

Participant information
Gender:
Skin conditions:
Country:

Personal reflections
Overall thoughts:
Interview setting:
Potential biases:
Reflection on interviewing:
Interview questions:
Changes:
Tentative codes:
Saturation:

Actions

Appendix 27: Participant quotes from online group interview study

#	Theme	Sub-theme(s)	Quotes
1	Visibility underpinning life course impairment		*"So physically it's very itchy, it's very sore. It stops me sleeping. It's, it's just generally very uncomfortable when it's particularly bad." (G6, Psoriasis, England)*
			"It was just like the um, affect it had around my legs and the back of my knees, and then um, because I'm quite into fitness as well, so that had a bit impact, and I had to stop exercising for about five months, completely, um, because my skin was so bad. And then again, when you stop doing the things that you're used to doing, it takes a toll on your mental health." (G1, Eczema, Wales)
			"Having a skin condition is visual - you can feel like an anomaly sometimes" (G4, Epidermolytic Hyperkeratosis, Wales)
			"but it had such great negative connotations for me and my self-image and my body image, which has led on to eating disorders, depression, PTSD. So many connotations that when I trace back, it is ... It's a lot to do with wanting to disappear, not be seen, not wanting to be seen with the skin that I had." (G2, Psoriasis, England)

	"So, I was so depressed, and my skin was the reason why I was depressed […] Like hopelessness, like hopelessness about my future, was like the biggest one. Like constantly knocking myself down and [...] like just feeling hopeless about life." (G3, Lamellar Ichthyosis, USA)
	"disgusting" (G7, Ichthyosis, England)
	"repulsive" (G8, Vitiligo, England).
	"I'd say the psychological side of it, is, is the low self-esteem, that's the biggest thing for me anyway." (G4, Ichthyosis Vulgaris, England)
	"Er, but it's just more of a … um, a visual thing for me. I think I'm treating it quite well and being treated quite well. Um, but it's more of a social thing, it's just a bit embarrassing, more than anything actually, for me." (G1, Psoriasis, England)
	"Worrying about social situations when I meet new people, especially possible sexual contacts" (G8, Multiple skin conditions, Denmark)
	"Um, it leaves weird ... a weird sort of atmosphere for you, where you've got this thing between you and other people, where perhaps

	they're not mentioning it. You know about it, they know about it, but it's something in the room that's [...] it's something that you feel like you should be dealing with, but at the same time you don't really want to deal with." (G7, Vitiligo, England)
	"I literally saw the dermatologist this afternoon and he called it [psoriasis] like asbestos on my scalp…" (G2, Psoriasis, England)
	"I think society and the media, expects us all to be this perfect air brushed beings, but we're not […] I honestly believed I would never have a relationship. Well, every boyfriend, whenever it broke up, I blamed my skin and I never, ever thought I would settle down, marry and have kids. […] So, um, yeah it's a lot of societal pressure and um, but the psychological impact is massive, absolutely." (G4, Psoriasis, England)
	"Yeah, talking about the mental thing is about becoming more and more isolated from people. […] I climbed Mont Blanc – I used to go climbing all the time. I rarely leave this house, other than to go to work. […] I go and see my mum and dad once a week, and once in a blue moon I will go and see somebody else. But other than that, this is, this is where I am." (G7, Vitiligo, England)

	"Dancing, yeah. Er, so that is a way for me to feel normal. I can dance quite close with people. Now, no-one ... Perhaps not the right word, but I don't get any comments and people seem to like me for me, and not for my skin. Er, so that was kind of a self ... er, a self-confidence boost." (G3, Netherton Syndrome, Sweden)
	"… so I knew I had to go to work […] but I would come home and like close the doors and I didn't want to see anybody and when it was like really hot, long sleeved tops on, long trousers, everything was covered and the only mirror I have in the house was the mirror for my face, that was it, I didn't want to see the rest of me." (G8, Vitiligo, England)
	"… people always say 'Oh, oh what's that on your face?' All the time, so I have to wear make-up to cover it. […] So, it's just I always get a little bit kind of nervous, if people see me without make-up for the first time. And it kind of makes me feel like people are staring. It makes me feel a little bit more insecure about myself." (G6, Hyperpigmentation, Wales)

		"I've actually I missed out on a whole career opportunity um, and I went for um, a TV presenting job, about 20 years ago, and as the makeup artist was doing my makeup, ready for my screen test, she said to me it's going to take me ages to cover up, and she pointed to my scars on my cheeks. […] I wished and hoped that one day that I will be able to get back from behind a camera…" (G1, Post-hypertrophic acne scarring & Hyperpigmentation, England)
		"Um, I actually chose a job which was fully remote working, um because I felt like I couldn't cope with going into an office." (G5, Psoriasis, England)
	Cumulative life course impairment (CLCI) and vulnerable patient sub-groups.	*"Yeah, so I've had my skin condition for 20 years, give or take, and I would say now it doesn't affect me whatsoever. […] But going out, because I used to work abroad, and I'm a scuba dive instructor, I used to have to wear swimwear and I became very confident in myself, by my job." (G1, Vitiligo, England)*
		"I didn't have vitiligo until a few years ago […] mine came as a bit of a shock and we didn't quite know what it was. So, in my experience, it's obviously, quite different to somebody else's […] um, having come to

	it late, later in life, um, didn't really know what it was, um, there hasn't been a great deal of support for, for me personally through um, you know, the doctor." (G5, Vitiligo, Wales)
	"… I'd sort of call it a late developer of psoriasis, I've only had in in the last five years. Um, being nearly 55, um, I sort of don't worry about things in some ways, maybe, that others have done, if they've been living with the condition for a longer period of time. I don't mind it, um, I'm sort of old enough and ugly enough for it not to affect me." (G1, Psoriasis, England)
	"… I didn't get it [vitiligo] until I was in my sixties […] I think it's easier when you get older, to a certain extent, because you ... You know, I'm me. My friends, you know, know what I'm like – but I'm still aware of people staring at me." (G2, Vitiligo, England)
	"And I did end up going to the doctors at one point, about feeling down […] It would always be just like oh, it's hormone related, I'm a teenager, I'm a child, you know, it would never actually be maybe my skin condition is the reason that feel the way I do. And I feel like there's that lack of support there, especially as a teenager, as a child […] it's different as an adult, because in a way, you can talk for

	yourself, whereas I was very reliant on my parents, to help me when I was younger." (G1, Vitiligo, England)
	"So, I suppose in sort of childhood, like school age, um, it's just something that would make me feel quite self-conscious […] sports or swimming um in that kind of environment, just made me feel very uncomfortable and different, which obviously, as a child, you don't like to, like to be, you wanna kind of fit in. […] but it's um, not very well known at all, so, I remember, um, some teachers um, sort of asking me what it was um, and as a child, it was very difficult to explain." (G5, Vitiligo, England)
	"… when my vitiligo came about, when I, when I was sort of, say like sort of 10, 11, 12 […] when as a young girl, you're starting to notice your body and things changing and happening and boys at school and all the rest of it." (G6, Vitiligo, England)
	"Being covered head-to-toe and turning up to school, at seven years old, stinking of tar. I had bandages on, with bloody knees. Nobody wanted to play with me, because I was like dripping in tar and things. So, yeah, very, very negative thoughts I've got as a child, with having this." (G1, Psoriasis, England)

	"I'm in 100% agreement with psychological, that's without a doubt, especially as a child, when I first got it. […] Um, but it was just having children stare at you and treat you differently, and being called like a skin disease then, things like that, psychologically, it's a big, big hit." (G1, Eczema, Wales)
	"Like growing up, I got made fun of. There isn't a day that I didn't get made fun of, that I didn't get stared at or felt different." (G3, Lamellar Ichthyosis, USA)
	"… I think society and the media, expects us all to be this perfect air brushed beings, but we're not, and um, I think that and just obviously, self-esteem, the whole mental health thing around skin disease is major. […] Um, and what I was gonna say about being a younger female, like I got psoriasis when I was eighteen, and it was really severe, widespread, um and all throughout my twenties, I honestly believed I would never have a relationship. Well, every boyfriend, whenever it broke up, I blamed my skin and I never, ever thought I would settle down, marry and have kids. And here we are, and I have two teenagers. So, um, yeah it's a lot of societal pressure and um, but

			the psychological impact is massive, absolutely. […] Cos you're so impressionable in your teens and it's the whole social aspect of your life, in your teens and twenties and thirties um, and you don't wanna be singled out." (G4, Psoriasis, England)
2	Seeking control amid uncertainty	Limitations to peoples' understanding of causal factors.	*"I feel like there's been a lot of ways of putting a plaster on it, why we can give you this cream, that cream, try this and that, but up until this day, I don't know what the root cause is." (G1, Eczema, Wales)*
			"Well I've got universal vitiligo, which means I am actually, I was born a brown skinned Indian, I'm an Indian woman and I've lost all my pigment […] and um, my father had vitiligo, I have vitiligo and my daughter has vitiligo." (G4, Vitiligo, England)
			"I've got a photo of my hand every year, but eventually, I, I, it would be almost nice to know if I ever will lose all the pigment or not? Just, just to know, like I've no idea and also I would like to know if it could affect my daughter. So, it's that unknown […] Um, so sometimes I find myself, like, checking, and like, cos she tanned up as well, and I'm like, is it starting, is it starting?" (G4, Vitiligo, Scotland)

	"Agree - it was a strong consideration when deciding whether to have children. Putting them through the same thing." (G2, Psoriasis, England)
	"So, it [hyperpigmentation] developed then, once I'd had the Mirena coil. […] they didn't tell me it would make it worse and within a year, it spread all over." (G6, Hyperpigmentation, Wales)
	"Um, the only time I've not had it [Psoriasis] was when I was pregnant, unbelievably. Since I gave birth, it came back twice as bad." (G5, Psoriasis, England)
	"First of all, you know, looking at what makes it worse, or aggravates it. For me, those examples would be sort of stress, which could be through work. It could be late nights; it could be having too much to drink. You know, and also windy weather sort of dries it out. […] I live with anxiety and certainly the two things completely go hand in hand." (G6, Eczema, England)
	"But the progression and the pathway might take me in a different direction at some point, who knows where it all leads? […] It's got a mind of its own (laughs), sometimes I think I'm in a great place, and I

		wake up the next morning and it's just kicked off, and I think, what … I just can't explain it." (G1, Psoriasis, England)
		"Day to day living. Every day is a new challenge. Every day is unknown." (G8, Netherton Syndrome, England)
	Regaining control through understanding, self-management and acceptance.	*"Um, for me, like two different things that have just been on my brain. I'm ... I love to work out; I'm a big fitness guru. Um, so getting in like my thirty minutes of working out or yoga and eating all the proper things that make me feel good, like inside of my body – and I also do feel like I help my skin somewhat. So, that's one. And then two is, managing my skin. […] Um, if I didn't do those things (bathing and ear irrigation), if I didn't take care of my skin […] then I just ... I, I hurt. Like my skin doesn't feel great." (G3, Lamellar Ichthyosis, USA)*
		"Looking after mental health is a core component of self-management" (G1, HS, Ireland)
		"I've recently started trying to get healthier - not just because of the psoriasis but also the co-morbidities linked (e.g. heart disease / diabetes). So I now want to make sure my BMI is healthy range etc.

	Also I find going to exercise classes and getting back out there is helping my confidence grow again" (G5, Psoriasis, England)
	"… er, working out, it's my absolutely and particularly during Covid anyway, but my outlet is, work, erm, exercise, erm, and also, erm, I do Yoga, walks, erm, and meditation, so I've been really focusing on that aspect of almost like stilling my mind and calming down and, as I said that level of activity and things like meditation apps have been a really good outlet, erm, for me personally for me to, to use, erm, not just for managing my skin but also just in terms of daily work pressures and things like that." (G8, Vitiligo, England)
	"Being able to keep my condition at bay so that it doesn't interfere with other aspects of my life." (G8, Eczema, England)
	"Er, yeah, so for me it's about gathering as much research online which I … I do, I look at different um, health therapies, er, different ways of managing it, so I don't just look at um, western medicine, but I also like to go down like the eastern medicine […] so something cheap and something that I can just do like within the house, instead of spending money and going to different clinics and therapies." (G1, Eczema, Wales)

	“I don’t know how to manage it at all. Like I just bounce back from cream to cream, from infection to infection. Um, tried every shampoo going, tried ... I took my list with me to the dermatologist today, of all the different steroid tablets, steroid creams, foams, the lot. I just ... Yeah, I don’t feel confident that I’m managing it at all […] I don’t really have any control over it. It’s not diet-based. I’ve tried to cut out diets…” (G2, Psoriasis, England)
	“Er, just if I don’t take care of myself, I don’t feel good. I’m not, I’m not presentable outside, more or less. Er, for me, I need to do this every day. It can’t wait, like until the next day. It needs to be done every day, because it’s ... My body runs like a twenty-four-hour watch. So, if I bath at ten in the morning one day and four in the morning the next day ... The four in the morning, it’s not happening. It’s been too short a time, so the skin hasn’t loosened up enough.” *(G3, Netherton Syndrome, Sweden)*

	"On the other side of then, there's almost like this thing of accepting that you've got a chronic condition that you're never going to cure." (G7, Psoriasis, Wales)
	"…the biggest part of vitiligo is acceptance" (G4, Vitiligo, Scotland)
	"… I had to accept because I know that otherwise it ends up in a spiraling level of lack of confidence and low self-esteem and it is something that obviously I have to live with every single waking hour of my life so, as I said, it's just one of those things that over time […] it's just something I've had to readjust my own thinking around, around how I perceive myself, erm, and, and building that confidence […] because otherwise it was consuming every single part of my life in terms of what I wore, er, social anxiety around meeting new people, you know, every single aspect of, of my life, it was touching on, and as I said I needed to take back that control." (G8, Vitiligo, England)
	"It's the one aspect of my life that I don't feel in control of and it kind of scares me, the fact that it's, because it's spreading across my body and it's spreading very quickly now. You know, there's no way of me stopping that. There's no, there's no cure for it. […] that's my biggest

			fear is that it will be everywhere, and I can’t do anything about it and I don’t have that you know, control over it. But then equally, I think coming to an acceptance and learning to love who I am, for me, without sounding too cheesy, is, is part of that battle and that would give me that control back” (G6, Psoriasis, England)
3	Existing support for people with skin conditions	Dismissal by health professionals.	*“I think GPs and all medical professionals are amazing, but more recognition for, for skin conditions. I think it’s sometimes passed off as just ‘Oh, it’s, it’s aesthetic’. But you know, it has a very physical and mental impact on a lot of people’s lives.” (G6, Psoriasis, England)*
			“…it was the hardest thing hearing it [diagnosis] from dermatologists, like there’s nothing we can do, and that was it, it was like just having a door close in your face, like there’s no hope.” (G1, Vitiligo, England)
			“You know, my son, who’s got really bad, horrendous acne on his back ... He’s twenty […] He’s had to go to the GP, and they’ve said: ‘We’re not ... We’re only seeing emergencies at the moment. So, that’s not ... We don’t need to see you.’ He needs, he needs medication for it.” (G7, Ichthyosis Vulgaris & Psoriasis, England)

	“Er, when I went to the GP and he gave me some, like, steroid cream, he spent most of his time telling me how expensive it was for him to give me that. […] That’s the level of interest he had in the condition.” (G7, Vitiligo, England)
	“I think quite often the appointments feel quite rushed […] I’m quite excited to have seen someone and that there’s a solution, um, and it’s quite often provided to me as this is what you have to do, rather than, these are some options.” (G5, Eczema, Wales)
	“Self-management is when the GP basically says: ‘You need to go away and do it, do it yourself, really.’ So, you know, on your own back, on your own back be it.” (G7, Ichthyosis Vulgaris & Psoriasis, England)
	“It’s not a problem that I raised. So, I guess that’s why no-one has talked about it with me in that way either […] So, if I don’t raise it as a problem ... It isn’t a problem, more or less.” (G3, Netherton Syndrome, Sweden)
	“I’d like self-management to be my side of a collaborative attempt at sorting or managing my condition, but too often it’s ... You know, the links that I have with my GP are very much: ‘Okay, you know, can I

		have another prescription, please?' – blah, blah, blah. […] I'd like to work hand-in-hand with somebody, knowing I've got to do my bit. I've got to keep to my medication regime, I've got to do my moisturising – all of that – but I'd like to have a little bit more of a collaboration with the healthcare professionals." (G7, Psoriasis, Wales)
		"I self-manage my condition completely, which is, which is because no-one else can really do anything about it." (G7, PC, Wales)
	Issues with treatment and healthcare services.	*"I go to the doctors and they say: 'Hm, we don't know. Just wait, more or less' – because there are no standard treatments to be aware of. So, it's trial and error." (G3, Netherton Syndrome, Sweden)*
		"Um, yeah, I think, yeah transparency is key and just being upfront with the information and not, not giving um, too much hope, cos there are obviously, treatments, but I think a lot of them aren't available for vitiligo on the NHS." (G5, Vitiligo, England)
		"… well I had quite a big course of the light therapy, however, we got to so many um, so many sessions in […] the Specialist said, "We're gonna stop it on the NHS now, but you can come and have your ninety seconds privately um and I'll carry on treating you that way."

	So, I was kind of, again, you know, a little bit left in limbo…" (G5, Vitiligo, Wales)
	"So, it is giving me further challenges to manage my skin condition, because one of the best creams I've had so far is difficult to get hold of […] I am told at the chemist that it's, that it's production issues, but I've been in touch with Eucerin and they deny there's any production issues." (G2, Eczema, England)
	"We haven't physically gone to America, but we're buying things [medication] from the States now, because you can't buy it over here..." (G7, Ichthyosis Vulgaris & Psoriasis, England)
	"I live in a very rural area, and in the last few years it's been very difficult to get dermatologist consultants, so um, I've certainly felt I've had to be a bit more proactive, and ask the GP um, for a bit of advice or to review the meds I'm on. […] it's just the accessibility […] I was being reviewed every sort of six months, but that hasn't been possible, because of the limited number of um, dermatologists in the area I live…" (G1, Eczema, Wales)

	"Erm, but I guess in the context of it being incredibly difficult to see an NHS dermatologist currently, erm, I've had to pay to go privately, so I think there is more of a burden on people to kind of work out what they want to do and seek help for themselves." (G8, Multiple skin conditions, England)
	"…with the effects the pandemic and things, you know, waiting times have just gone through the roof. They were bad enough before." (G7, Psoriasis, Wales)
	"… we know that GPs have to kind of go through first line, second line treatment, they have to kind of prove you failed them [laughs] you have to prove that you failed the previous treatments in order for them to consider referral […] So you have to faff around [laughs] for months and then they eventually say, 'oh okay, I'll refer you to secondary care' […] and he said it's almost no point referring because the waiting list is 12 months for my local dermatology service, so I just thought I'm going just, er, have to go privately unfortunately." (G8, Multiple skin conditions, England)

		"You know, it's eighteen months' wait to see a dermatologist, and then on the days you go and see a dermatologist, your skins looks really good and they're like: 'Well, sorry. You know, you're only ... I'm only seeing what I'm being presented with at the time.' So, then you've got to go back to square one again. It's only on the day that actually if I go in and my skin's bad, that they might consider seeing me again. It's ... And I don't think that's very fair…" (G7, Ichthyosis Vulgaris & Psoriasis, England)
	Psychological support is beneficial but limited and barriers exist.	*"It's alright dealing with it um, physically dealing with it, applying moisturiser, but it's the mental side of it, that, that's worse than anything I think. You can sort of learn to live with it to a degree, but it's just the psychological side of it, you get no help with that at all." (G4, Ichthyosis Vulgaris, England)*
		"Interviewer: just to clarify, so you've gone, you've gone to your GP and Dermatologist, saying that you would like some support with your mental health, psychological health. *Participant: Yeah. […] No, it's very much 'Oh why don't you try this cream?' or you know, like it's, it's a kind of, it goes down a medication route, yeah, at this point." (G6, Psoriasis, England)*

	"Like I liked the person that I was becoming in counselling and learning those tools of how to cope with certain thoughts that I had and stuff like that." (G3, Lamellar Ichthyosis, USA)
	"… my skin had made me feel very down and very depressed, and at the time the CBT was helpful, within its limitations. […] So I did learn some really good distraction techniques that were useful for grounding myself and very grounding in the moment […] I still use them, like you know, 20 years on. […] regulating my own emotions, so that I'm not reacting back out with anger, I'm not reacting back out feeling sad or, you know, even bursting into tears, which I had done on previous occasions as a child. But for me, it's just about regulating that emotion in that moment, and doing the breathing techniques." (G1, Post-Hypertrophic Acne Scarring & Hyperpigmentation, England)
	"… it impacts almost every domain of life, emotional, mental, physical, professional, sexual, social. Um, there isn't an area that it doesn't impact on. […] that's one aspect of living with a skin condition, that I've always struggled with. And from speaking with others who've the same condition as me, that has always been a struggle…" (G1, HS, Ireland)

	"…it's more of a cosmetic thing, I would say. […] I can't remember the last time I went to a dermatologist, but the last time I did go, they pretty much said to me, it's a cosmetic issue, there's nothing we can do." (G1, Vitiligo, England)
	"… we live in this world now where everybody who's famous and everything, they've all got about five psychologists that look after them and do alright. But I think for regular people, it kind of seems ... Certainly for me, it just ... It doesn't, it doesn't seem like that's something that I would be doing. […] I know this'll probably sound quite silly now, but I kind of feel like I'm not, I'm not mental. So, so, I don't ... Like I don't know what it's going to do for me, but at the same time a lot of what I go through is mental stuff." (G7, Vitiligo, England)
	"… I'm a bit of a ... kind of an ostrich. […] Er, I come from a family where we don't talk about things. Er, so it's never been a question, to talk about how I feel, or if I have a problem, or ... So, I haven't really talked about it that hard, frankly." (G3, Netherton Syndrome, Sweden)

	"And I'm lucky, really, I suppose [...] Jada Pinkett has got alopecia, which is an autoimmune condition. […] Would I swap it? No, I wouldn't swap it. So, you know, in the scheme of visible differences and skin conditions, it doesn't cause me any pain or discomfort." (G2, Vitiligo, England)
	"… you don't necessarily look for psychological support. […] but part of me thought: 'Oh, I've only got a skin condition.' You know, you're dealing with people with cancer, with motor neurone – blah, blah, blah – you know, and it's almost sort of something where you can just go quick ... you know, easily and find something and think: 'Well, actually, yeah, you do deserve to have a bit of psychological support,' even if it's online or something." (G7, Psoriasis, Wales)
	"I went through the college ministry […] and it [counselling] was free for two years, and then they stopped doing that. So, then it was about $100. Now, when I go, it's ... For an, for an hour's session, it's $180." (G3, Lamellar Ichthyosis, USA)

		"I felt at the time it was rather expensive, but it was one of the best investments I ever made. The return on this investment paid for itself many, many times." (G1, Hidradenitis Suppurativa, Ireland)
		"…and also it's about the fact that most of the professions wouldn't be automatically looking beyond their own domain." (G1, Psoriasis, Wales)
		"I've never been offered any sort of assistance with my mental health or like the medical model, of disability is so rampant in the hospital, and it's never really looked at, err, from a psychological perspective…" (G4, Epidermolytic Hyperkeratosis, Wales)
		"It's never, it's never offered, because it's ... I think it comes under the lines of mental health. […] But I don't think it's something that I would reach out to a doctor for, because if I can fix ... If my feet aren't bleeding, then I'm not in that state of mind. […] For me, if I was offered the support, I wouldn't take it anyway – mental support…" (G7, Ichthyosis Vulgaris & Psoriasis, England)
	Social support is important but limited.	*"… it's easier to cope with it when you're confident and you have a good support network around you, family […] But when you're*

		isolated, it's very hard to deal with, it magnifies it and you can't get your head in the right space to deal with something that's probably quite simple, because it's overwhelming I think." (G4, Vitiligo, England)
		"…And when I, and then of course, you have all the, very well-meaning friends who go 'Oh have you tired E45?' Yeah, no, just no." (G6, Eczema, England)
		"But I am lucky to have a great family network, but I don't feel like people without a skin condition can truly empathise with what I go through." (G4, Epidermolytic Hyperkeratosis, Wales)
	Poor awareness and understanding.	*"You can go to your doctor and they can say X, Y or Z, but they don't get it." (G1, HS, Ireland)*
		"I was told by a number of doctors 'I don't know what it is' you know, go home, you know, don't worry about it. It's nothing. And then I went to the Pharmacies. They didn't know, they didn't even tell me to wear sun-cream or, you know, or anything." (G6, Hyperpigmentation, Wales)

	"I've been to the GP with my feet, and they've looked at my feet and said: 'Oh, you've got Athlete's Foot.' […] I have to go back and say: 'Actually, no, I don't have that. This is my skin condition.' They're not aware of that skin condition. So, then they say: 'Well, it's about self-management.'" (G7, Ichthyosis Vulgaris & Psoriasis, England)
	"… within the Indian culture, err, vitiligo is sometimes looked upon as leprosy…" (G4, Vitiligo, England)
	"… I've had situations where people have come up and they've rubbed my skin to see if it's like, you know, it's coming off, or it's contagious or I've been burnt and obviously it isn't any of those, it is the vitiligo…" (G8, Vitiligo, England)
	"… they say, oh no, what's wrong, what have you done to yourself? And all of a sudden you feel like you did when you were ten years old and you're different from everybody else […] it's meant with kindness, it's not malicious at all, but it's those sorts of enquiries and things, just makes you feel a lot worse about yourself." (G5, Psoriasis, England)

	"… several years ago I started to open up and actually openly discuss it and actually that was quite an eye opener because friends for example hadn't realised the effect it had on every single aspect of my life, but when I was talking with them it was quite interesting to hear their perspectives and outlooks." (G8, Vitiligo, England)
	"Er, that's why I've done sort of CPD sessions with podiatrists […] So, increase the awareness of the condition to people who are most likely to see it, just because someone like a GP, with all the will in the world, is never going to have seen this before, because it's just so ... When you've got an ultra-rare ... something ultra-rare, it's just not really going to happen. […] Um, all in can do at the moment is share what, what I've got and, for me, put them [patients] in touch with this US-based charity, who can maybe get genetic testing for people and put them in touch with other people who've got the condition, to try and sort of give support." (G7, PC, Wales)
	"Um, it's not so much to do with self-management. It's more to do with perceptions of other people, and there's very little publicity, as far as I'm aware, about skin conditions. [..] because if people were

	more aware, then people probably wouldn't start at you, and you wouldn't feel so self-conscious." (G2, Vitiligo, England)
	"It's self-management for me is I sort of control things that I can control. I've never quite pinned down whether when my condition flares up or recedes, is it diet related, exercise related, stress related? So I can control my diet, control exercise, hopefully control stress, I think I can, you know, as in work related." (G1, Psoriasis, England)
	"…I've had this [psoriasis] since I was seven, but I've only just realised that psoriasis has got a connection to people having heart attacks and problems with the heart – and it's like: 'How has no-one ever told me?'…" (G1, Psoriasis, England)
	"About five years ago, I got a melanoma and I had to go to hospital, and it was only then that I read ... I got time to read the boards there in the, you know, dermatology-sort-of-clinic and found out that there was an ichthyosis support group […] But I'd gone sort of, you know, fifty-five years, you know, managing it with one type of cream, with nobody sort of saying: 'Well, you know, 1) there's an ichthyosis support group, or 2) there are different things to try.' You know, I now feel a little bit, you know, forgotten and sort of ... You know, you

		know, I’ve had to manage it myself, when possibly there’s been out there, all those years, some other avenues I could have explored to help me manage it better than what I’ve been doing.” (G2, Ichthyosis, England)
		“…I agree with [name]. Psychological aspect catches you unawares at times.” (G4, Vitiligo, England)
		“… there is something to be said about mixing with people who’ve got ... where their condition has got a similar impact, rather than you’ve got the same condition. […] I think what he [participant] is going through, other people with other sort of conditions, particularly people who have facial psoriasis and things like that, would be getting, you know, exactly the same sort of effect on their life as well. [...] Can we possibly learn and support each other with other conditions?” (G7, Psoriasis, Wales)
	Peer support; a double-edged sword.	*“I, I would say social media, so, these Facebook groups and stuff like that is a key source of support, in, in particular the vitiligo society […] I don’t know how you would know anything or speak to anybody if, if, that didn’t exist, if I’m quite honest.” (G4, Vitiligo, Scotland)*

	"I think the first time I spoke to someone err, was in my thirties, who had vitiligo, I'd never seen anyone with vitiligo, so, it, it did a lot to boost my confidence, that this person, who had it much worse than I did, was coping, and it, it, you know." (G4, Vitiligo, England)
	"I would highly recommend contacting every single group, every group that is relevant to your, to your condition […] Because not only do you pick up some really good hints and tips but you may find some really great, great partnerships or friendships or just get some, get some really good knowledge and experience from people in, in the same boat as you." (G6, Vitiligo, England)
	"… I found two accounts on Instagram, which is an app I use all the time. And they share their story and they share how they're getting on and the treatments they're going through. And that's probably the best thing ever for my mental health and has been, in terms of living with a skin condition. And we've reached out and we chat online and we say 'Oh, you know, having a really bad day' or 'It's flared up this week' or you know, 'Really itchy' […] just having someone there that knows how you feel. Really key." (G6, Psoriasis, England)

	"I'm often my own doctor, which is why I tend to rely a lot on the Ichthyosis Support Group. For example, I'll put in a post on there and say, right, this is happening to me now, is this new? Is this something that comes with age? Um, have either of you dealt with it? And straightaway, you know, I'll get um, universal comments from people err, offering support and help and what sort of treatments they've used. […] and something my Dermatologist couldn't answer, someone from Arizona in the US has been able to answer for me. It's just things like that really, the sort of collective experiences online, can help you get the support that you need. […] I kind of want the GPs to be able to help me, but unfortunately, I am relying on my own community." (G4, Epidermolytic Hyperkeratosis, Wales)
	"When I went onto some Support Groups on like Facebook and that. And they tell you like different things and they don't tell you that, or if you take like 20% like, Tretinoin for example, you're going to, you're going to be all scaly. And then obviously when that happened, I just thought 'Oh my God' I didn't realise it's because I had to have a small percent first of all, you know. So, yeah, just need to be aware, it just needs to be monitored, the people only share factual information and

			information that can’t, wouldn’t make somebody do it to burn their face and things like that, or skin, or anything.” (G6, Hyperpigmentation, Wales)
			“Another positive with this group is some of the information that’s exchanged here, how do you deal with this on a day-to-day basis? Something that a dermatologist or a specialist will never impart to you, and likely never will, because it hasn’t gone through a randomised clinical trial etc.” (G1, Hidradenitis Suppurativa, Ireland)
4	Patients’ attitudes and concerns	App meets need and desire for support.	*“Yeah it [the idea of the app], it’s nice actually, cos like, yeah, we don’t really have anything like this, I never really thought of it before. […] it’s very hard to get people to, to recognise that this [the impact of skin conditions] is a thing...” (G4, Vitiligo, Scotland)*
			“We deserve an App dedicated to us.” (G4, Psoriasis, England)
			“It’s that there isn’t like a one-stop shop for people with skin conditions generally. […] You just drive around the internet, trying to find something that’s going to fix this problem, when you can’t fix it. It’s just ... You've just got to manage it.” (G7, Ichthyosis Vulgaris & Psoriasis, England)

	“That it’s all in one place, would be useful, because you just don’t have that at the moment. […] when you’re given a new cream, like you search back twenty years: ‘Oh, I think I had that when I was fifteen or whatever.’ You know, to have it all in an app and all the information up to date, current, easily accessible, would be ideal I think.” (G2, Psoriasis, England)
	“… there’s so much misinformation online, none of the information, or very little information that we’re getting online or digitally, is regulated in any form. Now how do I know that if I go onto a site, unless I’m familiar with it, am I getting solid information here, is it evidence-based information, or is it just some idiot who’s watched a YouTube video and is a self-appointed expert? You know, let people who have the education, training, experience, impart, reputable information, that’s where I go, but not everyone does. There are lot of cynical people in life, who are trying to take the hard-earned money from your pocket, and are offering cures for conditions that are currently incurable. And we’re all constantly being inundated with nonsense messages along those lines. Not all people will have the

		wherewithal to wade through this and filter it effectively." (G1, Hidradenitis Suppurativa, Ireland)
	Appropriateness.	*"I personally wouldn't find it particularly helpful […] I've lived with it for a really long time and I've talked about it til the cows come home to other people who have it, and its, you know, it is what it is. […] if I developed psoriasis now, at this point in my life, then actually, I probably would find that level of support and community quite helpful, because, you know, it is completely new to you." (G5, Psoriasis, England)*
		"It would be a fantastic concept, this is an under researched area for skin conditions. And has the potential to be a valuable source for younger people (teenagers)." (G4, Epidermolytic Hyperkeratosis, Wales)
		"So important to focus on the younger age and develop the support as people get older." (G4, Psoriasis, England)
		"So, I don't know what it will look like, but you know things like creaming? Like if you've got to cream more, looking after the skin, I think that would be really good, purely because I think the more you

		get into something, the more it becomes a behaviour and you get more used to it. Especially with children with skin conditions, they don’t like creaming, they don’t like doing self-care as such, but if you do something in the app... I don’t know, they track it and it gets better, that might really help.” (G7, Lamellar Ichthyosis, Wales)
		“I think it is a good idea. It is how many people are used to engaging with others now. It won't be for everyone but will be for many.” (G6, Eczema, England)
		“Yeah, I think it’s a great idea, because we’re always on our phones, especially for like the younger generation, so teenagers or people in their early 20s.” (G1, Eczema, Wales)
	Concerns reflecting poor illness and intervention coherence.	*“I think there are already a plethora of Apps out there, that look at trying to improve mental health and physical health um, so, my question would probably be, what’s your different, what would be the differentiator of this App, to any one of those other Apps? Apart from the fact that it might focus in a little bit more on, on skin conditions, etc., which wouldn’t, wouldn’t be a bad thing. Um, more information is always better, but yeah, we, we would need to have some kind of differentiator to be effective.” (G5, Psoriasis, England)*

	"…although we all have different conditions, there was a lot of commonality and there's a lot
	"I would just express a wariness, or concern, about that. Sort of, you know, a skin for... a cream for ichthyosis may not be the same as a cream for something else, or somebody's experience, you know, who's got eczema, may not be relevant for somebody that's got ichthyosis, etc." (G2, Ichthyosis, England)
	"Great in principle, it depends on the content and how tailored it is to different skin conditions. Also wonder how suitable it would be for people with more substantial mental health problems eg major depression linked to their skin condition vs those with milder symptoms." (G8, Multiple skin conditions, England)
	"…That's what I was just trying to get my head around in terms of, of what it specifically intended to target, or if it's about a direction to resources around help or so forth or if there's a chat function for example [laughs], if you do want to talk to someone. […] it's a good idea in principle because if people have an out-, not an outlet but an app which they can use and they've got a, er, knowledge, [sighs]

			should I say a knowledge forum that's actually full of credible information is super important…" (G8, Vitiligo, England)
5	Patients' ideas for the app		*"It's just the fact that the App is dedicated, for people like us […] a massive part of that will be mental health, but also like, there is also the physical things that you go through, which is like, making sure that you're physically comfortable, and being put in touch with people, helps. Your three pillars, you've got the physical aspect, the social aspect and the mental health aspect." (G4, Vitiligo, Scotland)*
		Understanding me.	*"Not focused, but more into the subject regarding self-awareness of skin conditions. What the problems might be causing how you feel, the way you feel" (G3, Netherton Syndrome, Sweden)*
			"… often people in this, who are in this situation where exercise can help, they, they don't realise it, they don't see it. It, it's like, for example people who are, erm, who are depressive, with depression, exercise can help a lot, nothing to do with skin conditions but it could be the same thing, erm, you know, a lot of people here have said that exercise has helped them and a lot of people who have skin conditions probably wouldn't think of it, so just suggesting it, erm,

	just suggesting it to people that would be a positive thing…" (G8, Multiple skin conditions, Denmark)
	"I would love to get to a place where I can just accept it and me. That's my ultimate goal and I think that comes with time." (G6, Psoriasis, England) *"… and body functionality which is basically focusing on what your body can do, rather than just focusing on how it looks. There's lots of evidence that it can help people feel better about themselves and kind of increase positive body image, so shifting people's thinking away from, for example what they don't like about their body, to thinking about what it can do, so like, erm, I don't know, even things like it can digest, it helps you digest food or, erm, helps you be creative or helps you like walk or run and that kind of stuff, there's quite a lot of evidence that it's helpful." (G8, Eczema, England)*
	"I worked as a parent, supporting parents […] we try to help them, to give them, well to make them feel that this [vitiligo] is a small part of who their child is. You know, if they ensure their child is, sees that there are more aspects to their personality than their skin, it will hopefully, excuse me, hopefully support them." (G4, Vitiligo, England)

	"… but I think there has been a shift now to kind of more neutrality because I personally think it's quite hard to tell people, you, you should feel beautiful with your skin condition. I think for some people that's really difficult but perhaps it's more realistic to be accepting and just to be neutral about it. […] other people might be, erm, interested, this idea of like your body's a tool, it does stuff for you, it's not, it's not an aesthetic object, erm, which I think is quite an interesting, erm, concept." (G8, Multiple skin conditions, England)
	"… release you know, strong feelings that get generated in our kind of reaction to our own bodies, but how we think others are reacting, erm, and, erm, especially disgust, it's not something we talk about very much, erm, and in itself it feels quite shameful so I think, erm, I just feel like maybe kind of stuff that we wouldn't normally kind of want to talk about. I think an app would be a really good safe space to, to kind of explore some of those difficult feelings maybe, and then kind of normalise them, erm, and then maybe if there were some kind of strategies, erm, yeah…" (G8, Multiple skin conditions, England)

		"Emotional regulation techniques to deal with hurtful comments and lived examples of grounding techniques or mindfulness." (G1, Post-hypertrophic acne scarring & Hyperpigmentation, England)
		"In terms of psychological things, you could have exercises relating to breathing, meditation, challenging thoughts, increasing confidence with showing your condition, dealing with negative reactions from others etc. Like a toolkit." (G8, Eczema, England)
		"I'm just also quite against the term 'mindfulness' […] I'm just quite wary of apps that are like: 'Oh, you're head's really itching. So, why don't you go for a walk and it'll take your mind off it, or why you don't you do some meditation for five minutes, and then you'll feel great?' I suppose it's just balancing that like non-patronising aspect, but I do think it's a rally fantastic idea." (G2, Seborrheic dermatitis & Psoriasis, England)
	Understanding my skin condition.	*"I feel like for me, erm, and I guess quite a lot of people not being able to control, you're feeling out of control with something, you know, can impact how you feel but also how you feel could impact you*

	physically to being more aware of the kind of, er, relationship between those can help manage both." (G8, Eczema, England)
	"Control is a very important thing, it's one of the aspects I struggled with a lot […] educating myself about my condition has been empowering, and it's given me back some sense of control." (G1, Hidradenitis Suppurativa, Ireland)
	"… I suppose, certain things like blueberries or, you know, certain things that you think would be good for you because it's antioxidants actually can exac-exacerbate the problem. So things like that, that's what I mean when I say linked to some form of medical science behind it, not just a go do this, just because it's more virtuous, you know, it's more general health advisory but it's more tailored towards that condition, whatever that might be. I just think that would probably have more, personally speaking again, just more focus or purpose." (G8, Vitiligo, England)
	"I've heard, people are not wanting to do it [physical activity] because they're fearful of like not sweating. So, like ... I don't know. Again, factual ... Like you can still like be active and move your body. You just

	have to be mindful of like how hot you're getting." (G3, Lamellar Ichthyosis, USA)
	"I think yeah in terms of leading a, a healthier lifestyle, I think that's something that we, everyone is striving for […] they [doctors] always say oh yeah, you should reduce your stress. And you're like, that's not helpful, because all that does is increase your stress, trying to reduce your stress, it's not something you can actively choose, not to be stressed. Um, so, um, that's probably the, the least helpful advice, um, you know, maybe some coping mechanisms would be better." (G5, Psoriasis, England)
	"Being aware of all the different types of treatments and what's available to you would make you more in control, because then it's ... You have an informed choice of what treatments you have. […] Um, it would be interesting to see and know what other kind of illnesses are connected. […] A majority of people with psoriasis will then have psoriatic arthritis […] but you don't always get told what one can lead to. So, having an app that actually could explain other ... 'You know, how is it I'm tired and my iron level's okay?' Well, no, actually, its

	because you’ve got psoriasis. So, it’s ... It explains more about the illness as well.” (G2, Psoriasis, England)
	“… it should have maybe a button or a link that takes you to the actual certified factual information of what the condition is and what, what all of the treatments, the certified treatments that you have and percentages […] So, if it’s to do with, you know, psoriasis then it needs to have links to a page that actually is from a medical profession about psoriasis […] I think it would really be helpful.” (G6, Hyperpigmentation, Wales)
	“I’m terrified of my daughter getting it, like how, how she would react. […] I would like to know if it could affect my daughter. So, it’s that unknown.” (G4, Vitiligo, Scotland)
	“If you put something like that on the App, cos people are genuinely worried about having kids and passing it on to their generation, um, I’m sure, whether it could pick it up, I don’t know but it is quite a serious thing, cos you could sort of stop your child from having, you know, what you, what you’ve been through.” (G4, Ichthyosis Vulgaris, England)

	“Yeah, a subject that we’ve not touched on, and sort of certainly was of major consideration for my wife and myself, and that is hereditary sort of aspects, you know, before we had children, as to whether they were going to suffer from the same condition. So, whether, you know, advice, contacts, etc., on something like that would be of benefit?” (G2, Ichthyosis, England)
	“Um, the only time I’ve not had it was when I was pregnant, unbelievably. Since I gave birth, it came back twice as bad.” (G2, Psoriasis, England)
	“I have a lot of uncertainty about the future, with my condition, because I know yes, it’s a cosmetic thing, but my future children, will they have vitiligo, when? I know people have been pregnant, and they’ve actually had their pigment come back, so it’s little things like that, I have quite a bit of uncertainty.” (G1, Vitiligo, England)
	“And ironically, I’d had it from when I had my son, and it was a small patch. And then it developed so I haven’t always had it. So, it developed then, once I’d had the Mirena coil. They [doctors] didn’t tell me that it would make it worse. So, even though I told them that I’d

	got it, they didn't tell me it would make it worse and within a year, it spread all over. So then I, because I didn't know anything about it beforehand, now I do, I've researched a lot. But before, because I didn't, I didn't know what was happening. They said 'Well you can't just have the Mirena coil taken out now, you need to see it through for five years'." (G6, Hyperpigmentation, Wales)
	"Well as a woman, because of the hormones, when I had children, you know, then you have the menopause, err, you know, I'm guessing that probably women get infected more um." (G4, Vitiligo, England)
	"I've answered a lot of questions about pregnancy and ichthyosis […] I was just learning as I went […] Like as I'm getting older, like wanting to know, like if my skin ... What to expect of my skin, if it's better or worse as I get older? What do older women find more helpful? […] Um, like I've had people reach out about the whole genetics thing, asking me like if ... You know, did we go through genetics before we ... genetic counselling before we had babies? Um, and we did. So, I can, you know, point them in the right direction, where to go for that. Um, and then I've had a few women that have ichthyosis, that have

		reached out, wanting to know like if their skin changes at all while they're pregnant." (G3, Lamellar Ichthyosis, USA)
	Monitoring physical and psychological factors.	*"… And I guess that's probably one of the things with the app: you can recognise when you have flare-up. What did you mostly eat? Was it late nights? Was it alcohol? Was it spicy food? All these things that people say that it could be connected to. Or is it just the fact that, I don't know, it's part of that time of the month? You know, so it's like finding patterns, when you can understand maybe why you're where you're at." (G2, Psoriasis, England)*
		"Um, I can see how an App, could be useful, for tracking, what is happening with my skin, and the different variables that may or may not affect that. […] Perhaps it would be a more scientific kind of approach, if the App was sophisticated enough to easily put in information, um, but you know, regularly, and then maybe to track and see if there were some links between things that I hadn't perhaps really identified myself." (G5, Psoriasis, England)
		"I think it also would perhaps be a prompt to help you think about triggers that maybe you're overlooking. Erm, but even with rosacea it could be such a wide range, it could be what you've eaten, being in

	the sun, like having hot, it could be any… I think it would be a good prompt to think about is there anything you're missing?" (G8, Multiple skin conditions, England)
	"But if something enabled me to track those environmental factors and say again, you know, am I stressed, have I eaten healthily, what exercise have I taken, is it hot today, is it cold today, is it the winter, is it summer? […] There might not be a causal link between the two, but if I was to put in the app, I've eaten badly the last few days, the air pollution is really awful, I haven't had any exercise in the last few days. You know, red lights start flashing, go and change those things, it might be helpful" (G1, Psoriasis, England)
	"I started like a calorie-counting app and I'm finding that's working really good for me. […] I think it'd be really good to reinforce that behaviour as well, I think. It's making me focus on ... So, it's giving me a goal. […] I think, you know, if there's an app that will help you achieve your goal in something – for example, like I say, about skincare – then you know, seeing your skin improve will be the achievement. So, that's, that's just giving me a sense of achievement at the end of it then." (G7, Lamellar Ichthyosis, Wales)

	"Yeah, um, and I'm just agreeing with earlier comments about the ability to note what you've tried and the outcomes. It can be really hard to remember, and even when you're seeing a dermatologist and they've got all the information I front of them, they may not necessarily have comments about what has or hasn't worked, and it may not be your own view of what has and hasn't worked. […] If you can't get an appointment for ages, and then you're there, you've got ten minutes. You can't remember your questions; you can't remember your history. Um, yeah, that could be helpful." (G2, Psoriasis, England)
	"I suppose another utility of that which wouldn't necessarily be for like self-management would be that you could potentially take that to your dermatologist or GP, erm, if you've got quite a systematic way of like looking at links between those things, it could be useful in that respect as well." (G8, Eczema, England)
	"I know there's quite a lot of, erm, research and things around like fitness apps and sometimes they're actually kind of encouraging like unhealthy behaviours or people becoming quite obsessed or, erm, if people susceptible to eating exercise disorders that can be

		problematic, so I don’t think I have an answer that I think trying to make it useful but not trying to make it into one of those things where people feel like they have to be leading a certain lifestyle or doing a certain thing.” *(G8, Eczema, England)*
	Understanding others.	*“Support from other people with your condition is essential” (G6, Lamellar Ichthyosis, England).*
		“I’ve even like become friends with people through like the Facebook groups, like where we ... One of my close friends lives in Canada, but we Zoom and stuff like that from here, from time to time. But yeah, friends that I’ve made through the community groups.” (G3, Lamellar Ichthyosis, USA)
		“it’s about knowing people that have, are living with the same condition […] It really touches home, because you think ‘Oh my God, yeah, that, that lady or that guy has just written about something that, that’s exactly how I felt, and that’s exactly how, and it just makes you feel like you’re not the only one with this, you know, and there are millions of people out there, across the world, that are in exactly the same boat as you.” (G6, Vitiligo, England)

	"Another positive with this group is some of the information that's exchanged here, how do you deal with this on a day-to-day basis? Something that a dermatologist or a specialist will never impart to you, and likely never will, because it hasn't gone through a randomised clinical trial etc." (G1, Hidradenitis Suppurativa, Ireland)
	"I'm often my own doctor, which is why I tend to rely a lot on the Ichthyosis Support Group. For example, I'll put in a post on there and say, right, this is happening to me now, is this new? Is this something that comes with age? Um, have either of you dealt with it? And straightaway, you know, I'll get um, universal comments from people err, offering support and help and what sort of treatments they've used. […] and something my Dermatologist couldn't answer, someone from Arizona in the US has been able to answer for me. It's just things like that really, the sort of collective experiences online, can help you get the support that you need." (G4, Epidermolytic Hyperkeratosis, Wales)
	"Maybe some people's stories? So that people can see people with the same conditions and how they manage it." (G6, Eczema, England)

	“Hear, hear to hearing inspirational stories from others. Patients listen to other patients more than anyone else.” (G1, Hidradenitis Suppurativa, Ireland)
	“I just had a quick thought, I know this is about like an app, and everything is online, but maybe through this app, having like a face to face group, so whether there could be an option like, on this app, to have … you know, like changing the settings, so that people living close by, so if their postcodes meet, whether they could have like a workshop somewhere, like in a local community centre, where you can see people face to face. Because sometimes we can be so harsh over the screens, and then when you meet people face to face, and you physically see them, it kind of breaks down those barriers, and we become less harsh as well, because there’s more empathy towards another human being.” (G1, Eczema, Wales)
	“I don’t know, thinking that, er, if, if in the sort of, help of the psychological part that, erm… I, I think I, I wouldn’t look for, look for an app, I would, erm, look for people I could talk with maybe, erm, other people with the same conditions, er… I have a little bit of

		trouble, erm, sort of imagining how an app could help that much." (G8, Multiple skin conditions, Denmark)
		"My entire life, I've never met anybody other than my sister that has the same condition. Wouldn't it be great to meet other people who have the similar condition? You could sit down and say 'Look, this is my problem'. You know, how do you deal with this? And the sort of thing like an app you're talking about is great but it would be nice to meet people you know, like this." (G6, Lamellar Ichthyosis, England)
		"I think the first time I spoke to someone err, was in my thirties, who had vitiligo, I'd never seen anyone with vitiligo, so, it, it did a lot to boost my confidence, that this person, who had it much worse than I did, was coping, and it, it, you know. So, I think meeting face to face or even in a Zoom condition like this, would be very good, but I don't know how that would work with the App, could you organise it to do it, I don't know?" (G4, Vitiligo, England)
6	Barriers and facilitators to app use	*"For me, I wouldn't want the app to be too much effort. I don't want to document things, just maybe click when I feel the need." (G2, Vitiligo, England)*

	"… A simple, you know, is your skin red, yes or no? And I could just tick yes. Do you have pigmentation, yes? And keep it really, really simple…" (G1, Post-hypertrophic acne scarring & Hyperpigmentation, England)
	"… I use the Zoe app for Covid […] it's just got some simple yes/nos, you could maybe put other stuff around ratings in there, you know, my pain today is one to 10, whatever it might be." (G1, Psoriasis, England)
	"One way is that I'm a bit of a ... kind of an ostrich. […] Er, I come from a family where we don't talk about things. Er, so it's never been a question, to talk about how I feel, or if I have a problem, or ... So, I haven't really talked about it that hard, frankly." (G3, Netherton Syndrome, Sweden)
	"My husband, his family doesn't talk about feelings – ever – um, so we struggled a lot in the beginning of our marriage because of that, but ... Um, so like some people still think that mental health is just false. You know, that it's just something ... Like it's a very black and

	white area: you're happy or you're sad – and if you're said, you need to get happy." (G3, Lamellar Ichthyosis, USA)
	"yeah but do people think that they go to mental support because they're going mad or something like that? And there's still a bit of a stigma, a stigma in my mind, certainly. But there may be a stigma in people's mind. It's a skin condition at the end of the day. Yes, it does affect you mentally." (G6, Lamellar Ichthyosis, England)
	"[Moderator]: [participant] said 'no links to big pharma', [participant] do you want to say a bit more?" "[Participant]: Only that, erm, you know, I think being suspicious of anyone who you think is trying to sell you medications [laughs]. Erm, you know, I think it's important the developers have integrity, erm, and you feel like they genuinely have like patients best interests at heart and, so I think it would be good if the skin charities were kind of able to endorse the content and say, you know, this is a trustworthy source […] I think would give confidence." (G8, Multiple skin conditions, England)
	"Well, I was just going to say that I think of myself as being quite computer literate, but then I look at my grandchildren and I don't ... I'm nowhere in their league. […] you mustn't always make the

	assumption that everybody that has a skin condition is young and has grown up using their thumbs for technology, if you like." (G2, Vitiligo, England)
	"And then, like I said, like things like ... Since mental health is such a big thing, like sections for that. You know, seeking help for whether it's our condition or our mental health or ..." (G3, Lamellar Ichthyosis, USA)
	"Different icons/squares to click on with different sections (e.g., forum, tracker, information etc.)" (G8, Eczema, England)
	"The easiest answer is translation […] It needs to be accessible in a lot of languages, not perhaps only the standard English, Swedish ... Sorry, Spanish, French. The biggest – Chinese, perhaps. I don't know. […] It needs to get more accessible in more languages, I think." (G3, Netherton Syndrome, Sweden)
	"I know a lot of people with ichthyosis, obviously, it's global, it's worldwide, um, there are a lot of people in err, Italy, Spain, within Europe as well, with the condition, and they do try to communicate on our support groups, with like Translate […] So, I mean if there was

	an opportunity in terms of the accessibility for, um, Auto Translate or things like that, which you can access on Facebook and things, that would be something I think would help." (G4, Epidermolytic Hyperkeratosis, Wales)
	"Easy navigation, so, you've got an easy drop down menu, you can find things quickly, there's not lots of jargon and that way, people who aren't as text savvy as perhaps we are online, um, can still navigate, it shouldn't exclude people who are less text savvy, yeah." (G4, Psoriasis, England)
	"I think going direct to the Organisations/Societies and ask them to put the App on their site(s) and recommending members to download it. Also, Doctor surgeries advertising it and all Groups associated with skin conditions." (G6, Vitiligo, England)
	"If you could get backing or you know, just support from um, the, the various associations, err, patients support associations, I think that would be great, because I think we've become a bit sceptical, of who we believe and who we want to sort of associate ourselves with. We want to know it's a trusted resource, don't we? So, if the Psoriasis Association, recommends an App, or um, something similar, or I

	would trust something coming from their mouth rather than just Joe Bloggs in the street or um, just seeing something advertised somewhere. If you could get posters into Dermatology departments that would be good." (G4, Psoriasis, England)
	"Having a small cost would deter those that aren't kind of genuine, but then equally you don't want to exclude people from being able to access it on a financial basis. […] I think about the term 'Social prescribing' you know, a doctor could prescribe it almost as a support tool for those that couldn't necessarily access it." (G6, Psoriasis, England)
	"Yeah, it needs to be free […] People might not be able to afford to do a membership. You know, I don't ... It's not very fair." (G7, Ichthyosis Vulgaris & Psoriasis, England)
	"I think with people accessing it, because even if it was quite cheap to buy, if people have got limited income or are spending money on quite a lot of other helps, then I think it [no cost] would open it up to more people." (G1, Psoriasis, Wales)

	"… you have to take into account, not everybody has a Smart Phone and an App and it can be difficult. […] We need to work on a variety of devices as well, so, a lot, a lot of the time, some of these Apps are designed in a way that, that you, you don't need a new phone but you need a relatively, but this sort of thing, you want it to be able to work on, anything, so, your development costs would be a lot higher to test it." (G4, Vitiligo, Scotland)
	"I'm not very technical (chuckling) but what I was thinking was, to be able to use it offline as much as possible, um, obviously, not everyone actually has internet at home etc., so, so the people can, if, they may have to use the internet to download it, and maybe every so often, to update it, […] yeah if you could perform as much of the functions offline as well, it might help people that maybe just don't have their own kind of broadband at home and are just using their phone data for all of their internet uses." (G5, Psoriasis, England)
	"cos I've used um, like fitness tracking App um and then yeah, having to enter your food in, and yeah, managed it for about a week and then it's like, it's a lot of work, what am I actually getting for this, it's just telling me what I already know […] if it is sophisticated enough to

	really go into the granular of what you're eating, what you're sleeping, what's the weather like at that time? Um, so, you can really narrow down on what it is, then it could be beneficial. Um, but yeah, my, my kind of personal experience is that yeah, the tracking Apps do take quite a bit of input um, for maybe not so much gain." (G5, Psoriasis, England)
	"I always start off really well with these tracking Apps and I am like the perfect student for the first three days and then I just am really bad at them…" (G5, Psoriasis, England)
	"So, all the facets that we've talked about, whether it's educational, social, psychological, diet, or whatever, all of those would come in and if I saw that by participating in what the App had to offer, led to my skin, being better and me being able to help it to be better, absolutely, that would keep me in, keep me in, I'd be thinking, I've things to do (chuckling)." (G5, Psoriasis, England)
	"I guess people who might use the app at the end, so people like us, erm, maybe doing like think aloud interviews or something like that, where someone tries to walk through it and then goes, oh, I don't understand where this is or, oh this is really hard to use or that kind of

	thing, I think is really important because even if it's got really good information on it, if people find it really inaccessible or clunky then they probably won't use it." (G8, Eczema, England)
	"I think it depends what the main purpose of the App is gonna be, if it's tracking, I think having kind of rewards and goals […] if you log seven days in a row, you might have a smiley face or something […] there's a recognition of what you're putting in. If it's an information App, um, then obviously, just making sure that the, the content is regularly updated, um, so that there's a reason for people to go in, um, um, or if, even if the content is not updated regularly, um, it's at least reviewed regularly." (G4, Psoriasis, England)
	"It's got to be something that's live and current. […] I mean if you think about you know like, sort of Facebook or Twitter, people go back to it because it's live feed all the time. So they want to know what's going on now or what's happened an hour ago or yesterday or two days ago or whatever. […] But there has to be something that's live and updated constantly to get people to keep going back so they don't feel like they're missing out on something." (G6, Vitiligo, England)

Personal choice and autonomy.	*"Um, so, it would be good if the App just, you could go in and out of it […] if you think, yeah, I've kind of conquered it for a few months and then you kind of have to go back with your tail behind your legs and be like, oh it's come back again. Um, so, just that kind of, you may not be getting people using it, day in, day out, constantly, but it would be nice, if there's, if it's easy for people to take a break from it and then step back in." (G5, Psoriasis, England)*
	"I can't help but to gravitate towards this, that it needs to have some kind of reminders for people in this particular app, in order to do things and in order to make space in their life for these new healthier ways of living, you know." (G6, Hyperpigmentation, Wales).
	"A simple thing that I found very effective in the group I do, is to post an upbeat message every day, a nice, simple quote. […] Just something positive, simple, something to hope for, I think. […] You know, things can get better, things can improve. Moods change, feelings change, etc., etc., today's a bad day, but tomorrow may be a good day, that type of thing." (G1, Hidradenitis Suppurativa, Ireland)

	"I've got a few Instagram pages that I follow that have these, it's almost like these daily motivational affirmations or quotes […] it can help with lifting the mood […] but it might be something to consider for having within the app […] to help with that positive outlook and that body confidence, erm, as you said it, it works well for me as cliched and cheesy as it is..." (G8, Vitiligo, England)
	"I, I personally think that too many prompts and too many reminders could, could perhaps have negative connotations, because if you're already beating yourself up because, you know, you perhaps think you've done something that aggravated your skin condition because you're […] it could have a negative downside, make you feel worse." (G2, Vitiligo, England)
	"Personally I hate them. […] It's like you're being told off, because it's like oh yeah, it's a reminder that you haven't done it, it's like then it turns into a chore. […] I assume most people have heard of Wordle by now, I do it every day, like it's … I'll just have it whilst I'm drinking like my morning coffee, and I'll give it a go, you know. But that's because I have a genuine interest, I don't have a notification, and be like oh

	yeah, need to do Wordle. But Duolingo, yeah, I deleted that ages ago, because it started to annoy me, so yeah." (G1, Vitiligo, England)
	"I think generally the notifications are really annoying, but you're talking about how to get people to keep using the app in the future and, erm, there's one way that might do it, if, if they didn't very often [laughs], because often, often the problem with notifications is that they, they come too often, so people finish up, er, blocking them or, or uninstalling the app that sends them or whatever." (G8, Multiple skin conditions, Denmark)
	"So it's a reminder that the app's there, but also it is that little bit of hope, rather than being annoying that you haven't done this today, or oh yeah, like pick up your phone, go on the app, it's still there, but without being in your face." (G1, Vitiligo, England)
	"Yeah, it's just reminders that you get on your phone, that the user can control when, what time of day might be best to update, not that I always do these things, but you know, if it's, if you've got something popping up at a regular time, every day, then you might be more inclined to, to update something." (G5, Psoriasis, England)

	"Yeah, if I thought that whoever was holding the information were reputable […] if it was a university, health organisation, someone like that, I'd have no problem whatsoever." (G1, Hidradenitis Suppurativa, Ireland)
	"Fine as long as proper data protocols, clear use and not vehicle for data mining or selling." (G2, Psoriasis, England)
	"I think on this type of app […] we would have to give a lot more of our health and personal information I think, just because of the way the app is. So I just think it's about making the user know and be aware that this kind of information would be beneficial to give." (G1, Eczema, Wales)
	"Everyone just downloads things and clicks accept on anything. Everyone says like: 'Oh, I'm terrified about my data being stolen.' Then as soon as they've got an app or something and it needs accepting to use it, they just accept it and off they go. So, I'd be surprised if anyone actually cared about that – but maybe they do?" (G7, Vitiligo, England)

		“I think some people wouldn't want to share information unless they were anonymous.” (G8, Multiple skin conditions, Denmark)
		“I mean, they could make some sort of username that has nothing to do with their personal information. […] Like I’m an open book, so I can put ... I could put my name, if I wanted to do that. So, that way, like you’re covering people that want to build the community, and then people that would rather remain, remain anonymous.” (G3, Lamellar Ichthyosis, USA)
	Look and feel of the app.	*“Able to use it if you have multiple skin conditions ie not made to pick one main one in order to use the app.” (G8, Multiple skin conditions, England)*
		“I know within the netherton syndrome community, most people have eye problems so bigger fonts is a great idea.” (G8, Netherton Syndrome, England)
		Captions, audio, visual, use of colour.” (G5, Psoriasis, England) *“During Covid, I was one of the First Responders and the app was just so clinical and clunky and not very easy to use. And just something that’s really simple, it’s got some nice graphics, etc. You know, it just,*

	it doesn't look like your GP's website basically, which are notoriously not easy to use. But yeah, I think just a bit more friendly, a bit more welcoming. Something that is aesthetically pleasing, that you would want to go and look at as opposed to going onto an app and going 'Oh, okay right, it's just words, it's just text, that kind of thing'." (G6, Psoriasis, England)
	"I've been reading recently about the psychology of colours and a lot of health authorities use blue and green scrubs etc., etc., it inspires confidence and intelligence, etc., etc., there's a lot to sort of psychology of colour." (G1, Hidradenitis Suppurativa, Ireland)
	"… but I do think that the idea of sort of looking at what some of the gyms do may not be a bad idea. […] It's all about, you know, let's, let's be positive and let's talk about food and let's talk about this and that. and you know, like pictures of people living their full life, which is what I suppose we're wanting to, to do here." (G6, Eczema, England)

Appendix 28: Perceived barriers and facilitators mapped against the COM-B Model (Michie et al. 2011b)

Theoretical concept		**Barriers**	**Facilitators**
Capability	***Physical***	Burden of manually entering data. Sometimes linked to experiencing physical symptoms, such as pain.	Simplify the format of questions; include response options to questions that users can select, such as single (e.g., yes/no) or multiple-choice questions and numeric rating scales.
		Physical health, symptoms (e.g., pain) and comorbidities associated with skin conditions (e.g., impaired vision in people with Netherton Syndrome)	Include on-screen captions and audio-descriptions.
			Carefully consider use of fonts, text size and colour scheme.
		People living with more than one skin condition.	Acknowledge complexity and allow for people to specify that they have multiple skin conditions, instead of asking them to specify one or their main condition.
	Psychological	Beliefs about mental health and help seeking (self-stigma).	None suggested.
		Beliefs (skepticism) about pharmaceutical companies and their motives (relates to industry sponsorship).	Endorsement from credible sources (e.g., patient organisations) as well as a pharmaceutical company.
		Safety concerns around the use of digital technology and social media platforms.	Subscription fee (to deter people with ulterior motives from accessing the app).

		Concerns about privacy and data sharing.	Transparency around data handling and use; adherence to data protection protocols (GDPR).
			Those responsible for handling and managing data are trustworthy.
			Option to register anonymously.
		Lacking skills to use technology.	None suggested.
		Self-efficacy (confidence in own ability to use technology).	A simple, user-friendly interface with distinct sections that are easy to navigate.
		Existing and unhelpful strategies for coping with difficult emotions (e.g., avoidance).	None suggested.
		Language – English language only.	Translate content into other languages.
		Health literacy.	Use of lay language, avoid jargon.
			Vary how information is presented and include visual, as well as written, content.
Opportunity	***Social***	Public stigma and social or familial norms around mental health and seeking support.	None suggested.
		Poor awareness of the app.	Make the app available via the app store.
			Endorsement from credible sources (e.g., health providers and patient organisations).

			Promotion by credible sources (e.g., health professionals and patient organisations) in trusted settings (e.g., GP surgeries).
	Physical	Accessibility – cost of app.	Make the app available on prescription.
			Make the app free to access.
		No access to a smartphone.	Develop a web-based app that is accessible via different digital technologies.
		Limited or no access to the internet.	Include downloadable content.
Motivation	***Reflective***	Personal health and well-being will influence the extent to which a person feels motivated to, or actually engages with the an app, especially apps including a self-monitoring function that relies on users to consistently track triggers associated with their condition or general health.	Seeing physical improvements in the skin.
			Personalised feedback on progress.
			Virtual rewards.
			Push notifications including messages that are positively framed and inspire users.
			Gathering and incorporating user feedback, potentially through research involving prospective users.
			Ensure the app is not prescriptive and can be used flexibly. Allow users to choose when, how often and how long they use the app for.
		Regular push notifications.	Include messages that serve as a reminder, rather than an instruction, to use the app.

			Allow users to specific when and how often they receive push notifications from the app.
Other		Apps that look and feel like clinical settings.	Create a positive user experience; an app that feels welcoming, friendly and calming.
			A blue or green colour scheme; these colours facilitate a sense of calm and are similar to the design of other apps for health, fitness and well-being.

GDPR, General data protection regulation.

Appendix 29: Online survey

Development of a New Health Technology Application to Support People with Dermatological Conditions

Online survey

Introduction

Skin conditions can have a major impact on people's lives. The global coronavirus pandemic has challenged people's ability to cope with and manage their skin condition more than usual. People might need more support to overcome these challenges.

Researchers in the School of Healthcare Sciences at Cardiff University have developed an online survey to understand people's views, experiences, and needs in relation to managing ***all*** aspects of a skin condition. By 'all aspects' we mean physical, psychological, social, economic and daily factors related to your condition.

The survey findings will be used to develop a new smartphone application (app) to support people to better understand their condition and live well in their own skin.

You are invited to complete this questionnaire and answer questions about:

- You and your skin condition.
- How you manage and cope with your skin condition.
- Types of support that are available to help you manage all aspects of your skin condition.
- Extra support that you might want or need from a mobile app to manage all aspects of your skin condition effectively.

The questionnaire will take no more than 15 minutes to complete. Your responses will be **anonymous**.

Please feel free to share this questionnaire with as many people as possible who have a skin condition, the more diversity we get the more we will learn.

Thank you from the members of the research team at Cardiff University.

Go to next page

Consent to take part

Please read the participant information sheet [insert hyperlink to PIS]. You can download and save the participant information sheet for your own records if you wish. Please confirm you are happy to complete this survey by agreeing yes to the following questions:

1. I am 18 years of age or over. *Required.

   Yes ☐ No ☐

2. I have a skin condition. *Required.

   Yes ☐ No ☐

3. I understand that by ticking this box I am giving consent to taking part in this research study. I have been provided with a participant information sheet and I understand that by agreeing to participate, the data that I provide will be analysed and published. I understand that the data that I provide is anonymous; that I cannot be identified at any point. (Please tick to confirm consent). *Required.

   Yes ☐ No ☐

If all yes responses, go to part 1: ‘about you’.

If any no responses, go to ‘thank you’ page.

Part 1: About you

The following questions are about you and your skin condition. Please read the instructions for each question carefully. *All required.

1. In which country do you live? If you live in the UK, please state the nation you live in

   ………………………….

2. What is your age?

   ………

3. What gender do you identify with? Tick one box.

Male	☐
Female	☐
Other	☐
Prefer not to say	☐
If other, please specify	………..

Black (African, Afro-Caribbean, African-Canadian descent)	☐
East Asian (Chinese, Korean, Japanese, Taiwanese descent	☐
Latino (Latin American, Hispanic descent)	☐
Middle Eastern (Arab, Persian, West Asian descent, e.g., Afghan, Egyptian, Iranian, etc.)	☐

South Asian (East Indian, Pakistani, Sri Lankan, Indo-Caribbean, etc.) ☐

Southeast Asian (Filipino, Vietnamese, Cambodian, Thai, etc.) ☐

White (European descent) ☐

Prefer not to say ☐

Other ☐

If other, please specify:

……….

4. What option best describes your ethnic origin or background? Tick <u>one</u> box.
5. What skin condition you have? If you have more than one condition, state the name of the condition that affects you most <u>first</u>

   ……….

Go to Part 2

Part 2: The impact of managing your skin condition on you and your life

We want to know how managing your skin condition affects you day to day. Please indicate the extent to which you agree or disagree with the statements below by ticking one box for each statement. *All required.

Managing my skin condition…

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Is Expensive					
Takes time and effort					
Impacts on my work/education					
Impacts on my daily activities (e.g., chores)					
Impacts on my leisure time (e.g., playing sport, watching TV)					
Impacts on my social life					
impacts on my relationships with friends and family					
Impacts on my romantic relationships					
Impacts me physically (e.g., symptoms, fatigue)					
Impacts me psychologically (e.g., my emotions and mood)					
Impacts my life goals and ambitions					

If there is anything else you wish to tell us in relation to the impact of how managing your skin condition impacts you and your life, please write in the box below. *Optional.

Go to part 3

Part 3: Coping with your skin condition

We are interested to know how you cope with your skin condition. Some of the statements below are very similar so please read each statement carefully and tick one box for each statement. *All required.

	I haven't been doing this at all (e.g., never)	I have been doing this a little bit (e.g., sometimes)	I've been doing this a medium amount (e.g., often)	I've been doing this a lot (e.g., almost always)
I've been turning to work or other activities to take my mind off things				
I've been concentrating my efforts on doing something about the situation I'm in				
I've been saying to myself "this isn't real".				
I've been using alcohol or other drugs to make myself feel better.				
I've been getting emotional support from others.				
I've been giving up trying to deal with it.				
I've been taking action to try to make the situation better.				

I've been refusing to believe that it has happened.				
I've been saying things to let my unpleasant feeling escape.				
I've been getting help and advice from other people.				
I've been using alcohol or other drugs to help me get through it				
I've been trying to see it in a different light, to make it seem more positive.				
I've been criticizing myself.				
I've been trying to come up with a strategy about what to do.				
I've been getting comfort and understanding from someone.				
I've been giving up the attempt to cope.				
I've been looking for something good in what is happening.				

I've been making jokes about it.				
I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.				
I've been accepting the reality of the fact that it has happened.				
I've been expressing my negative feelings.				
I've been trying to find comfort in my religion or spiritual beliefs.				
I've been trying to get advice or help from other people about what to do.				
I've been learning to live with it.				
I've been thinking hard about what steps to take.				
I've been blaming myself for things that happened.				
I've been praying or meditating.				

I’ve been making fun of the situation.				
I’ve been keeping physically active.				
I’ve been smoking cigarettes.				
I’ve been trying to hide my condition from others.				
I’ve been eating healthy foods.				
I’ve been spending time learning about my condition.				
I’ve been spending time learning how best to manage my condition.				
I’ve been taking part in advocacy or voluntary work.				
I’ve been trying to get enough sleep.				
I’ve been taking my medication as prescribed by my doctor.				

If there is anything else you wish to tell us about how you cope with your skin condition, please write in the box below. *Optional.

Go to part 4

Part 4: Existing support for managing ***all*** aspects your skin condition

We want to know about the types of support that are currently available to you to help you manage ***all*** aspects of your skin condition. Tick one box for each statement. *All required.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
What I do can determine whether my condition gets better or worse					

To manage all aspects of my skin condition, I receive support from…

	Always (i.e., all the time)	Often (i.e., frequently)	Sometimes (i.e., occasionally)	Rarely (i.e., hardly ever)	Never (i.e., not at all)
Healthcare professionals					
My family and friends					
A patient organisation					
A psychologist, therapist, or counsellor					
People online or on social media					

To manage all aspects of my skin condition, I use…

	Always	Often	Sometimes	Rarely	Never

	(i.e., all the time)	(i.e., frequently)	(i.e., occasionally)	(i.e., hardly ever)	(i.e., not at all)
Written self-help materials (e.g., leaflets, books)					
Digital self-help materials (e.g., internet, websites, mobile app)					
Treatment that has been prescribed by a healthcare professional					

If there is anything else you wish to tell us about the types of support that are currently available to help you manage all aspects of your condition, please write in the box below. *Optional.

Part 5: Your views on the new mobile application (app)

We want to develop a new mobile application (app) that helps people to manage all aspects of their skin condition effectively. We want to know what you think about this idea. Please indicate how *acceptable* this idea is to you by ticking one box. *Required.

	Acceptable	Slightly acceptable	Undecided	Slightly unacceptable	Not acceptable
The idea of a new smartphone app that helps me to live well with my condition is…					

If you would like to explain your answer, please write in the text box below. *Optional.

We have come up with some ideas for the new mobile app and are interested to understand your views on the look, contents, and functions of the app. Please indicate how *important* the following are to you and tick one box for each statement. *All required.

The new app…

	Extremely important	Very important	Moderately important	Slightly important	Not at all important
…is developed in collaboration with health professionals involved in the care of people with skin conditions					

…is developed in collaboration with people with skin conditions					
…is developed in collaboration with organisations that represent people living with a skin condition(s)					
…is endorsed/supported by health professionals					
…is endorsed/supported by organisations that represent people living with a skin condition(s)					
…is endorsed/supported by local, national, or international health authorities					
…is free to access					
…offers the option to connect with other people with skin conditions					
…provides information on the impact of food/diet on your skin condition					
…provides information on the impact of physical activity on your skin condition					

…provides information on the impact of smoking on your skin condition					
…provides information on the impact that drinking alcohol can have on your skin condition					
…provides information on the impact of sleep on your skin condition					
…provides practical tips for coping well with a skin condition					
…offers practical tips on how to be more physically active with a skin condition					
…offers practical tips on how to improve sleep quality					
…offers practical tips on how to quit smoking					
…offers practical tips on how to reduce alcohol intake					
…offers practical tips on how to maintain a healthy diet					
…offers practical tips on managing itch					

…offers practical tips on how to take my treatment as prescribed					
…is personalised to individual users					
…contains interactive activities for users to engage with					
…offers virtual points/rewards for completing activities within the app					
…offers the opportunity to identify, plan and monitor personal goals					
…provides visual feedback (e.g., graphical data) on personal progress					
…offers the option to receive reminders or alerts					
…provides information on how living with a skin condition can impact on mood					
…offers practical tips for managing low mood (e.g., anxiety and depression).					
…offers the opportunity to monitor mood and emotions					

…offers practical tips on how to stay motivated					
…provides information on the social impact of living with a skin condition					
…offers strategies for managing social interactions					
…offers strategies for managing social anxiety					
…gives users a sense of personal control over the condition					
…gives users a sense of continuity of care					
…increases people's awareness of their skin condition (e.g., symptom variability)					

If there is anything else that you feel that you would want or need from a new app that is designed to support you to live well with your skin condition, please type in the box below. *Optional.

Go to 'Thank you for take part in this online survey'

Thank you for taking part in this online survey:

Thank you for sharing your views and experiences with us, we appreciate the time you have taken to complete this questionnaire.

We are running online group interviews to further understand the views of people living with skin conditions on the development of a new mobile app to support health and well-being.

If you would like to take part in an online group interview, or would like to be informed about other studies related to this project in the future, please state your **name** and **email address** in the box below.

Alternatively, you can email Rachael Hewitt (PhD student, Cardiff University): hewittr2@cardiff.ac.uk

Thank you:

Thank you for your time. Please help us to improve by telling us why you chose not to participate in this research study. *Optional.

As you did not consent to take part in this survey there will be no further questions.

We are undertaking group interviews online to further understand what people with skin conditions think and feeling about the development of a new mobile app that supports health and well-being.

If you would like to take part in an online group interview or would like to be informed about related research studies in the future, please state your **name** and **email address** in the box below.

Alternatively, you can email Rachael Hewitt (PhD student, Cardiff University): hewittr2@cardiff.ac.uk

Appendix 30: Categories of coping according to the Brief Cope (Carver 1997)

Problem-focused	Emotion-focused	Dysfunctional
Active coping	Acceptance	Behavioural disengagement
Seeking instrumental support	Seeking emotional support	Denial
Planning	Humour	Self-blame
	Positive reframing	Self-distraction
	Religion	Substance use
		Venting

Appendix 31: Categories of coping according to Meyer (2001)

Adaptive	Maladaptive
Acceptance	Behavioural disengagement
Active coping	Denial
Humour	Self-blame
Positive reframing	Self-distraction
Planning	Substance use
Religion	Venting
Seeking emotional support	
Seeking instrumental support	

Appendix 32: Items on coping and health behaviours that are not included in the Brief COPE (Carver 1997)

Health-protective	**Health-threatening**	**Other**
Physical activity	Smoking cigarettes/tobacco	Hide/camouflage condition
Healthy eating		
Sleep		
Learning about skin condition		
Learning how to self-managing skin condition		
Volunteering or taking part in advocacy work		
Taking medication as prescribed		

Appendix 33: Examples of written content for survey advertisement

1	Do you live with a skin condition (anywhere in the world)? If so, take a short survey in English to help researchers at Cardiff University to understand how they can best support people to live well with a skin condition using a new mobile app. (survey URL)
2	Calling all adults (18+) living with a skin condition. Take part in a short survey to share your experiences of living with and managing your skin condition. People from all countries with a broad range of conditions welcome. (survey URL)
3	Attention all adults living with a skin condition! Researchers at Cardiff University are looking for people with X condition or living in X region to take part in a short survey to understand how they can people to live well with a skin condition using a new mobile app. (survey URL)
4	Research opportunity for adults living with skin conditions. Cardiff University needs your help to create a new mobile app that supports people to live well with a skin condition. Take part in a short survey and tell us your experiences of managing your skin condition and share your ideas for the new mobile app. (survey URL)

Appendix 34: Examples of visual content for survey advertisement

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

Adults living with

Eczema

Take part in an **online survey** and tell researchers how they can help people to live well with Eczema using a new smartphone app.

Do you have a **skin condition**?

If so, researchers at Cardiff University need your help. Take part in an online survey and share your views and ideas on the development of a new smartphone app that aims to support adults living with skin conditions to improve their mental health and well-being.

Take the online survey here:
https://cardiff.onlinesurveys.ac.uk/living-with-skin-conditions-mobile-app

Or email Rachael Hewitt (lead researcher):
hewittr2@cardiff.ac.uk

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

Online survey

for adults with

Acne

Help researchers at Cardiff University to understand how they can support the psychological health of people living with acne using a new mobile app.

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

Appendix 35: List of skin conditions reported by survey respondents

Acne, acne vulgaris, actinic keratosis, alopecia, alopecia areata, dermographism, palmoplantar pustulosis, hidradenitis suppurativa, rosacea, vitiligo, no melanin, pachyonychia congenita, subacute cutaneous lupus erythematosus, lichen sclerosus, lichen planus, skin cancer, granuloma annulare, pemphigus, pemphigus vulgaris, pemphigus herpetiformis, bullous pemphigoid, eczema, atopic eczema, atopic dermatitis, contact dermatitis, seborrheic dermatitis, dermatitis, ichthyosis, X-linked ichthyosis, autosomal recessive congenital ichthyosis (ARCI), ichthyosis vulgaris, ichthyosis simplex, bullous Ichthyosis, nonbullous congenital ichthyosiform erythroderma, ichthyosis bullosa of siemens, lamellar ichthyosis, netherton syndrome, erythrokeratoderma variabilis (EKV), epidermolytic ichthyosis, palmoplantar kratoderma (PPK), loricrin keratoderma, psoriasis, plaque psoriasis, scalp psoriasis, palmoplantar psoriasis, nail psoriasis, guttate psoriasis, pustular psoriasis, acrodermatitis continua of hallopeau, flexural psoriasis, inverse psoriasis, eye psoriasis, psoriatic arthritis, osteoarthritis.

Appendix 36: Descriptive statistics on the impact of managing a skin condition, for the full sample

	Number (*n*) and percentage (%) of responses											
***Stem* and items**	**Strongly agree**		**Agree**		**Neither agree nor disagree**		**Disagree**		**Strongly disagree**		**No response provided**	
Managing my skin condition…												
Is expensive	129	34.9	139	37.6	48	13	41	11.1	13	3.5	-	-
Takes time and effort	218	58.9	126	34.1	13	3.5	9	2.4	4	1.1	-	-
Impacts my daily activities	160	43.2	117	31.6	37	10.0	46	12.4	10	2.7	-	-
Impacts my leisure time	133	35.9	129	34.9	44	11.9	49	13.2	15	4.1	-	-
Impacts my social life	154	41.6	122	33.0	38	10.3	37	10.0	19	5.1	-	-
Impacts my relationships	118	31.9	118	31.9	55	14.9	52	14.1	27	7.3	-	-
Impacts my romantic relationships	177	47.8	96	25.9	43	11.6	35	9.5	19	5.1	-	-

Impacts me physically	190	51.4	99	26.8	32	8.6	30	8.1	19	5.1	-	-
Impacts me psychologically	206	55.7	106	28.6	37	10.0	15	4.1	6	1.6	-	-
Impacts my life goals and ambitions	125	33.8	100	27.0	64	17.3	50	13.5	31	8.4	-	-

Appendix 37: Descriptive statistics on personal controllability, for the full sample

	Number (*n*) and percentage (%) of responses									
Item	**Strongly agree**		**Agree**		**Neither agree nor disagree**		**Disagree**		**Strongly disagree**	
What I do can determine whether my condition gets better or worse	105	28.4	145	39.2	70	18.9	33	8.9	17	4.6

Appendix 38: Descriptive statistics on coping strategies, for the full sample

			Number (*n*) and percentage (%) of responses							
Coping category	**Coping strategy**	**Item**	**I've been doing this a lot**		**I've been doing this a medium amount**		**I've been doing this a little bit**		**I haven't been doing this at all**	
Dysfunctional	Behavioural disengagement	I've been giving up trying to deal with it	44	11.9	71	19.2	111	30.0	144	38.9
		I've been giving up the attempt to cope	34	9.2	44	11.9	85	23.0	207	55.9
	Substance use	I've been using alcohol or other drugs to make myself feel better	24	6.5	23	6.2	49	13.2	274	74.1
		I've been using alcohol or other drugs to help me get through it	23	6.2	18	4.9	45	12.2	284	76.8
	Denial	I've been saying to myself "this isn't real"	24	6.5	30	8.1	59	15.9	257	69.5

		I’ve been refusing to believe that it has happened	16	4.3	25	6.8	54	14.6	275	74.3
	Self-distraction	I’ve been turning to work or other activities to take my mind off things	46	12.4	75	20.3	113	30.5	136	36.8
		I’ve been doing something to think about it less	51	13.8	74	20.0	106	28.6	139	37.6
	Self-blame	I’ve been criticizing myself	89	24.1	80	21.6	74	20.0	127	34.3
		I’ve been blaming myself for things that happened	38	10.3	53	14.3	68	18.4	211	57.0
	Venting	I’ve been expressing my negative feelings	32	8.6	68	18.4	136	36.8	134	36.2
		I’ve been saying things to let my unpleasant feeling escape	21	5.7	50	13.5	89	24.1	210	56.8
Emotion-focused	Humour	I’ve been making jokes about it	38	10.3	71	19.2	82	22.2	179	48.4
		I’ve been making fun of the situation	33	8.9	50	13.5	73	19.7	214	57.8

	Acceptance	I've been accepting the reality of the fact that it has happened	119	32.2	121	32.7	79	21.4	51	13.8
		I've been learning to live with it	138	37.3	130	35.1	70	18.9	32	8.6
	Religion	I've been trying to find comfort in my religion or spiritual beliefs	31	8.4	22	5.9	31	8.4	286	77.3
		I've been praying or meditating	32	8.6	30	8.1	51	13.8	257	69.5
	Positive reframing	I've been trying to see it in a different light, to make it seem more positive	32	8.6	75	20.3	115	31.1	148	40.0
		I've been looking for something good in what is happening	36	9.7	55	14.9	86	23.2	193	52.2
	Emotional support	I've been getting emotional support from others	37	10.0	70	18.9	122	33.0	141	38.1

		I’ve been getting comfort and understanding from someone	39	10.5	72	19.5	109	29.5	150	40.5
Problem-focused	Information support	I’ve been getting help and advice from other people	44	11.9	88	23.8	127	34.3	111	30.0
		I’ve been trying to get advice or help from other people about what to do	39	10.5	94	25.4	121	32.7	116	31.4
	Planning	I’ve been trying to come up with a strategy about what to do.	59	15.9	128	34.6	108	29.2	75	20.3
		I’ve been thinking hard about what steps to take	68	18.4	103	27.8	120	32.4	79	21.4
	Active coping	I’ve been concentrating my efforts on doing something about the situation I’m in	74	20.0	112	30.3	121	32.7	63	17.0
		I’ve been taking action to try to make the situation better	110	29.7	127	34.3	98	26.6	35	9.5

Additional items										
Health-protective behaviours	Physical activity	I've been keeping physically active	67	18.1	96	25.9	122	33.0	85	23.0
	Diet	I've been eating healthy foods	66	17.8	141	38.1	108	29.2	55	14.9
	Learning about condition	I've been spending time learning about my condition	110	29.7	129	34.9	91	24.6	40	10.8
	Learning about self-management	I've been spending time learning how best to manage my condition	112	30.3	126	34.1	97	26.2	35	9.5
	Volunteering and advocacy	I've been taking part in advocacy or voluntary work	33	8.9	25	6.8	46	12.4	266	71.9
	Sleep	I've been trying to get enough sleep	80	21.6	140	37.8	103	27.8	47	12.7
	Treatment adherence	I've been taking my medication as prescribed by my doctor	163	44.1	83	22.4	60	16.2	64	17.3

Health-threatening behaviours	Smoking	I’ve been smoking cigarettes	38	10.3	14	3.8	17	4.6	301	81.4
Other	Hiding the skin	I’ve been trying to hide my condition from others	121	32.7	93	25.1	83	22.4	73	19.7

Appendix 39: Descriptive statistics on existing support, for the full sample

	Number (*n*) and percentage (%) of responses									
***Stem* and items**	**Always (i.e., all the time)**		**Often (i.e., frequently)**		**Sometimes (i.e., occasionally)**		**Rarely (i.e., hardly ever)**		**Never (i.e., not at all)**	
To manage all aspects of my skin condition, I receive support from…										
Healthcare professionals	58	15.7	79	21.4	110	29.7	93	25.1	30	8.1
My family and friends	50	13.5	77	20.8	109	29.5	82	22.2	52	14.1
A patient organisation	11	3.0	25	6.8	47	12.7	54	14.6	233	63.0
A psychologist, therapist or counsellor	7	1.9	18	4.9	27	7.3	43	11.6	275	74.3
People online or on social media	33	8.9	72	19.5	89	24.1	64	17.3	112	30.3
To manage all aspects of my skin condition, I use…										
Written self-help materials	5	1.4	32	8.6	78	21.1	90	24.3	165	44.6
Digital self-help materials	38	10.3	92	24.9	118	31.9	47	12.7	75	20.3
Medication prescribed by a healthcare professional	175	47.3	92	24.9	51	13.8	19	5.1	33	8.9

Appendix 40: Descriptive statistics on perceived acceptability of MiDerm, for the full sample

Stem	**Number (*n*) and percentage (%) of responses**									
	Acceptable		**Slightly acceptable**		**Undecided**		**Slightly unacceptable**		**Not acceptable**	
The idea of a new mobile app that helps me to live well with my condition is…	255	68.9	44	11.9	60	16.2	5	1.4	6	1.6

Appendix 41: Descriptive statistics on ideas for MiDerm, for the full sample

***Stem* and items**	**Number (*n*) and percentage (%) of responses**											
The new app…	**Extremely important**		**Very important**		**Moderately important**		**Slightly important**		**Not at all important**		**No response provided**	
Is developed in collaboration with health professionals	270	73.0	64	17.3	27	7.3	2	0.5	5	1.4	2	0.5
Is developed in collaboration with people with a skin condition(s)	322	87.0	37	10.0	9	2.4	0	0	2	0.5	-	-
Is developed in collaboration with organisations that represent people with a skin condition(s)	202	54.6	101	27.3	53	14.3	8	2.2	3	0.8	3	0.8
Is endorsed by healthcare professionals	276	74.6	67	18.1	21	5.7	2	0.5	3	0.8	1	0.3
Is endorsed by patient organisations	250	67.6	79	21.4	30	8.1	7	1.9	3	0.8	1	0.3

Is endorsed by health authorities	234	63.2	91	24.6	33	8.9	6	1.6	5	1.4	1	0.3
Is free to access	302	81.6	49	13.2	15	4.1	1	0.3	3	0.8	-	-
Offers the option to connect with other people with a skin condition(s)	148	40.0	99	26.8	84	22.7	19	5.1	20	5.4	-	-
Offers information on the impact of diet on your skin condition(s)	214	57.8	107	28.9	37	10.0	8	2.2	4	1.1	-	-
Offers tips for eating a healthy diet	164	44.3	108	29.2	59	15.9	21	5.7	18	4.9		
Offers information on the impact of physical activity on your skin condition(s)	206	55.7	118	31.9	37	10.0	4	1.1	5	1.4	-	-
Offers tips for keeping physically active with a skin condition(s)	210	56.8	103	27.8	38	10.3	9	2.4	9	2.4	1	0.3
Offers information on the impact of smoking on your skin condition(s)	142	38.4	76	20.5	59	15.9	25	6.8	67	18.1	1	0.3
Offers tips for quitting smoking	118	31.9	76	20.5	59	15.9	27	7.3	90	24.3	-	-

Offers information on the impact of drinking alcohol on your skin condition(s)	149	40.3	92	24.9	61	16.5	26	7.0	42	11.4	-	-
Offers tips for reducing alcohol intake	113	30.5	81	21.9	71	19.2	33	8.9	72	19.5	-	-
Offers information on the impact of sleep on your skin condition(s)	184	49.7	105	28.4	61	16.5	9	2.4	9	2.4	2	0.5
Offers tips for improving sleep quality	204	55.1	112	30.3	35	9.5	10	2.7	8	2.2	1	0.3
Offers tips for coping well with a skin condition(s)	276	74.6	66	17.8	22	5.9	1	0.3	4	1.1	1	0.3
Offers tips for managing itch	261	70.5	69	18.6	26	7.0	7	1.9	7	1.9	-	-
Offers tips for taking treatment as prescribed	203	54.9	82	22.2	53	14.3	18	4.9	14	3.8	-	-
Is tailored to individual users	186	50.3	107	28.9	58	15.7	10	2.7	8	2.2	1	0.3
Offers interactive activities	141	38.1	105	28.4	74	20.0	28	7.6	22	5.9	-	-
Offers virtual points/rewards	84	22.7	74	20.0	85	23.0	49	13.2	78	21.1	-	-

Offers the opportunity to identify, plan and monitor personal goals	119	32.2	104	28.1	84	22.7	34	9.2	28	7.6	1	0.3
Offers visual feedback on personal progress	134	36.2	105	28.4	70	18.9	32	8.6	29	7.8	-	-
Offers the option to receive reminders	121	32.7	95	25.7	82	22.2	30	8.1	41	11.1	1	0.3
Offers information on how having a skin condition(s) can impact mood	203	54.9	103	27.8	44	11.9	13	3.5	6	1.6	1	0.3
Offers tips for managing low mood	247	66.8	74	20.0	24	6.5	15	4.1	9	2.4	1	0.3
Offers the option to monitor mood and emotions	177	47.8	91	24.6	59	15.9	21	5.7	22	5.9	-	-
Offers the option to monitor physical symptoms	185	50.0	100	27.0	54	14.6	16	4.3	13	3.5	2	0.5
Offers tips for staying motivated	157	42.4	114	30.8	65	17.6	17	4.6	16	4.3	1	0.3
Offers information on the social impact of skin conditions	186	50.3	108	29.2	49	13.2	16	4.3	11	3.0	-	-

Offers tips for managing social interactions	157	42.4	108	29.2	62	16.8	23	6.2	20	5.4	-	-
Offers tip for managing social anxiety	168	45.4	97	26.2	56	15.1	24	6.5	21	5.7	4	1.1
Gives users a sense of personal control	217	58.6	95	25.7	41	11.1	9	2.4	5	1.4	3	0.8
Gives users a sense of continuity of care	195	52.7	97	26.2	53	14.3	15	4.1	9	2.4	1	0.3
Increases people’s awareness of their skin condition	214	57.8	96	25.9	45	12.2	8	2.2	6	1.6	1	0.3

Appendix 42: Descriptive statistics on the impact of managing a skin condition, by condition category

	Number (*n*) and percentage (%) of responses									
Skin condition	**Strongly Agree**		**Agree**		**Neither agree nor disagree**		**Disagree**		**Strongly Disagree**	
Managing my skin condition is expensive										
Psoriasis	50	31.1	69	42.9	23	14.3	15	9.3	4	2.5
Ichthyosis	21	37.5	18	32.1	10	17.9	7	12.5	-	-
Multiple conditions	13	44.8	11	37.9	1	3.4	4	13.8	-	-
Eczema	7	38.9	7	38.9	1	5.6	2	11.1	1	5.6
Vitiligo	2	22.2	2	22.2	1	11.1	1	11.1	3	33.3
Hidradenitis Suppurativa	18	54.5	11	33.3	2	6.1	1	3.0	1	3.0
Lichen Sclerosus	7	20.6	10	29.4	6	17.6	9	26.5	2	5.9
Acne	1	50.0	-	-	-	-	-	-	1	50.0
Lupus Erythematosus	1	33.3	2	66.7	-	-	-	-	-	-
Pachyonychia Congenita	1	33.3	-	-	2	66.7	-	-	-	-
Pemphigus	1	33.3	1	33.3	1	33.3	-	-	-	-
Pemphigoid	1	50.0	1	50.0	-	-	-	-	-	-

Rosacea	-	-	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	-	-	1	100.0	-	-	-	-
Aktinic Keratosis	-	-	1	100.0	-	-	-	-	-	-
Epidermolysis Bullosa	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	-	-	-	-	-	-	1	100.0	-	-
Skin and joint conditions	5	45.5	5	45.5	-	-	1	9.1	-	-
Skin and mental health conditions	-	-	1	100.0	-	-	-	-	-	-
Managing my skin condition takes time and effort										
Psoriasis	101	62.7	52	32.3	5	3.1	3	1.9	-	-
Ichthyosis	36	64.3	18	32.1	1	1.8	1	1.8	-	-
Multiple conditions	21	72.4	7	24.1	1	3.4	-	-	-	-
Eczema	6	33.3	11	61.1	1	5.6	-	-	-	-
Vitiligo	3	33.3	3	33.3	-	-	1	11.1	2	22.2
Hidradenitis Suppurativa	19	57.6	12	36.4	1	3.0	-	-	1	3.0
Lichen Sclerosus	16	47.1	14	41.2	2	5.9	2	5.9	-	-
Acne	1	50.0	1	50.0	-	-	-	-	-	-
Lupus Erythematosus	-	-	3	100.0	-	-	-	-	-	-

Pachyonychia Congenita	3	100.0	-	-	-	-	-	-	-	-
Pemphigus	2	66.7	-	-	1	33.3	-	-	-	-
Pemphigoid	1	50.0	1	50.0	-	-	-	-	-	-
Rosacea	-	-	-	-	-	-	1	100.0	-	-
Lichen Planus	-	-	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-
Loss of pigment	-	-	-	-	-	-	-	-	1	100.0
Skin and joint conditions	7	63.6	2	18.2	1	9.1	1	9.1	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-
Managing my skin condition impacts my daily activity										
Psoriasis	51	31.7	58	36.0	23	14.3	26	16.1	3	1.9
Ichthyosis	27	48.2	14	25.0	4	7.1	10	17.9	1	1.8
Multiple conditions	16	55.2	10	34.5	3	10.3	-	-	-	-
Eczema	6	33.3	9	50.0	1	5.6	2	11.1	-	-
Vitiligo	1	11.1	2	22.2	-	-	2	22.2	4	44.4

Hidradenitis Suppurativa	25	75.8	6	18.2	1	3.0	-	-	1	3.0
Lichen Sclerosus	17	50.0	10	29.4	3	8.8	4	11.8	-	-
Acne	-	-	1	50.0	-	-	1	50.0	-	-
Lupus Erythematosus	1	33.3	2	66.7	-	-	-	-	-	-
Pachyonychia Congenita	3	100.0	-	-	-	-	-	-	-	-
Pemphigus	2	66.7	1	33.3	-	-	-	-	-	-
Pemphigoid	1	50.0	-	-	1	50.0	-	-	-	-
Rosacea	-	-	-	-	-	-	-	-	1	100.00
Lichen Planus	-	-	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	-	-	-	-	1	100.0	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-
Skin and joint conditions	7	63.6	3	27.3	-	-	1	9.1	-	-
Managing my skin condition impacts my leisure time										
Psoriasis	45	28.0	58	36.0	20	12.4	33	20.5	5	3.1

Ichthyosis	20	35.7	19	33.9	7	12.5	9	16.1	1	1.8
Multiple conditions	15	51.7	10	34.5	2	6.9	1	3.4	1	3.4
Eczema	4	22.2	8	44.4	4	22.2	1	5.6	1	5.6
Vitiligo	-	-	1	11.1	2	22.2	2	22.2	4	44.4
Hidradenitis Suppurativa	21	63.6	9	27.3	2	6.1	-	-	1	3.0
Lichen Sclerosus	16	47.1	13	38.2	3	8.8	1	2.9	1	2.9
Acne	-	-	1	50.0	1	50.0	-	-	-	-
Lupus Erythematosus	1	33.3	2	66.7	-	-	-	-	-	-
Pachyonychia Congenita	3	100.0	-	-	-	-	-	-	-	-
Pemphigus	-	-	2	66.7	1	33.3	-	-	-	-
Pemphigoid	-	-	1	50.0	1	50.0	-	-	-	-
Rosacea	-	-	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-
Loss of pigment	-	-	-	-	-	-	1	100.0	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-

Skin and joint conditions	6	54.5	3	27.3	1	9.1	1	9.1	-	-
Managing my skin condition impacts my social life										
Psoriasis	58	36.0	59	36.6	17	10.6	21	13.0	6	3.7
Ichthyosis	21	37.5	18	32.1	9	16.1	5	8.9	3	5.4
Multiple conditions	17	58.6	7	24.1	2	6.9	3	10.3	-	-
Eczema	3	16.7	8	44.4	2	11.1	2	11.1	3	16.7
Vitiligo	3	33.3	-	-	1	11.1	2	22.2	3	33.3
Hidradenitis Suppurativa	23	69.7	9	27.3	-	-	-	-	1	3.0
Lichen Sclerosus	15	44.1	11	32.4	4	11.8	2	5.9	-	-
Acne	-	-	1	50.0	1	50.0	-	-	-	-
Lupus Erythematosus	3	100.0	-	-	-	-	-	-	-	-
Pachyonychia Congenita	2	66.7	1	33.3	-	-	-	-	-	-
Pemphigus	-	-	2	66.7	1	33.3	-	-	-	-
Pemphigoid	-	-	1	50.0	1	50.0	-	-	-	-
Rosacea	-	-	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	-	-	1	100.0	-	-	-	-	-	-

Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-
Loss of pigment	-	-	-	-	-	-	1	100.0	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-
Skin and joint conditions	8	72.7	2	18.2	-	-	1	9.1	-	-
Managing my skin condition impacts my relationships										
Psoriasis	45	28.0	52	32.3	24	14.9	29	18.0	11	6.8
Ichthyosis	15	26.8	17	30.4	10	17.9	9	16.1	5	8.9
Multiple conditions	12	41.4	9	31.0	4	13.8	4	13.8	-	-
Eczema	4	22.2	4	22.2	3	16.7	3	16.7	4	22.2
Vitiligo	2	22.2	-	-	2	22.2	2	22.2	3	33.3
Hidradenitis Suppurativa	19	57.6	9	27.3	4	12.1	-	-	1	3.0
Lichen Sclerosus	11	32.4	14	41.2	6	17.6	1	2.9	2	5.9
Acne	-	-	1	50.0	-	-	1	50.0	-	-
Lupus Erythematosus	1	33.3	2	66.7	-	-	-	-	-	-
Pachyonychia Congenita	1	33.3	1	33.3	1	33.3	-	-	-	-
Pemphigus	-	-	3	100.0	-	-	-	-	-	-

Pemphigoid	-	-	1	50.0	1	50.0	-	-	-	-
Rosacea	-	-	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	-	-	1	100.0	-	-	-	-	-	-
Epidermolysis Bullosa	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	-	-	-	-	-	-	1	100.0	-	-
Skin and mental health	1	100.0	-	-	-	-	-	-	-	-
Skin and joint conditions	6	54.5	3	27.3	-	-	2	18.2	-	-
Managing my skin condition impacts my romantic relationships										
Psoriasis	65	40.4	45	28.0	22	13.7	17	10.6	12	7.5
Ichthyosis	26	46.4	14	25.0	7	12.5	8	14.3	1	1.8
Multiple conditions	17	58.6	7	24.1	2	6.9	3	10.3	-	-
Eczema	4	22.2	9	50.0	2	11.1	1	5.6	2	11.1
Vitiligo	3	33.3	2	22.2	3	33.3	-	-	1	11.1
Hidradenitis Suppurativa	26	78.8	4	12.1	1	3.0	2	6.1	-	-
Lichen Sclerosus	23	67.6	8	23.5	2	5.9	1	2.9	-	-
Acne	-	-	-	-	-	-	-	-	2	100.0

Lupus Erythematosus	-	-	3	100.0	-	-	-	-	-	-
Pachyonychia Congenita	-	-	1	33.3	1	33.3	1	33.3	-	-
Pemphigus	2	66.7	1	33.3	-	-	-	-	-	-
Pemphigoid	1	50.0	1	50.0	-	-	-	-	-	-
Rosacea	-	-	-	-	-	-	-	-	1	100.0
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	1	100.0	-	-	-	-
Epidermolysis Bullosa	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	-	-	-	-	1	100.0	-	-	-	-
Skin and mental health	1	100.0	-	-	-	-	-	-	-	-
Skin and joint conditions	7	63.6	1	9.1	1	9.1	2	18.2	-	-
Managing my skin condition impacts me physically										
Psoriasis	76	47.2	48	29.8	15	9.3	16	9.9	6	3.7
Ichthyosis	21	37.5	15	26.8	11	19.6	5	8.9	4	7.1
Multiple conditions	19	65.5	9	31.0	1	3.4	-	-	-	-
Eczema	7	38.9	7	38.9	1	5.6	3	16.7	-	-
Vitiligo	-	-	-	-	1	11.1	4	44.4	4	44.4

Hidradenitis Suppurativa	30	90.0	2	6.1	1	3.0	-	-	-	-
Lichen Sclerosus	16	47.1	14	41.2	-	-	2	5.9	2	5.9
Acne	-	-	1	50.0	-	-	-	-	1	50.0
Lupus Erythematosus	2	66.7	1	33.3	-	-	-	-	-	-
Pachyonychia Congenita	3	100.0	-	-	-	-	-	-	-	-
Pemphigus	2	66.7	1	33.3	-	-	-	-	-	-
Pemphigoid	1	50.0	1	50.0	-	-	-	-	-	-
Rosacea	-	-	-	-	-	-	-	-	1	100.0
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	1	100.0	-	-	-	-
Epidermolysis Bullosa	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	-	-	-	-	-	-	-	-	1	100.0
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-
Skin and joint conditions	10	90.9	-	-	1	9.1	-	-	-	-
Managing my skin condition impacts me psychologically										
Psoriasis	87	54.0	55	34.2	13	8.1	5	3.1	1	0.6

Ichthyosis	21	37.5	13	23.2	13	23.2	7	12.5	2	3.6
Multiple conditions	22	75.9	7	24.1	-	-	-	-	-	-
Eczema	6	33.3	10	55.6	2	11.1	-	-	-	-
Vitiligo	2	22.2	4	44.4	1	11.1	1	11.1	1	11.1
Hidradenitis Suppurativa	27	81.8	5	15.2	1	3.0	-	-	-	-
Lichen Sclerosus	21	61.8	7	20.6	5	14.7	1	2.9	-	-
Acne	-	-	-	-	-	-	1	50.0	1	50.0
Lupus Erythematosus	1	33.3	2	66.7	-	-	-	-	-	-
Pachyonychia Congenita	2	66.7	-	-	1	33.3	-	-	-	-
Pemphigus	1	33.3	2	66.7	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	-	-	-	-	-	-	-	-	1	100.0
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-

Skin and joint conditions	10	90.0	-	-	1	9.1	-	-	-	-
Managing my skin condition impacts my life goals and ambitions										
Psoriasis	46	28.6	38	23.6	32	19.9	29	18.0	16	9.9
Ichthyosis	16	28.6	14	25.0	13	23.2	11	19.6	2	3.6
Multiple conditions	13	44.8	13	44.8	2	6.9	1	3.4	-	-
Eczema	4	22.2	3	16.7	5	27.8	3	16.7	3	16.7
Vitiligo	2	22.2	3	33.3	-	-	1	11.1	3	33.3
Hidradenitis Suppurativa	20	60.6	9	27.3	3	9.1	-	-	1	3.0
Lichen Sclerosus	9	26.5	11	32.4	8	23.5	4	11.8	2	5.9
Acne	-	-	-	-	-	-	-	-	2	100.0
Lupus Erythematosus	-	-	2	66.7	1	33.3	-	-	-	-
Pachyonychia Congenita	2	66.7	1	33.3	-	-	-	-	-	-
Pemphigus	1	33.3	2	66.7	-	-	-	-	-	-
Pemphigoid	-	-	2	100.0	-	-	-	-	-	-
Rosacea	-	-	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-

Epidermolysis Bullosa	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-
Skin and joint conditions	8	72.7	1	9.1	-	-	1	9.1	1	9.1

Appendix 43: Descriptive statistics on personal controllability, by condition category

	Number (*n*) and percentage (%) of responses									
Skin condition	**Strongly Agree**		**Agree**		**Neither agree nor disagree**		**Disagree**		**Strongly Disagree**	
	What I do can determine whether my condition gets better or worse									
Psoriasis	39	24.2	61	37.9	39	24.2	16	9.9	6	3.7
Ichthyosis	24	42.9	21	37.5	6	10.7	4	7.1	1	1.8
Multiple conditions	6	20.7	15	51.7	2	6.9	4	13.8	2	6.9
Eczema	6	33.3	9	50.0	3	16.7	-	-	-	-
Vitiligo	-	-	2	22.2	4	44.4	1	11.1	2	22.2
Hidradenitis Suppurativa	10	30.3	8	24.2	6	18.2	5	15.2	4	12.1
Lichen Sclerosus	12	35.3	19	55.9	2	5.9	-	-	1	2.9
Acne	1	50.0	-	-	1	50.0	-	-	-	-
Lupus Erythematosus	-	-	2	66.7	1	33.3	-	-	-	-
Pachyonychia Congenita	-	-	-	-	1	33.3	1	33.3	1	33.3
Pemphigus	1	33.3	2	66.7	-	-	-	-	-	-
Pemphigoid	1	50.0	-	-	1	50.0	-	-	-	-

Rosacea	-	-	1	100.0	-	-	-	-	-	-
Lichen Planus	-	-	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	-	-	1	100.0	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-
Skin and joint conditions	3	27.3	3	27.3	3	27.3	2	18.2	-	-

Appendix 44: Descriptive statistics on coping strategies, by condition category

	Number (*n*) and percentage (%) of responses							
Skin condition	**I've been doing this a lot**		**I've been doing this a medium amount**		**I've been doing this a little bit**		**I haven't been doing this at all**	
I've been giving up trying to deal with it								
Psoriasis	18	11.2	41	25.5	55	34.2	47	29.2
Ichthyosis	7	12.5	6	10.7	13	23.2	30	53.6
Multiple conditions	4	13.8	5	17.2	10	34.5	10	34.5
Eczema	1	5.6	5	27.8	6	33.3	6	33.3
Vitiligo	1	11.1	2	22.2	2	22.2	4	44.4
Hidradenitis Suppurativa	4	12.1	7	21.2	13	39.4	9	27.3
Lichen Sclerosus	1	2.9	3	8.8	6	17.6	24	70.6
Acne	-	-	-	-	-	-	2	100.0
Lupus Erythematosus	1	33.3	-	-	-	-	2	66.7
Pachyonychia Congenita	-	-	-	-	-	-	3	100.0
Pemphigus	1	33.3	-	-	1	33.3	1	33.3

Pemphigoid	-	-	-	-	-	-	2	100.0
Rosacea	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	-	-	1	100.0	-	-
Aktinic Keratosis	-	-	-	-	-	-	1	100.0
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-
Loss of pigment	-	-	1	100.0	-	-	-	-
Skin and mental health conditions	-	-	-	-	-	-	1	100.0
Skin and joint conditions	6	54.5	1	9.1	3	27.3	1	9.1
I've been giving up the attempt to cope								
Psoriasis	14	8.7	19	11.8	40	24.8	88	54.7
Ichthyosis	5	8.9	2	3.6	8	14.3	41	73.2
Multiple conditions	4	13.8	3	10.3	8	27.6	14	48.3
Eczema	1	5.6	2	11.1	6	33.3	9	50.0
Vitiligo	1	11.1	2	22.2	2	22.2	4	44.4
Hidradenitis Suppurativa	3	9.1	8	24.2	6	18.2	16	48.5
Lichen Sclerosus	-	-	6	17.6	8	23.5	20	58.8
Acne	-	-	-	-	1	50.0	1	50.0

Lupus Erythematosus	-	-	-	-	-	-	3	100.0
Pachyonychia Congenita	1	33.3	-	-	-	-	2	66.7
Pemphigus	-	-	1	33.3	1	33.3	1	33.3
Pemphigoid	-	-	-	-	-	-	2	100.0
Rosacea	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	-	-	-	-	1	100.0
Aktinic Keratosis	-	-	-	-	-	-	1	100.0
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	1	100.0	-	-
Skin and joint conditions	4	36.4	1	9.1	3	27.3	3	27.3
I've been using alcohol or other drugs to make myself feel better								
Psoriasis	9	5.6	13	8.1	21	13.0	118	73.3
Ichthyosis	4	7.1	1	1.8	9	16.1	42	75.0
Multiple conditions	1	3.4	2	6.9	4	13.8	22	75.9
Eczema	2	11.1	2	11.1	3	16.7	11	61.1
Vitiligo	1	11.1	-	-	2	22.2	6	66.7

Hidradenitis Suppurativa	2	6.1	1	3.0	3	9.1	27	81.8
Lichen Sclerosus	2	5.9	2	5.9	5	14.7	25	73.5
Acne	-	-	-	-	-	-	2	100.0
Lupus Erythematosus	-	-	-	-	-	-	3	100.0
Pachyonychia Congenita	-	-	-	-	-	-	3	100.0
Pemphigus	-	-	-	-	-	-	3	100.0
Pemphigoid	-	-	-	-	1	50.0	1	50.0
Rosacea	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	1	100.0	-	-	-	-
Aktinic Keratosis	-	-	-	-	-	-	1	100.0
Epidermolysis Bullosa	-	-	-	-	-	-	1	100.0
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	1	100.0	-	-
Skin and joint conditions	2	18.2	1	9.1	-	-	8	72.7
I've been using alcohol or other drugs to help me get through it								
Psoriasis	10	6.2	8	5.0	21	13.0	122	75.8

Ichthyosis	5	8.9	2	3.6	6	10.7	43	76.8
Multiple conditions	-	-	3	10.3	4	13.8	22	75.9
Eczema	2	11.1	2	11.1	2	11.1	12	66.7
Vitiligo	1	11.1	-	-	2	22.2	6	66.7
Hidradenitis Suppurativa	-	-	1	3.0	2	6.1	30	90.9
Lichen Sclerosus	2	5.9	-	-	6	17.6	26	76.5
Acne	-	-	-	-	-	-	2	100.0
Lupus Erythematosus	-	-	-	-	-	-	3	100.0
Pachyonychia Congenita	-	-	-	-	-	-	3	100.0
Pemphigus	-	-	-	-	-	-	3	100.0
Pemphigoid	-	-	-	-	1	50.0	1	50.0
Rosacea	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	1	100.0	-	-	-	-
Aktinic Keratosis	-	-	-	-	-	-	1	100.0
Epidermolysis Bullosa	-	-	-	-	-	-	1	100.0
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	1	100.0	-	-

Skin and joint conditions	2	18.2	1	9.1	-	-	8	72.7
I've been saying to myself "this isn't real"								
Psoriasis	4	2.5	11	6.8	22	13.7	124	77.0
Ichthyosis	1	1.8	5	8.9	6	10.7	44	78.6
Multiple conditions	4	13.8	3	10.3	6	20.7	16	55.2
Eczema	1	5.6	3	16.7	-	-	14	77.8
Vitiligo	1	11.1	-	-	3	33.3	5	55.6
Hidradenitis Suppurativa	4	12.1	2	6.1	10	30.3	17	51.5
Lichen Sclerosus	5	14.7	4	11.8	8	23.5	17	50.0
Acne	1	50.0	-	-	-	-	1	50.0
Lupus Erythematosus	-	-	-	-	1	33.3	2	66.7
Pachyonychia Congenita	-	-	-	-	-	-	3	100.0
Pemphigus	-	-	-	-	-	-	3	100.0
Pemphigoid	-	-	-	-	-	-	2	100.0
Rosacea	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	-	-	-	-	1	100.0
Aktinic Keratosis	-	-	-	-	-	-	1	100.0

Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	-	-	1	100.0
Skin and joint conditions	2	18.2	1	18.2	2	18.2	5	45.5
I've been refusing to believe that it has happened								
Psoriasis	3	1.9	11	6.8	22	13.7	125	77.6
Ichthyosis	2	3.6	1	1.8	5	8.9	48	85.7
Multiple conditions	2	6.9	2	6.9	5	17.2	20	69.0
Eczema	2	11.1	1	5.6	1	5.6	14	77.8
Vitiligo	1	11.1	1	11.1	-	-	7	77.8
Hidradenitis Suppurativa	2	6.1	2	6.1	10	30.3	19	57.6
Lichen Sclerosus	1	2.9	5	14.7	6	17.6	22	64.7
Acne	-	-	-	-	-	-	2	100.0
Lupus Erythematosus	-	-	-	-	1	33.3	2	66.7
Pachyonychia Congenita	-	-	-	-	-	-	3	100.0
Pemphigus	-	-	-	-	-	-	3	100.0

Pemphigoid	-	-	-	-	-	-	2	100.0
Rosacea	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	-	-	-	-	1	100.0
Aktinic Keratosis	-	-	-	-	-	-	1	100.0
Epidermolysis Bullosa	-	-	-	-	-	-	1	100.0
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	1	100.0	-	-
Skin and joint conditions	2	18.2	2	18.2	3	27.3	4	36.4
I’ve been turning to work or other activities to take my mind off things								
Psoriasis	21	13.0	31	19.3	56	34.8	53	32.9
Ichthyosis	5	8.9	7	12.5	12	21.4	32	57.1
Multiple conditions	2	6.9	10	34.5	11	37.9	6	20.7
Eczema	5	27.8	3	16.7	5	27.8	5	27.8
Vitiligo	-	-	2	22.2	2	22.2	5	55.6
Hidradenitis Suppurativa	5	15.2	7	21.2	7	21.2	14	42.4
Lichen Sclerosus	1	2.9	8	23.5	13	38.2	12	35.3
Acne	1	50.0	-	-	-	-	1	50.0

Lupus Erythematosus	1	33.3	2	66.7	-	-	-	-
Pachyonychia Congenita	-	-	-	-	-	-	3	100.0
Pemphigus	-	-	-	-	2	66.7	1	33.3
Pemphigoid	2	100.0	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-
Lichen Planus	-	-	-	-	1	100.0	-	-
Aktinic Keratosis	-	-	-	-	1	100.0	-	-
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	-	-	1	100.0
Skin and joint conditions	2	18.2	4	36.4	2	18.2	3	27.3
I’ve been doing something to think about it less								
Psoriasis	21	13.0	35	21.7	42	26.1	63	39.1
Ichthyosis	7	12.5	6	10.7	14	25.0	29	51.8
Multiple conditions	3	10.3	10	34.5	11	37.9	5	17.2
Eczema	4	22.2	4	22.2	4	22.2	6	33.3
Vitiligo	1	11.1	2	22.2	1	11.1	5	55.6

Hidradenitis Suppurativa	3	9.1	6	18.2	16	48.5	8	24.2
Lichen Sclerosus	4	11.8	6	17.6	11	3.4	13	38.2
Acne	1	50.0	-	-	-	-	1	50.0
Lupus Erythematosus	-	-	3	100.0	-	-	-	-
Pachyonychia Congenita	-	-	-	-	1	33.3	2	66.7
Pemphigus	1	33.3	1	33.3	-	-	1	33.3
Pemphigoid	2	100.0	-	-	-	-	-	-
Rosacea	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	-	-	-	-	1	100.0
Aktinic Keratosis	-	-	-	-	1	100.0	-	-
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	1	100.0	-	-
Skin and joint conditions	3	27.3	1	9.1	3	27.3	4	36.4
I've been criticizing myself								
Psoriasis	42	26.1	41	25.5	29	18.0	49	30.4

Ichthyosis	8	14.3	12	21.4	9	16.1	27	48.2
Multiple conditions	7	24.1	7	24.1	10	34.5	5	17.2
Eczema	1	5.6	6	33.3	2	11.1	9	50.0
Vitiligo	4	44.4	-	-	-	-	5	55.6
Hidradenitis Suppurativa	15	45.5	6	18.2	4	12.1	8	24.2
Lichen Sclerosus	5	14.7	6	17.6	8	23.5	15	44.1
Acne	-	-	-	-	2	100.0	-	-
Lupus Erythematosus	-	-	-	-	3	100.0	-	-
Pachyonychia Congenita	-	-	-	-	-	-	3	100.0
Pemphigus	-	-	1	33.3	1	33.3	1	33.3
Pemphigoid	2	-	-	-	1	50.0	1	50.0
Rosacea	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	-	-	-	-	1	100.0
Aktinic Keratosis	-	-	-	-	1	100.0	-	-
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	1	100.0	-	-

Skin and joint conditions	6	54.5	1	9.1	2	18.2	2	18.2
I've been blaming myself for things that happened								
Psoriasis	12	7.5	22	13.7	31	19.3	96	59.6
Ichthyosis	4	7.1	5	8.9	5	8.9	42	75.0
Multiple conditions	2	6.9	8	27.6	6	20.7	13	44.8
Eczema	1	5.6	3	16.7	3	16.7	11	61.1
Vitiligo	1	11.1	1	11.1	1	11.1	6	66.7
Hidradenitis Suppurativa	10	30.3	4	12.1	8	24.2	11	33.3
Lichen Sclerosus	4	11.8	6	17.6	7	20.6	17	50.0
Acne	-	-	-	-	1	50.0	1	50.0
Lupus Erythematosus	-	-	-	-	2	66.7	1	33.3
Pachyonychia Congenita	-	-	-	-	-	-	3	100.0
Pemphigus	1	33.3	-	-	1	33.3	1	33.3
Pemphigoid	-	-	-	-	-	-	2	100.0
Rosacea	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	-	-	-	-	1	100.0
Aktinic Keratosis	-	-	-	-	1	100.0	-	-

Epidermolysis Bullosa	-	-	-	-	-	-	1	100.0
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	1	100.0	-	-
Skin and joint conditions	2	18.2	4	36.4	1	9.1	4	36.4
I've been expressing my negative feelings								
Psoriasis	15	9.3	33	20.5	61	37.9	52	32.3
Ichthyosis	5	8.9	2	3.6	17	30.4	32	57.1
Multiple conditions	2	6.9	4	13.8	11	37.9	12	41.4
Eczema	2	11.1	4	22.2	5	27.8	7	38.9
Vitiligo	-	-	3	33.3	3	33.3	3	33.3
Hidradenitis Suppurativa	4	12.1	8	24.2	11	33.3	10	30.3
Lichen Sclerosus	3	8.8	7	20.6	15	44.1	9	26.5
Acne	-	-	-	-	1	50.0	1	50.0
Lupus Erythematosus	-	-	-	-	3	100.0	-	-
Pachyonychia Congenita	-	-	1	33.3	-	-	2	66.7
Pemphigus	-	-	3	100.0	-	-	-	-

Pemphigoid	-	-	-	-	1	50.0	1	50.0
Rosacea	-	-	-	-	1	100.0	-	-
Lichen Planus	-	-	1	100.0	-	-	-	-
Aktinic Keratosis	-	-	-	-	1	100.0	-	-
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-
Loss of pigment	-	-	-	-	1	100.0	-	-
Skin and mental health conditions	-	-	-	-	-	-	1	100.0
Skin and joint conditions	1	9.1	2	18.2	4	36.4	4	36.4
I've been saying things to let my unpleasant feelings escape								
Psoriasis	9	5.6	24	14.9	36	22.4	92	57.1
Ichthyosis	2	3.6	3	5.4	12	21.4	39	69.6
Multiple conditions	2	6.9	4	13.8	8	27.6	15	51.7
Eczema	1	5.6	4	22.2	2	11.1	11	61.1
Vitiligo	-	-	2	22.2	3	33.3	4	44.4
Hidradenitis Suppurativa	2	6.1	6	18.2	10	30.3	15	45.5
Lichen Sclerosus	2	5.9	4	11.8	10	29.4	18	52.9
Acne	-	-	-	-	-	-	2	100.0

Lupus Erythematosus	-	-	-	-	2	66.7	1	33.3
Pachyonychia Congenita	-	-	-	-	-	-	3	100.0
Pemphigus	1	33.3	-	-	2	66.7	-	-
Pemphigoid	-	-	1	50.0	-	-	1	50.0
Rosacea	-	-	-	-	1	100.0	-	-
Lichen Planus	-	-	-	-	-	-	1	100.0
Aktinic Keratosis	-	-	-	-	1	100.0	-	-
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	-	-	1	100.0
Skin and joint conditions	1	9.1	2	18.2	1	9.1	7	63.6
I've been making jokes about it								
Psoriasis	215	9.3	33	20.5	33	20.5	80	49.7
Ichthyosis	5	8.9	5	8.9	14	25.0	32	57.1
Multiple conditions	3	10.3	9	31.0	7	24.1	10	34.5
Eczema	4	22.2	4	22.2	4	22.2	6	33.3
Vitiligo	2	22.2	1	11.1	4	44.4	2	22.2

Hidradenitis Suppurativa	2	6.1	7	21.2	8	24.2	16	48.5
Lichen Sclerosus	4	11.8	5	14.7	6	17.6	19	55.9
Acne	-	-	-	-	1	50.0	1	50.0
Lupus Erythematosus	-	-	3	100.0	-	-	-	-
Pachyonychia Congenita	-	-	-	-	-	-	3	100.0
Pemphigus	-	-	-	-	2	66.7	1	33.3
Pemphigoid	1	50.0	-	-	-	-	1	50.0
Rosacea	-	-	-	-	1	100.0	-	-
Lichen Planus	-	-	1	100.0	-	-	-	-
Aktinic Keratosis	-	-	-	-	-	-	1	100.0
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-
Loss of pigment	-	-	-	-	-	-	1	100.0
Skin and mental health conditions	-	-	-	-	-	-	1	100.0
Skin and joint conditions	2	18.2	3	27.3	2	18.2	4	36.4
I’ve been making fun of the situation								
Psoriasis	13	8.1	19	11.8	36	22.4	93	57.8

Ichthyosis	5	8.9	4	7.1	8	14.3	39	69.6
Multiple conditions	3	10.3	7	24.1	7	24.1	12	41.4
Eczema	2	11.1	3	16.7	6	33.3	7	38.9
Vitiligo	2	22.2	2	22.2	1	11.1	4	44.4
Hidradenitis Suppurativa	3	9.1	4	12.1	5	15.2	21	63.6
Lichen Sclerosus	2	5.9	4	11.8	7	20.6	21	61.8
Acne	-	-	-	-	-	-	2	100.0
Lupus Erythematosus	-	-	3	100.0	-	-	-	-
Pachyonychia Congenita	-	-	-	-	-	-	3	100.0
Pemphigus	-	-	1	33.3	1	33.3	1	33.3
Pemphigoid	-	-	1	50.0	-	-	1	50.0
Rosacea	-	-	-	-	1	100.0	-	-
Lichen Planus	-	-	1	100.0	-	-	-	-
Aktinic Keratosis	-	-	-	-	-	-	1	100.0
Epidermolysis Bullosa	-	-	-	-	-	-	1	100.0
Loss of pigment	-	-	-	-	-	-	1	100.0
Skin and mental health conditions	-	-	-	-	-	-	1	100.0

Skin and joint conditions	3	27.3	1	9.1	1	9.1	6	54.5
I’ve been accepting the reality of the fact that it has happened								
Psoriasis	49	30.4	63	39.1	27	16.8	22	13.7
Ichthyosis	22	39.3	12	21.4	11	19.6	11	19.6
Multiple conditions	9	31.0	7	24.1	8	27.6	5	17.2
Eczema	3	16.7	4	22.2	4	22.2	7	38.9
Vitiligo	3	33.3	3	33.3	3	33.3	-	-
Hidradenitis Suppurativa	9	27.3	13	39.4	9	27.3	2	6.1
Lichen Sclerosus	10	29.4	11	32.4	12	35.3	1	2.9
Acne	1	50.0	-	-	-	-	1	50.0
Lupus Erythematosus	-	-	-	-	3	100.0	-	-
Pachyonychia Congenita	2	66.7	-	-	-	-	1	33.3
Pemphigus	2	66.7	1	33.3	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-
Lichen Planus	-	-	1	100.0	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-

Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-		1	100.0	-	-	-
Skin and joint conditions	5	45.5	4	36.4	1	9.1	1	9.1
I've been Learning to live with it								
Psoriasis	58	36.0	61	37.9	30	18.6	12	7.5
Ichthyosis	27	48.2	14	25.0	8	14.3	7	12.5
Multiple conditions	11	37.9	8	27.6	7	24.1	3	10.3
Eczema	4	22.2	6	33.3	7	38.9	1	5.6
Vitiligo	2	22.2	4	44.4	1	11.1	2	22.2
Hidradenitis Suppurativa	11	33.3	14	42.4	5	15.2	3	9.1
Lichen Sclerosus	14	41.2	10	29.4	9	26.5	1	2.9
Acne	1	50.0	-	-	1	50.0	-	-
Lupus Erythematosus	1	33.3	2	66.7	-	-	-	-
Pachyonychia Congenita	1	33.3	1	33.3	-	-	1	33.3
Pemphigus	1	33.3	2	66.7	-	-	-	-

Pemphigoid	2	100.0	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-
Lichen Planus	-	-	-	-	1	100.0	-	-
Aktinic Keratosis	-	-	1	100.0	-	-	-	-
Epidermolysis Bullosa	-	-		1	100.0	-	-	-
Loss of pigment	-	-	-	-	-	-	1	100.0
Skin and mental health conditions	-	-	-	-	-	-	1	100.0
Skin and joint conditions	5	45.5	5	45.5	1	9.1	-	-
I've been trying to find comfort in my religion or spiritual beliefs								
Psoriasis	6	3.7	8	5.0	10	6.2	137	85.1
Ichthyosis	6	10.7	3	5.4	5	8.9	42	75.0
Multiple conditions	3	10.3	-	-	4	13.8	22	75.9
Eczema	1	5.6	4	22.2	1	5.6	12	66.7
Vitiligo	1	11.1	-	-	1	11.1	7	77.8
Hidradenitis Suppurativa	5	15.2	2	6.1	4	12.1	22	66.7
Lichen Sclerosus	1	2.9	3	8.8	4	11.8	26	76.5
Acne	1	50.0	-	-	-	-	1	50.0

Lupus Erythematosus	-	-	-	-	1	33.3	2	66.7
Pachyonychia Congenita	1	33.3	-	-	-	-	2	66.7
Pemphigus	1	33.3	1	33.3	-	-	1	33.3
Pemphigoid	2	100.0	-	-	-	-	-	-
Rosacea	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	-	-	-	-	1	100.0
Aktinic Keratosis	-	-	-	-	-	-	1	100.0
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	-	-	1	100.0
Skin and joint conditions	2	18.2	1	9.1	-	-	8	72.7
I've been praying or meditating								
Psoriasis	7	4.3	11	6.8	19	11.8	124	77.0
Ichthyosis	5	8.9	4	7.1	5	8.9	42	75.0
Multiple conditions	5	17.2	1	3.4	3	10.3	20	69.0
Eczema	1	5.6	2	11.1	4	22.2	11	61.1
Vitiligo	1	11.1	-	-	3	33.3	5	55.6

Hidradenitis Suppurativa	5	15.2	4	12.1	3	9.1	21	63.6
Lichen Sclerosus	1	2.9	5	14.7	8	23.5	20	58.8
Acne	1	50.0	-	-	-	-	1	50.0
Lupus Erythematosus	-	-	-	-	3	100.0	-	-
Pachyonychia Congenita	1	33.3	-	-	-	-	2	66.7
Pemphigus	1	33.3	1	33.3	-	-	1	33.3
Pemphigoid	2	100.0	-	-	-	-	-	-
Rosacea	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	-	-	-	-	1	100.0
Aktinic Keratosis	-	-	-	-	-	-	1	100.0
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-
Loss of pigment	-	-	-	-	-	-	1	100.0
Skin and mental health conditions	-	-	-	-	-	-	1	100.0
Skin and joint conditions	2	18.2	2	18.2	2	18.2	5	45.5
I've been getting emotional support from others								
Psoriasis	11	6.8	29	18.0	54	33.5	67	41.6

Ichthyosis	3	5.4	10	17.9	15	26.8	28	50.0
Multiple conditions	3	10.3	5	17.2	13	44.8	8	27.6
Eczema	4	22.2	5	27.8	6	33.3	3	16.7
Vitiligo	2	22.2	1	11.1	1	11.1	5	55.6
Hidradenitis Suppurativa	4	12.1	8	24.2	10	30.3	11	33.3
Lichen Sclerosus	4	11.8	8	23.5	13	38.2	9	26.5
Acne	1	50.0	-	-	-	-	1	50.0
Lupus Erythematosus	-	-	-	-	2	66.7	1	33.3
Pachyonychia Congenita	-	-	-	-	-	-	3	100.0
Pemphigus	1	33.3	-	-	2	66.7	-	-
Pemphigoid	1	50.0	-	-	-	-	1	50.0
Rosacea	-	-	-	-	1	100.0	-	-
Lichen Planus	-	-	1	100.0	-	-	-	-
Aktinic Keratosis	-	-	-	-	-	-	1	100.0
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-
Loss of pigment	-	-	-	-	-	-	1	100.0
Skin and mental health conditions	-	-	-	-	-	-	1	100.0

Skin and joint conditions	3	27.3	2	18.2	5	45.5	1	9.1
I've been getting comfort and understanding from someone								
Psoriasis	15	9.3	33	20.5	44	27.3	69	42.9
Ichthyosis	5	8.9	10	17.9	15	26.8	26	46.4
Multiple conditions	5	17.2	6	20.7	10	34.5	8	27.6
Eczema	1	5.6	6	33.3	7	38.9	4	22.2
Vitiligo	-	-	2	22.2	2	22.2	5	55.6
Hidradenitis Suppurativa	4	12.1	5	15.2	9	27.3	15	45.5
Lichen Sclerosus	5	14.7	5	14.7	13	38.2	11	32.4
Acne	1	50.0	-	-	-	-	1	50.0
Lupus Erythematosus	-	-	-	-	2	66.7	1	33.3
Pachyonychia Congenita	-	-	-	-	1	33.3	2	66.7
Pemphigus	-	-	1	33.3	-	-	2	66.7
Pemphigoid	1	50.0	-	-	-	-	1	50.0
Rosacea	-	-	-	-	1	100.0	-	-
Lichen Planus	-	-	1	100.0	-	-	-	-
Aktinic Keratosis	-	-	-	-	-	-	1	100.0

Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	1	100.0	-	-
Skin and joint conditions	1	9.1	2	18.2	4	36.4	4	36.4
I've been getting help and advice from other people								
Psoriasis	15	9.3	34	21.1	54	33.5	58	36.0
Ichthyosis	1	1.8	8	14.3	23	41.1	24	42.9
Multiple conditions	7	24.1	8	27.6	11	37.9	3	10.3
Eczema	1	5.6	6	33.3	8	44.4	3	16.7
Vitiligo	1	11.1	1	11.1	1	11.1	6	66.7
Hidradenitis Suppurativa	4	12.1	11	33.3	11	33.3	7	21.2
Lichen Sclerosus	11	32.4	12	35.3	9	26.5	2	5.9
Acne	1	50.0	-	-	1	50.0	-	-
Lupus Erythematosus	-	-	-	-	3	100.0	-	-
Pachyonychia Congenita	-	-	-	-	-	-	3	100.0
Pemphigus	-	-	1	33.3	2	66.7	-	-

Pemphigoid	1	50.0	-	-	1	50.0	-	-
Rosacea	-	-	1	100.0	-	-	-	-
Lichen Planus	-	-	1	50.0	-	-	-	-
Aktinic Keratosis	-	-	-	-	1	100.0	-	-
Epidermolysis Bullosa	-	-	1	50.0	-	-	-	-
Loss of pigment	-	-	-	-	1	50.0	-	-
Skin and mental health conditions	-	-	-	-	-	-	1	100.0
Skin and joint conditions	2	18.2	4	36.4	1	9.1	4	36.4
I've been trying to get advice or help from other people about what to do								
Psoriasis	16	9.9	37	23.0	55	34.2	53	32.9
Ichthyosis	2	3.6	9	16.1	17	30.4	28	50.0
Multiple conditions	4	13.8	11	37.9	10	34.5	4	13.8
Eczema	1	5.6	5	27.8	8	44.4	4	22.2
Vitiligo	-	-	2	22.2	1	11.1	6	66.7
Hidradenitis Suppurativa	5	15.2	9	27.3	11	33.3	8	24.2
Lichen Sclerosus	7	20.6	14	41.2	7	20.6	6	17.6
Acne	1	50.0	-	-	1	50.0	-	-

Lupus Erythematosus	-	-	-	-	3	100.0	-	-
Pachyonychia Congenita	-	-	-	-	1	33.3	2	66.7
Pemphigus	1	33.3	1	33.3	1	33.3	-	-
Pemphigoid	-	-	1	50.0	1	50.0	-	-
Rosacea	-	-	-	-	1	100.0	-	-
Lichen Planus	-	-	1	100.0	-	-	-	-
Aktinic Keratosis	-	-	-	-	1	100.0	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-
Loss of pigment	-	-	-	-	1	100.0	-	-
Skin and mental health conditions	-	-	-	-	1	100.0	-	-
Skin and joint conditions	2	18.2	3	27.3	1	9.1	5	45.5
I've been trying to come up with a strategy about what to do								
Psoriasis	25	15.5	57	35.4	50	31.1	29	18.0
Ichthyosis	4	7.1	13	23.2	18	32.1	21	37.5
Multiple conditions	6	20.7	10	34.5	10	34.5	3	10.3
Eczema	4	22.2	9	50.0	2	11.1	3	16.7
Vitiligo	-	-	3	33.3	3	33.3	3	33.3

Hidradenitis Suppurativa	4	12.1	15	45.5	9	27.3	5	15.2
Lichen Sclerosus	9	26.5	11	32.4	7	20.6	7	20.6
Acne	1	50.0	-	-	1	50.0	-	-
Lupus Erythematosus	-	-	1	33.3	2	66.7	-	-
Pachyonychia Congenita	-	-	1	33.3	-	-	2	66.7
Pemphigus	2	66.7	1	33.3	-	-	-	-
Pemphigoid	-	-	1	50.0	-	-	1	50.0
Rosacea	-	-	-	-	1	100.0	-	-
Lichen Planus	-	-	1	100.0	-	-	-	-
Aktinic Keratosis	-	-	1	100.0	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	-	-	1	100.0
Skin and joint conditions	3	27.3	3	27.3	5	45.5	-	-
I've been thinking hard about what steps to take								
Psoriasis	28	17.4	53	32.9	54	33.5	26	16.1

Ichthyosis	8	14.3	9	16.1	15	26.8	24	42.9
Multiple conditions	5	17.2	8	27.6	13	44.8	3	10.3
Eczema	4	22.2	4	22.2	5	27.8	5	27.8
Vitiligo	-	-	4	44.4	2	22.2	3	33.3
Hidradenitis Suppurativa	5	15.2	10	30.3	13	39.4	5	15.2
Lichen Sclerosus	8	23.5	9	26.5	11	32.4	6	17.6
Acne	-	-	-	-	-	-	2	100.0
Lupus Erythematosus	-	-	2	66.7	1	33.3	-	-
Pachyonychia Congenita	-	-	-	-	-	-	3	100.0
Pemphigus	2	66.7	-	-	1	33.3	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-
Rosacea	-	-	-	-	-	-	1	100.0
Lichen Planus	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	-	-	1	100.0

Skin and joint conditions	3	27.3	3	27.3	5	45.5	-	-
I've been trying to see it in a different light, to make it seem more positive								
Psoriasis	14	8,7	25	15.5	55	34.2	67	41.6
Ichthyosis	3	5.4	10	17.9	14	25.0	29	51.8
Multiple conditions	1	3.4	10	34.5	8	27.6	10	34.5
Eczema	2	11.1	6	33.3	3	16.7	7	38.9
Vitiligo	-	-	4	44.4	4	44.4	1	11.1
Hidradenitis Suppurativa	2	6.1	7	21.2	13	39.4	11	33.3
Lichen Sclerosus	4	11.8	6	17.6	8	23.5	16	47.1
Acne	1	50.0	-	-	1	50.0	-	-
Lupus Erythematosus	-	-	2	66.7	1	33.3	-	-
Pachyonychia Congenita	-	-	-	-	1	33.3	2	66.7
Pemphigus	1	33.3	1	33.3	-	-	1	33.3
Pemphigoid	1	50.0	-	-	1	50.0	-	-
Rosacea	-	-	-	-	1	100.0	-	-
Lichen Planus	-	-	-	-	-	-	1	100.0
Aktinic Keratosis	-	-	-	-	1	100.0	-	-

Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	-	-	1	100.0
Skin and joint conditions	2	18.2	4	36.4	3	27.3	2	18.2
I've been looking for something good in what is happening								
Psoriasis	15	9.3	16	9.9	44	27.3	86	53.4
Ichthyosis	3	5.4	7	12.5	14	25.0	32	57.1
Multiple conditions	4	13.8	6	20.7	9	31.0	10	34.5
Eczema	2	11.1	6	33.3	2	11.1	8	44.4
Vitiligo	1	11.1	3	33.3	2	22.2	3	33.3
Hidradenitis Suppurativa	2	6.1	5	15.2	8	24.2	18	54.5
Lichen Sclerosus	2	5.9	5	14.7	2	5.9	25	73.5
Acne	1	50.0	-	-	-	-	1	50.0
Lupus Erythematosus	-	-	1	33.3	1	33.3	1	33.3
Pachyonychia Congenita	-	-	-	-	1	33.3	2	66.7
Pemphigus	2	66.7	-	-	-	-	1	33.3

Pemphigoid	1	50.0	1	50.0	-	-	-	-
Rosacea	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	-	-	-	-	1	100.0
Aktinic Keratosis	-	-	-	-	-	-	1	100.0
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	1	100.0	-	-
Skin and joint conditions	2	18.2	4	36.4	2	18.2	3	27.3
I've been concentrating my efforts on doing something about the situation I'm in								
Psoriasis	35	21.7	52	32.3	47	29.2	27	16.8
Ichthyosis	4	7.1	11	19.6	23	41.1	18	32.1
Multiple conditions	4	13.8	12	41.4	8	27.6	5	17.2
Eczema	2	11.1	6	33.3	9	50.0	1	5.6
Vitiligo	-	-	2	22.2	3	33.3	4	44.4
Hidradenitis Suppurativa	8	24.2	12	36.4	10	30.3	3	9.1
Lichen Sclerosus	12	35.3	7	20.6	13	38.2	2	5.9
Acne	1	50.0	-	-	-	-	1	50.0

Lupus Erythematosus	-	-	2	66.7	1	33.3	-	-
Pachyonychia Congenita	-	-	1	33.3	1	33.3	1	33.3
Pemphigus	1	33.3	1	33.3	1	33.3	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-
Rosacea	-	-	-	-	1	100.0	-	-
Lichen Planus	-	-	-	-	1	100.0	-	-
Aktinic Keratosis	-	-	1	100.0	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	1	100.0	-	-
Skin and joint conditions	4	36.4	4	36.4	2	18.2	1	9.1
I've been taking action to try to make the situation better								
Psoriasis	44	27.3	58	36.0	46	28.6	13	8.1
Ichthyosis	10	17.9	20	35.7	15	26.8	11	19.6
Multiple conditions	10	34.5	9	31.0	8	27.6	2	6.9
Eczema	7	38.9	5	27.8	5	27.8	1	5.6
Vitiligo	-	-	5	55.6	1	11.1	3	33.3

Hidradenitis Suppurativa	9	27.3	13	39.4	8	24.2	3	9.1
Lichen Sclerosus	18	52.9	7	20.6	8	23.5	1	2.9
Acne	1	50.0	-	-	1	50.0	-	-
Lupus Erythematosus	1	33.3	2	66.7	-	-	-	-
Pachyonychia Congenita	-	-	1	33.3	1	33.3	1	33.3
Pemphigus	2	66.7	1	33.3	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-
Rosacea	-	-	-	-	1	100.0	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	-	-	1	100.0	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	1	100.0	-	-
Skin and joint conditions	4	36.4	4	36.4	3	27.3	-	-
I've been keeping physically active								
Psoriasis	31	19.3	39	24.2	54	33.5	37	23.0

Ichthyosis	14	25.0	14	25.0	16	28.6	12	21.4
Multiple conditions	3	10.3	9	31.0	11	37.9	6	20.7
Eczema	1	5.6	9	50.0	5	27.8	3	16.7
Vitiligo	2	22.2	2	22.2	3	33.3	2	22.2
Hidradenitis Suppurativa	6	18.2	7	21.2	12	36.4	8	24.2
Lichen Sclerosus	5	14.7	9	26.5	11	32.4	9	26.5
Acne	-	-	-	-	1	100.0	-	-
Lupus Erythematosus	-	-	1	33.3	2	66.7	-	-
Pachyonychia Congenita	1	33.3	-	-	1	33.3	1	33.3
Pemphigus	-	-	2	66.7	1	33.3	-	-
Pemphigoid	-	-	2	100.0	-	-	-	-
Rosacea	-	-	-	-	1	100.0	-	-
Lichen Planus	-	-	-	-	1	100.0	-	-
Aktinic Keratosis	-	-	1	100.0	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-
Loss of pigment	-	-	-	-	-	-	1	100.0
Skin and mental health conditions	-	-	-	-	-	-	1	100.0

Skin and joint conditions	4	36.4	-	-	2	18.2	5	45.5
I’ve been eating healthy foods								
Psoriasis	26	16.1	68	42.2	43	26.7	24	14.9
Ichthyosis	12	21.4	13	23.2	19	33.9	12	21.4
Multiple conditions	6	20.7	12	41.4	11	37.9	-	-
Eczema	2	11.1	8	44.4	6	33.3	2	11.1
Vitiligo	1	11.1	4	44.4	1	11.1	3	33.3
Hidradenitis Suppurativa	7	21.2	14	42.4	8	24.2	4	12.1
Lichen Sclerosus	3	8.8	16	47.1	10	29.4	5	14.7
Acne	1	50.0	-	-	-	-	1	50.0
Lupus Erythematosus	-	-	1	33.3	2	66.7	-	-
Pachyonychia Congenita	-	-	1	33.3	1	33.3	1	33.3
Pemphigus	2	66.7	-	-	1	33.3	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-
Rosacea	1	100.0	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-

Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-
Loss of pigment	-	-	-	-	-	-	1	100.0
Skin and mental health conditions	-	-	-	-	1	100.0	-	-
Skin and joint conditions	1	9.1	3	27.2	5	45.5	2	18.2
I've been spending time learning about my condition								
Psoriasis	42	26.1	60	37.3	39	24.2	20	12.4
Ichthyosis	12	21.4	12	21.4	22	39.3	10	17.9
Multiple conditions	7	24.1	14	48.3	7	24.1	1	3.4
Eczema	5	27.8	6	33.3	5	27.8	2	11.1
Vitiligo	1	11.1	4	44.4	3	33.3	1	11.1
Hidradenitis Suppurativa	13	39.4	14	42.4	5	15.2	1	3.0
Lichen Sclerosus	18	52.9	9	26.5	4	11.8	3	8.8
Acne	1	50.0	-	-	1	50.0	-	-
Lupus Erythematosus	-	-	3	100.0	-	-	-	-
Pachyonychia Congenita	2	66.7	1	33.3	-	-	-	-
Pemphigus	2	66.7	1	33.3	-	-	-	-

Pemphigoid	2	100.0	-	-	-	-	-	-
Rosacea	-	-	-	-	1	100.0	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-
Loss of pigment	-	-	-	-	1	100.0	-	-
Skin and mental health conditions	-	-	-	-	1	100.0	-	-
Skin and joint conditions	3	27.3	4	36.4	2	18.2	2	18.2
I've been spending time learning how best to manage my condition								
Psoriasis	44	27.3	56	34.8	47	29.2	14	8.7
Ichthyosis	12	21.4	17	30.4	18	32.1	9	16.1
Multiple conditions	8	27.6	15	51.7	5	17.2	1	3.4
Eczema	5	27.8	3	16.7	7	38.9	3	16.7
Vitiligo	-	-	4	44.4	4	44.4	1	11.1
Hidradenitis Suppurativa	14	42.4	11	33.3	6	18.2	2	6.1
Lichen Sclerosus	17	50.0	9	26.5	5	14.7	3	8.8
Acne	1	50.0	-	-	1	50.0	-	-

Lupus Erythematosus	-	-	3	100.0	-	-	-	-
Pachyonychia Congenita	2	66.7	1	33.3	-	-	-	-
Pemphigus	1	33.3	2	66.7	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-
Rosacea	-	-	-	-	1	100.0	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	-	-	1	100.0
Skin and joint conditions	3	27.3	4	36.4	3	27.3	1	9.1
I've been taking part in advocacy or voluntary work								
Psoriasis	4	2.5	9	5.6	16	9.9	132	82.0
Ichthyosis	7	12.5	4	7.1	7	12.5	38	67.9
Multiple conditions	4	13.8	1	3.4	4	13.8	20	69.0
Eczema	4	22.2	3	16.7	2	11.1	9	50.0
Vitiligo	3	33.3	1	11.1	-	-	5	55.6

Hidradenitis Suppurativa	1	3.0	4	12.1	6	18.2	22	66.7
Lichen Sclerosus	3	8.8	1	2.9	4	11.8	26	76.5
Acne	-	-	-	-	-	-	2	100.0
Lupus Erythematosus	3	100.0	-	-	-	-	-	-
Pachyonychia Congenita	2	66.7	-	-	-	-	1	33.3
Pemphigus	-	-	1	33.3	-	-	2	66.7
Pemphigoid	-	-	-	-	1	50.0	1	50.0
Rosacea	-	-	-	-	1	100.0	-	-
Lichen Planus	-	-	-	-	-	-	1	100.0
Aktinic Keratosis	-	-	-	-	-	-	1	100.0
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-
Loss of pigment	-	-	-	-	1	100.0	-	-
Skin and mental health conditions	-	-	-	-	-	-	1	100.0
Skin and joint conditions	2	18.2	-	-	4	36.4	5	45.5
I've been trying to get enough sleep								
Psoriasis	35	21.7	57	35.4	45	28.0	24	14.9

Ichthyosis	10	17.9	15	26.8	18	32.1	13	23.2
Multiple conditions	4	13.8	16	55.2	8	27.6	1	3.4
Eczema	3	16.7	7	38.9	7	38.9	1	5.6
Vitiligo	2	22.2	3	33.3	2	22.2	2	22.2
Hidradenitis Suppurativa	6	18.2	16	48.5	6	18.2	5	15.2
Lichen Sclerosus	7	20.6	14	41.2	13	38.2	-	-
Acne	1	50.0	-	-	-	-	1	50.0
Lupus Erythematosus	-	-	2	66.7	1	33.3	-	-
Pachyonychia Congenita	2	66.7	1	33.3	-	-	-	-
Pemphigus	1	33.3	2	66.7	-	-	-	-
Pemphigoid	1	50.0	1	50.0	-	-	-	-
Rosacea	1	100.0	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	-	-	1	100.0	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	1	100.0	-	-

Skin and joint conditions	5	45.5	4	36.4	2	18.2	-	-
I've been taking my medication as prescribed by my doctor								
Psoriasis	52	32.3	55	34.2	30	18.6	24	14.9
Ichthyosis	24	42.9	8	14.3	11	19.6	13	23.2
Multiple conditions	15	51.7	5	17.2	4	13.8	5	17.2
Eczema	6	33.3	2	11.1	6	33.3	4	22.2
Vitiligo	-	-	3	33.3	2	22.2	4	44.4
Hidradenitis Suppurativa	19	57.6	4	12.1	3	9.1	7	21.2
Lichen Sclerosus	26	76.5	3	8.8	2	5.9	3	8.8
Acne	1	50.0	1	50.0	-	-	-	-
Lupus Erythematosus	2	66.7	1	33.3	-	-	-	-
Pachyonychia Congenita	2	66.7	-	-	-	-	1	33.3
Pemphigus	3	100.0	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-
Rosacea	1	100.0	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	-	-	1	100.0

Epidermolysis Bullosa	1	100.0	-	-	-	-	-	-
Loss of pigment	-	-	-	-	-	-	1	100.0
Skin and mental health conditions	-	-	-	-	1	100.0	-	-
Skin and joint conditions	8	72.7	1	9.1	1	9.1	1	9.1
I've been smoking cigarettes								
Psoriasis	16	9.9	10	6.2	10	6.2	125	77.6
Ichthyosis	2	3.6	-	-	2	3.6	52	92.9
Multiple conditions	4	13.8	-	-	2	6.9	23	79.3
Eczema	3	16.7	-	-	-	-	15	83.3
Vitiligo	1	11.1	-	-	1	11.1	7	77.8
Hidradenitis Suppurativa	6	18.2	2	6.1	2	6.1	23	69.7
Lichen Sclerosus	2	5.9	2	5.9	-	-	30	88.2
Acne	-	-	-	-	-	-	2	100.0
Lupus Erythematosus	-	-	-	-	-	-	3	100.0
Pachyonychia Congenita	-	-	-	-	-	-	3	100.0
Pemphigus	-	-	-	-	-	-	3	100.0

Pemphigoid	-	-	-	-	-	-	2	100.0
Rosacea	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	-	-	-	-	1	100.0
Aktinic Keratosis	-	-	-	-	-	-	1	100.0
Epidermolysis Bullosa	-	-	-	-	-	-	1	100.0
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	-	-	1	100.0
Skin and joint conditions	3	27.3	-	-	-	-	8	72.7
I've been trying to hide my condition from others								
Psoriasis	58	36.0	40	24.8	36	22.4	27	16.8
Ichthyosis	15	26.8	14	25.0	14	25.0	13	23.2
Multiple conditions	10	34.5	13	44.8	4	13.8	2	6.9
Eczema	3	16.7	6	33.3	5	27.8	4	22.2
Vitiligo	4	44.4	1	11.1	2	22.2	2	22.2
Hidradenitis Suppurativa	14	42.4	10	30.3	2	6.1	7	21.2
Lichen Sclerosus	9	26.5	5	14.7	10	29.4	10	29.4
Acne	-	-	1	50.0	-	-	1	50.0

Lupus Erythematosus	-	-	-	-	3	100.0	-	-
Pachyonychia Congenita	1	33.3	-	-	-	-	2	66.7
Pemphigus	-	-	1	33.3	-	-	2	66.7
Pemphigoid	-	-	-	-	2	100.0	-	-
Rosacea	-	-	-	-	-	-	1	100.0
Lichen Planus	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	1	100.0	-	-
Skin and joint conditions	4	36.4	2	18.2	3	27.3	2	18.2

Appendix 45: Descriptive statistics on existing support, by condition category

	Number (*n*) and percentage (%) of responses									
Skin condition	**Always (i.e. all the time)**		**Often (i.e. frequently)**		**Sometimes (i.e. occasionally)**		**Rarely (i.e. hardly ever)**		**Never (i.e. not at all)**	
To manage all aspects of my skin condition I receive support from Healthcare Professionals										
Psoriasis	21	13.0	37	23.0	53	32.9	41	25.5	9	5.6
Ichthyosis	14	25.0	5	8.9	9	16.1	20	35.7	8	14.3
Multiple conditions	1	3.4	11	37.9	8	27.6	7	24.1	2	6.9
Eczema	1	5.6	2	11.1	8	44.4	5	27.8	2	11.1
Vitiligo	-	-	2	22.2	1	11.1	3	33.3	3	33.3
Hidradenitis Suppurativa	4	12.1	8	24.2	12	36.4	6	18.2	3	9.1
Lichen Sclerosus	7	20.6	8	23.5	14	41.2	5	14.7	-	-
Acne	1	50.0	-	-	1	50.0	-	-	-	-
Lupus Erythematosus	-	-	1	33.3	2	66.7	-	-	-	-
Pachyonychia Congenita	1	33.3	-	-	-	-	1	33.3	1	33.3
Pemphigus	2	66.7	1	33.3	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-

Rosacea	-	-	-	-	-	-	1	100.0	-	-
Lichen Planus	-	-	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	-	-	1	100.0	-	-
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-	-	-
Loss of pigment	-	-	-	-	-	-	-	-	1	100.0
Skin and mental health conditions	-	-	-	-	-	-	-	-	1	100.0
Skin and joint conditions	4	36.4	3	27.3	1	9.1	2	18.2	1	9.1
To manage all aspects of my skin condition I receive support from my friends and family										
Psoriasis	19	11.8	38	23.6	49	30.4	35	21.7	20	12.4
Ichthyosis	13	23.2	8	14.3	11	19.6	13	23.2	11	19.6
Multiple conditions	2	6.9	6	20.7	12	41.4	6	20.7	3	10.3
Eczema	2	11.1	5	27.8	6	33.3	5	27.8	-	-
Vitiligo	-	-	1	11.1	3	33.3	2	22.2	3	33.3
Hidradenitis Suppurativa	5	15.2	7	21.2	12	36.4	5	15.2	4	12.1
Lichen Sclerosus	2	5.9	6	17.6	10	29.4	8	23.5	8	23.5
Acne	1	50.0	-	-	1	50.0	-	-	-	-
Lupus Erythematosus	-	-	-	-	1	33.3	1	33.3	1	33.3

Pachyonychia Congenita	1	33.3	-	-	-	-	-	-	2	66.7
Pemphigus	1	33.3	-	-	-	-	2	66.7	-	-
Pemphigoid	1	50.0	-	-	-	-	1	50.0	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	-	-	1	100.0	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-
Loss of pigment	-	-	1	100.0	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	1	100.0	-	-	-	-
Skin and joint conditions	2	18.2	3	27.3	3	27.3	3	27.3	-	-
To manage all aspects of my skin condition I receive support from a patient organisation										
Psoriasis	4	2.5	6	3.7	15	9.3	24	14.9	112	69.6
Ichthyosis	3	5.4	3	5.4	13	23.2	10	17.9	27	48.2
Multiple conditions	1	3.4	1	3.4	2	6.9	5	17.2	20	100.0
Eczema	1	5.6	-	-	3	16.7	2	11.1	12	66.7
Vitiligo	1	11.1	3	33.3	-	-	1	11.1	4	44.4

Hidradenitis Suppurativa	-	-	3	9.1	4	12.1	4	12.1	22	66.7
Lichen Sclerosus	1	2.9	3	8.8	2	5.9	6	17.6	22	64.7
Acne	-	-	-	-	-	-	-	-	2	100.0
Lupus Erythematosus	-	-	2	66.7	1	33.3	-	-	-	-
Pachyonychia Congenita	-	-	1	33.3	1	33.3	-	-	1	33.3
Pemphigus	-	-	1	33.3	1	33.3	-	-	1	33.3
Pemphigoid	-	-	-	-	1	50.0	1	50.0	-	-
Rosacea	-	-	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	-	-	-	-	1	100.0
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-	-	-
Loss of pigment	-	-	-	-	-	-	-	-	1	100.0
Skin and mental health conditions	-	-	-	-	-	-	1	100.0	-	-
Skin and joint conditions	-	-	1	9.1	3	27.3	-	-	7	63.6
To manage all aspects of my skin condition I receive support from a psychologist, therapist or counsellor										
Psoriasis	4	2.5	6	3.7	9	5.6	14	8.7	128	79.5

Ichthyosis	-	-	-	-	3	5.4	8	14.3	45	80.4
Multiple conditions	1	3.4	2	6.9	1	3.4	6	20.7	19	65.5
Eczema	1	5.6	1	5.6	1	5.6	2	11.1	13	72.2
Vitiligo	-	-	1	11.1	1	11.1	2	22.2	5	55.6
Hidradenitis Suppurativa	-	-	3	9.1	6	18.2	3	9.1	21	63.6
Lichen Sclerosus	-	-	4	11.8	1	2.9	3	8.8	26	76.5
Acne	-	-	-	-	-	-	-	-	1	100.0
Lupus Erythematosus	-	-	-	-	-	-	2	66.7	1	33.3
Pachyonychia Congenita	-	-	-	-	-	-	-	-	3	100.0
Pemphigus	-	-	1	33.3	-	-	1	33.3	1	33.3
Pemphigoid	-	-	-	-	-	-	-	-	2	100.0
Rosacea	-	-	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	-	-	-	-	-	-	1	100.0
Aktinic Keratosis	-	-	-	-	-	-	-	-	1	100.0
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-	-	-
Loss of pigment	-	-	-	-	-	-	-	-	1	100.0
Skin and mental health conditions	-	-	-	-	1	100.0	-	-	-	-

Skin and joint conditions	1	9.1	-	-	3	27.3	2	18.2	5	45.5
To manage all aspects of my skin condition I receive support from people online or on social media										
Psoriasis	7	4.3	24	14.9	41	25.5	32	19.9	57	35.4
Ichthyosis	2	3.6	5	8.9	9	16.1	14	25.0	26	46.4
Multiple conditions	2	6.9	10	34.5	7	24.1	4	13.8	6	20.7
Eczema	-	-	-	-	6	33.3	7	28.9	5	27.8
Vitiligo	1	11.1	3	33.3	2	22.2	1	11.1	2	22.2
Hidradenitis Suppurativa	8	24.2	9	27.3	12	36.4	-	-	4	12.1
Lichen Sclerosus	10	29.4	16	47.1	5	14.7	2	5.9	1	2.9
Acne	1	50.0	-	-	-	-	-	-	1	50.0
Lupus Erythematosus	-	-	-	-	2	66.7	1	33.3	-	-
Pachyonychia Congenita	-	-	-	-	-	-	-	-	3	100.0
Pemphigus	1	33.3	-	-	-	-	-	-	2	66.7
Pemphigoid	-	-	-	-	1	50.0	-	-	1	50.0
Rosacea	-	-	-	-	-	-	-	-	1	100.0
Lichen Planus	-	-	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	-	-	-	-	1	100.0

Epidermolysis Bullosa	-	-	-	-	-	-	1	100.0	-	-
Loss of pigment	-	-	-	-	-	--	-	-	1	100.0
Skin and mental health conditions	-	-	-	-	1	100.0	-	-	-	-
Skin and joint conditions	1	9.1	4	36.4	3	27.3	1	9.1	2	18.2
To manage all aspects of my skin condition, I use written self-help materials										
Psoriasis	3	1.9	15	9.3	34	21.1	38	23.6	71	44.1
Ichthyosis	-	-	1	1.8	10	17.9	13	23.2	32	57.1
Multiple conditions	-	-	3	10.3	8	27.6	9	31.0	9	31.0
Eczema	-	-	-	-	3	16.7	5	27.8	10	55.6
Vitiligo	-	-	-	-	2	22.2	4	44.4	3	33.3
Hidradenitis Suppurativa	1	3.0	4	12.1	13	39.4	4	12.1	11	33.3
Lichen Sclerosus	-	-	4	11.8	7	20.6	10	29.4	13	38.2
Acne	-	-	-	-	-	-	-	-	2	100.0
Lupus Erythematosus	-	-	3	100.0	-	-	-	-	-	--
Pachyonychia Congenita	-	-	-	-	-	-	-	-	3	100.0
Pemphigus	-	-	1	33.3	-	-	-	-	2	66.7

Pemphigoid	-	-	-	-	-	-	-	-	2	100.0
Rosacea	-	-	-	-	-	--	-	-	1	100.0
Lichen Planus	-	-	-	-	-	-	1	100.0	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-	-	-
Loss of pigment	-	-	-	-	-	-	-	-	1	100.0
Skin and mental health conditions	-	-	-	-	-	-	1	100.0	-	-
Skin and joint conditions	-	-	1	9.1	-	-	5	45.5	5	45.5
To manage all aspects of my skin condition, I use digital self-help materials										
Psoriasis	12	7.5	39	24.2	57	35.4	20	12.4	33	20.5
Ichthyosis	1	1.8	4	7.1	18	32.1	9	16.1	24	42.9
Multiple conditions	5	17.2	6	20.7	7	24.1	8	27.6	3	10.3
Eczema	-	-	4	22.2	9	50.0	4	22.2	1	5.6
Vitiligo	1	11.1	1	11.1	5	55.6	-	-	2	22.2
Hidradenitis Suppurativa	6	18.2	13	39.4	10	30.3	2	6.1	2	6.1
Lichen Sclerosus	9	26.5	15	44.1	4	11.8	3	8.8	3	8.8
Acne	1	50.0	-	-	-	-	-	-	1	50.0

Lupus Erythematosus	-	-	2	66.7	1	33.3	-	-	-	-
Pachyonychia Congenita	-	-	-	-	1	33.3	-	-	2	66.7
Pemphigus	1	33.3	2	66.7	-	-	-	-	-	-
Pemphigoid	-	-	1	50.0	-	-	-	-	1	50.0
Rosacea	-	-	-	-	1	100.0	-	-	-	-
Lichen Planus	-	-	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-	-	-
Loss of pigment	-	-	-	-	-	-	-	-	1	100.0
Skin and mental health conditions	-	-	-	-	1	100.0	-	-	-	-
Skin and joint conditions	1	9.1	4	36.3	3	27.3	1	9.1	2	18.2
To manage all aspects of my skin condition, I use medication prescribed by a healthcare professional										
Psoriasis	67	41.6	53	32.9	26	16.1	7	4.3	8	5.0
Ichthyosis	30	53.6	7	12.5	4	7.1	3	5.4	12	21.4
Multiple conditions	14	48.3	10	34.5	4	13.8	-	-	1	3.4
Eczema	4	22.2	8	44.4	3	16.7	-	-	3	16.7
Vitiligo	1	11.1	2	22.2	1	11.1	3	33.3	2	22.2

Hidradenitis Suppurativa	13	39.4	6	18.2	7	21.2	3	9.1	4	12.1
Lichen Sclerosus	29	85.3	4	11.8	-	-	1	2.9	-	-
Acne	1	50.0	-	-	1	50.0	-	-	-	-
Lupus Erythematosus	1	33.3	2	66.7	-	-	-	-	-	-
Pachyonychia Congenita	-	-	-	-	-	-	1	33.3	2	66.7
Pemphigus	3	100.0	-	-	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-
Rosacea	-	-	-	-	2	100.0	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-	-	-
Loss of pigment	-	-	-	-	-	-	-	-	1	100.0
Skin and mental health conditions	-	-	-	-	-	-	1	100.0	-	-
Skin and joint conditions	8	72.7	-	-	3	27.3	-	-	-	-

Appendix 46: Descriptive statistics on the perceived acceptability of MiDerm, by skin condition category

	Number (*n*) and percentage (%) of responses									
Skin condition	**Acceptable**		**Slightly acceptable**		**Undecided**		**Slightly unacceptable**		**Not acceptable**	
The idea of a new mobile app that helps me to live well with my condition is…										
Psoriasis	110	68.3	21	13	26	16.1	2	1.2	2	1.2
Ichthyosis	34	60.7	5	8.9	14	25.0	1	1.8	2	3.6
Multiple conditions	19	65.5	4	13.8	5	17.2	-	-	1	3.4
Eczema	13	72.2	4	22.2	1	5.6	-	-	-	-
Vitiligo	6	66.7	1	11.1	2	22.2	-	-	-	-
Hidradenitis Suppurativa	26	78.8	3	9.1	4	12.1	-	-	-	-
Lichen Sclerosus	23	67.6	4	11.8	7	20.6	-	-	-	-
Acne	1	50.0	-	-	-	-	1	50	-	-
Lupus Erythematosus	2	66.7	1	33.3	-	-	-	-	-	-
Pachyonychia Congenita	2	66.7	-	-	-	-	1	33.3	-	-
Pemphigus	3	100.0	-	-	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-

Rosacea	-	-	1	100.0	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-
Skin and joint conditions	9	81.8	-	-	1	9.1	-	-	1	9.1

Appendix 47: Descriptive statistics on ideas for MiDerm, by skin condition category

	Number (*n*) and percentage (%) of responses											
Skin condition	**Extremely important**		**Very important**		**Moderately important**		**Slightly important**		**Not at all important**		**No response provided**	
The app is developed in collaboration with healthcare professionals												
Psoriasis	128	79.5	24	14.9	6	3.7	2	1.2	1	0.6	-	-
Ichthyosis	34	60.7	13	23.2	8	14.3	-	-	1	1.8	-	-
Multiple conditions	18	62.1	5	17.2	5	17.2	-	-	1	3.4	-	-
Eczema	11	61.1	4	22.2	3	16.7	-	-	-	-	-	-
Vitiligo	6	66.7	-	-	2	22.2	-	-	-	-	1	11.1
Hidradenitis Suppurativa	21	63.6	11	33.3	-	-	-	-	-	-	1	3.0
Lichen Sclerosus	28	82.4	3	8.8	2	5.9	-	-	1	2.9	-	-
Acne	2	100.0	-	-	-	-	-	-	-	-	-	-
Lupus Erythematosus	1	33.3	2	66.7	-	-	-	-	-	-	-	-
Pachyonychia Congenita	3	100.0	-	-	-	-	-	-	-	-	-	-
Pemphigus	3	100.0	-	-	-	-	-	-	-	-	-	-

Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	1	100.0	-	-	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	1	100.0	-	-	-	-	-	
skin and joint conditions	9	81.8	1	9.1	-	-	-	-	1	9.1	-	
The app is endorsed by healthcare professionals												
Psoriasis	120	74.5	34	21.1	6	3.7	1	0.6	-	-	-	-
Ichthyosis	37	66.1	13	23.2	5	8.9	1	1.8	-	-	-	-
Multiple conditions	20	69.0	4	13.8	3	10.3	-	-	1	3.4	1	3.4
Eczema	15	83.3	-	-	3	16.7	-	-	-	-	-	-
Vitiligo	6	66.7	1	11.1	2	22.2	-	-	-	-	-	-
Hidradenitis Suppurativa	27	81.8	6	18.2	-	-	-	-	-	-	-	-
Lichen Sclerosus	29	85.3	4	11.8	-	-	-	-	1	2.9	-	-

Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	2	66.7	1	33.3	-	-	-	-	-	-
Pachyonychia Congenita	3	100.0	-	-	-	-	-	-	-	-	-	-
Pemphigus	2	66.7	-	-	1	33.3	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	1	100.0	-	-	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	1	100.0	-	-	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	
skin and joint conditions	9	81.8	1	9.1	-	-	-	-	1	9.1	-	
The app is endorsed by health authorities												
Psoriasis	104	64.6	44	27.3	5	3.1	5	3.1	2	1.2	1	0.6
Ichthyosis	30	53.6	17	30.4	8	14.3	1	1.8	-	-	-	-

Multiple conditions	14	50.0	5	17.9	8	28.6	-	-	1	3.6	-	-
Eczema	10	55.6	3	16.7	5	27.8	-	-	-	-	-	-
Vitiligo	5	55.6	2	22.2	2	22.2	-	-	-	-	-	-
Hidradenitis Suppurativa	27	81.1	6	18.2	-	-	-	-	-	-	-	-
Lichen Sclerosus	24	70.6	7	20.6	2	5.9	-	-	1	2.9	-	-
Acne	1	50.0	-	-	1	50.0	-	-	-	-	-	-
Lupus Erythematosus	-	-	2	66.7	1	33.3	-	-	-	-	-	-
Pachyonychia Congenita	2	66.7	1	33.3	-	-	-	-	-	-	-	-
Pemphigus	2	66.7	-	-	1	33.3	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	1	100.0	-	-	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-

Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	
skin and joint conditions	7	63.6	3	27.3	-	-	-	-	1	9.1	-	
The app is developed in collaboration with people living with skin conditions												
Psoriasis	145	90.1	15	9.3	1	0.6	-	-	1	0.6	-	-
Ichthyosis	45	80.4	6	10.7	5	8.9	-	-	-	-	-	-
Multiple conditions	27	93.1	2	6.9	-	-	-	-	-	-	-	-
Eczema	13	72.2	4	22.2	1	5.6	-	-	-	-	-	-
Vitiligo	8	88.9	-	-	1	11.1	-	-	-	-	-	-
Hidradenitis Suppurativa	30	90.9	3	9.1	-	-	-	-	-	-	-	-
Lichen Sclerosus	30	88.2	2	5.9	1	2.9	-	-	1	2.9	-	-
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	2	66.7	1	33.3	-	-	-	-	-	-	-	-
Pachyonychia Congenita	3	100.0	-	-	-	-	-	-	-	-	-	-
Pemphigus	3	100.0	-	-	-	-	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-

Rosacea	1	100.0	-	-	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	
skin and joint conditions	8	72.7	2	18.2	-	-	-	-	1	9.1	-	
The app is developed in collaboration with patient organisations												
Psoriasis	94	58.4	43	26.7	20	12.4	2	1.2	1	0.6	1	0.6
Ichthyosis	32	58.9	11	19.6	11	19.6	1	1.8	-	-	1	1.8
Multiple conditions	13	44.8	9	31.0	5	17.2	2	6.9	-	-	-	-
Eczema	3	16.7	8	44.4	7	38.9	-	-	-	-	-	-
Vitiligo	6	66.7	1	11.1	2	22.2	-	-	-	-	-	-
Hidradenitis Suppurativa	19	57.6	11	33.3	2	6.1	-	-	-	-	1	3.0
Lichen Sclerosus	17	50.0	9	26.5	5	14.7	2	5.9	1	2.9	-	-
Acne	1	50.0	-	-	-	-	1	50.0	-	-	-	-

Lupus Erythematosus	-	-	3	100.0	-	-	-	-	-	-	-	-
Pachyonychia Congenita	3	100.0	-	-	-	-	-	-	-	-	-	-
Pemphigus	3	100.0	-	-	-	-	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	1	100.0	-	-	-	-	-	
skin and joint conditions	6	54.5	4	36.4	-	-	-	-	1	9.1	-	
The app is endorsed by patient organisations												
Psoriasis	110	68.3	39	24.2	7	4.3	4	2.5	1	0.6	1	0.6
Ichthyosis	35	62.5	12	21.4	8	14.3	1	1.8	-	-	-	-
Multiple conditions	19	65.5	4	13.8	5	17.2	1	3.4	-	-	-	-

Eczema	11	61.1	4	22.2	3	16.7	-	-	-	-	-	-
Vitiligo	6	66.7	1	11.1	2	22.2	-	-	-	-	-	-
Hidradenitis Suppurativa	26	78.8	7	21.2	-	-	-	-	-	-	-	-
Lichen Sclerosus	23	67.6	6	17.6	2	5.9	1	2.9	2	5.9	-	-
Acne	2	100.0	-	-	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	2	66.7	1	33.3	-	-	-	-	-	-
Pachyonychia Congenita	3	100.0	-	-	-	-	-	-	-	-	-	-
Pemphigus	2	66.7	-	-	1	33.3	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	1	100.0	-	-	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	-	-	1	100.0	-	-	-	-	-	-	-	

skin and joint conditions	7	63.6	2	18.2	1	9.1	-	-	1	9.1	-	
The app is free to access												
Psoriasis	135	83.9	20	12.4	4	2.5	1	0.6	1	0.6	-	-
Ichthyosis	43	76.8	7	12.5	6	10.7	-	-	-	-	-	-
Multiple conditions	27	93.1	2	6.9	-	-	-	-	-	-	-	-
Eczema	15	83.3	2	11.1	1	5.6	-	-	-	-	-	-
Vitiligo	5	55.6	1	11.1	3	33.3	-	-	-	-	-	-
Hidradenitis Suppurativa	29	87.9	4	12.1	-	-	-	-	-	-	-	-
Lichen Sclerosus	29	85.3	3	8.8	1	2.9	-	-	1	2.9	-	-
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	3	100.0	-	-	-	-	-	-	-	-
Pachyonychia Congenita	3	100.0	-	-	-	-	-	-	-	-	-	-
Pemphigus	1	33.3	2	66.7	-	-	-	-	-	-	-	-
Pemphigoid	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-

Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	1	100.0	-	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-
Skin and joint conditions	8	72.7	2	18.2	-	-	-	-	1	9.1	-	
The app is tailored to users											
Psoriasis	81	50.3	52	32.3	19	11.8	5	3.1	3	1.9	1	0.6
Ichthyosis	25	44.6	14	25.0	13	23.2	1	1.8	3	5.4	-	-
Multiple conditions	13	44.8	12	41.4	4	13.8	-	-	-	-	-	-
Eczema	5	27.8	6	33.3	7	38.9	-	-	-	-	-	-
Vitiligo	4	44.4	3	33.3	2	22.2	-	-	-	-	-	-
Hidradenitis Suppurativa	25	75.8	4	12.1	3	9.1	1	3.0	-	-	-	-
Lichen Sclerosus	19	55.9	9	26.5	3	8.8	2	5.9	1	2.9	-	-
Acne	2	100.0	-	-	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	1	33.3	2	66.7	-	-	-	-	-	-

Pachyonychia Congenita	3	100.0	-	-	-	-	-	-	-	-	-	-
Pemphigus	2	66.7	-	-	1	33.3	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	-	-	-	-	1	100.0	-	-	-	-	-	-
Lichen Planus	-	-	1	100.0	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	-	-	-	-	1	100.0	-	-	-	-		
Skin and joint conditions	3	27.3	4	36.4	2	18.2	1	9.1	1	9.1		
The app allows users to set goals and develop action plans												
Psoriasis	50	31.1	47	29.2	40	24.8	13	8.1	10	6.2	1	0.6
Ichthyosis	13	23.2	12	21.4	17	30.4	9	16.1	5	8.9	-	-
Multiple conditions	7	24.1	11	37.9	3	10.3	5	17.2	3	10.3	-	-
Eczema	6	33.3	8	44.4	2	11.1	-	-	2	11.1	-	-
Vitiligo	3	33.3	3	33.3	2	22.2	1	11.1	-	-	-	-

Hidradenitis Suppurativa	21	63.6	6	18.2	4	12.1	2	6.1	-	-	-	-
Lichen Sclerosus	6	17.6	13	38.2	8	23.5	2	5.9	5	14.7	-	-
Acne	1	50.0	-	-	1	50.0	-	-	-	-	-	-
Lupus Erythematosus	-	-	-	-	2	66.7	1	33.3	-	-	-	-
Pachyonychia Congenita	1	33.3	1	33.3	-	-	-	-	1	33.3	-	-
Pemphigus	2	66.7	-	-	1	33.3	-	-	-	-	-	-
Pemphigoid	1	50.0	-	-	1	50.0	-	-	-	-	-	-
Rosacea	-	-	-	-	1	100.0	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	-	-	1	100.0	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	5	45.5	2	18.2	2	18.2	-	-	2	18.2	-	-

The app provides visual feedback on personal progress												
Psoriasis	60	37.3	48	29.8	26	16.1	16	9.9	11	6.8	-	-
Ichthyosis	15	26.8	16	28.6	14	25.0	6	10.7	5	8.9	-	-
Multiple conditions	6	20.7	8	27.6	9	31.0	4	13.8	2	6.9	-	-
Eczema	8	44.4	6	33.3	1	5.6	-	-	3	16.7	-	-
Vitiligo	4	44.4	4	44.4	1	11.1	-	-	-	-	-	-
Hidradenitis Suppurativa	18	54.5	8	24.2	5	15.2	2	6.1	-	-	-	-
Lichen Sclerosus	11	32.4	8	23.5	8	23.5	3	8.8	4	11.8	-	-
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	-	-	2	66.7	1	33.3	-	-	-	-
Pachyonychia Congenita	1	33.3	1	33.3	-	-	-	-	1	33.3	-	-
Pemphigus	2	66.7	-	-	1	33.3	-	-	-	-	-	-
Pemphigoid	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Rosacea	-	-	-	-	1	100.0	-	-	-	-	-	-
Lichen Planus	-	-	1	100.0	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	-	-	-	-	1	100.0	-	-

Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	5	45.5	2	18.2	2	18.2	-	-	2	18.2	-	-
The app includes interactive activities												
Psoriasis	63	39.1	47	29.2	33	20.5	10	6.2	8	5.0	-	-
Ichthyosis	18	32.1	13	23.2	17	30.4	7	12.5	1	1.8	-	-
Multiple conditions	10	34.5	10	34.5	4	13.8	3	10.3	2	6.9	-	-
Eczema	6	33.3	4	22.2	4	22.2	2	11.1	2	11.1	-	-
Vitiligo	2	22.2	5	55.6	2	22.2	-	-	-	-	-	-
Hidradenitis Suppurativa	16	48.5	11	33.3	5	15.2	-	-	1	3.0	-	-
Lichen Sclerosus	12	35.3	10	29.4	3	8.8	4	11.8	5	14.7	-	-
Acne	1	50.0	-	-	1	50.0	-	-	-	-	-	-
Lupus Erythematosus	-	-	-	-	2	66.7	1	33.3	-	-	-	-

Pachyonychia Congenita	2	66.7	-	-	-	-	-	-	1	33.3	-	-
Pemphigus	2	66.7	1	33.3	-	-	-	-	-	-	-	-
Pemphigoid	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Rosacea	-	-	-	-	1	100.0	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	-	-	1	100.0	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	5	45.5	2	18.2	2	18.2	-	-	2	18.2	-	-
The app offers virtual points or rewards												
Psoriasis	33	20.5	33	20.5	41	25.5	20	12.4	34	21.1	-	-
Ichthyosis	13	23.2	12	21.4	10	17.9	9	16.1	12	21.4	-	-
Multiple conditions	4	13.8	4	13.8	8	27.6	6	20.7	7	24.1	-	-
Eczema	5	27.8	4	22.2	3	16.7	2	11.1	4	22.2	-	-
Vitiligo	1	11.1	2	22.2	4	44.4	-	-	2	22.2	-	-

Hidradenitis Suppurativa	13	39.4	8	24.2	4	12.1	5	15.2	3	9.1	-	-
Lichen Sclerosus	7	20.6	8	23.5	4	11.8	4	11.8	11	32.4	-	-
Acne	1	50.0	-	-	-	-	1	50.0	-	-	-	-
Lupus Erythematosus	-	-	-	-	2	66.7	1	33.3	-	-	-	-
Pachyonychia Congenita	1	33.3	-	-	1	33.3	-	-	1	33.3	-	-
Pemphigus	1	33.3	-	-	1	33.3	-	-	1	33.3	-	-
Pemphigoid	1	50.0	-	-	1	50.0	-	-	-	-	-	-
Rosacea	-	-	-	-	1	100.0	-	-	-	-	-	-
Lichen Planus	-	-	-	-	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	-	-	-	-	1	100.0	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	2	18.2	2	18.2	4	36.4	1	9.1	2	18.2	-	-

The app allows users to monitor physical symptoms												
Psoriasis	85	52.8	48	29.8	19	11.8	6	3.7	2	1.2	1	0.6
Ichthyosis	17	30.4	20	35.7	12	21.4	3	5.4	3	5.4	1	1.8
Multiple conditions	18	62.1	1	3.4	5	17.2	2	6.9	3	10.3	-	-
Eczema	10	55.6	2	11.1	4	22.2	1	5.6	1	5.6	-	-
Vitiligo	4	44.4	2	22.2	2	22.2	1	11.1	-	-	-	-
Hidradenitis Suppurativa	20	60.6	11	33.3	2	6.1	-	-	-	-	-	-
Lichen Sclerosus	17	50.0	11	32.4	3	8.8	2	5.9	1	2.9	-	-
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	-	-	2	66.7	1	33.3	-	-	-	-
Pachyonychia Congenita	1	33.3	1	33.3	-	-	-	-	1	33.3	-	-
Pemphigus	2	66.7	-	-	1	33.3	-	-	-	-	-	-
Pemphigoid	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Rosacea	-	-	-	-	1	100.0	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	1	100.0	-	-	-	-	-	-

Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	6	54.5	1	9.1	2	18.2	-	-	2	18.2	-	-
The app allows users to monitor mood and emotions												
Psoriasis	82	50.9	46	28.6	21	13.0	5	3.1	7	4.3	-	-
Ichthyosis	18	32.1	15	26.8	10	17.9	6	10.7	7	12.5	-	-
Multiple conditions	15	51.7	3	10.3	8	27.6	3	10.3	-	-	-	-
Eczema	7	38.9	3	16.7	5	27.8	1	5.6	2	11.1	-	-
Vitiligo	4	44.4	3	33.3	2	22.2	-	-	-	-	-	-
Hidradenitis Suppurativa	22	66.7	9	27.3	2	6.1	-	-	-	-	-	-
Lichen Sclerosus	14	41.2	9	26.5	4	11.8	4	11.8	3	8.8	-	-
Acne	1	50.0	-	-	1	50.0	-	-	-	-	-	-
Lupus Erythematosus	-	-	-	-	2	66.7	1	33.3	-	-	-	-

Pachyonychia Congenita	1	33.3	-	-	-	-	1	33.3	1	33.3	-	-
Pemphigus	2	66.7	-	-	1	33.3	-	-	-	-	-	-
Pemphigoid	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Rosacea	-	-	-	-	1	100.0	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	1	100.0	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	1	100.0	-	-	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	--	-	-	-
Skin and joint conditions	6	54.5	1	9.1	2	18.2	-	-	2	18.2	-	-
The app offers the option to receive reminder notifications												
Psoriasis	51	31.7	40	24.8	41	25.5	15	9.3	14	8.7	-	-
Ichthyosis	13	23.2	18	32.1	12	21.4	5	8.9	8	14.3	-	-
Multiple conditions	10	34.5	5	17.2	6	20.7	3	10.3	5	17.2	-	-
Eczema	7	38.9	2	11.1	4	22.2	1	5.6	4	22.2	-	-
Vitiligo	3	33.3	2	22.2	3	33.3	1	11.1	-	-	-	-

Hidradenitis Suppurativa	14	42.4	13	39.4	4	12.1	1	3.0	1	3.0	-	-
Lichen Sclerosus	10	29.4	10	29.4	5	14.7	3	8.8	5	14.7	1	2.9
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	-	-	3	100.0	-	-	-	-	-	-
Pachyonychia Congenita	2	66.7	-	-	-	-	-	-	1	33.3	-	-
Pemphigus	1	33.3	1	33.3	-	-	-	-	1	33.3	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	-	-	-	-	1	100.0	-	-	-	-	-	-
Lichen Planus	-	-	-	-	1	100.0	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	-	-	1	100.0	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	5	45.5	2	18.2	2	18.2	-	-	2	18.2	-	-

The app offers the option to connect with other people with a skin condition(s)												
Psoriasis	54	33.5	43	26.7	43	26.7	12	7.5	9	5.6	-	-
Ichthyosis	23	41.1	18	32.1	10	17.9	2	3.6	3	5.4	-	-
Multiple conditions	11	37.9	9	31.0	6	20.7	2	6.9	1	3.4	-	-
Eczema	6	33.3	7	38.9	2	11.1	1	5.6	2	11.1	-	-
Vitiligo	4	44.4	2	22.2	3	33.3	-	-	-	-	-	-
Hidradenitis Suppurativa	25	75.8	4	12.1	4	12.1	-	-	-	-	-	-
Lichen Sclerosus	12	35.3	9	26.5	9	26.5	2	5.9	2	5.9	-	-
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	-	-	3	100.0.0	-	-	-	-	-	-
Pachyonychia Congenita	1	33.3	1	33.3	1	33.3	-	-	-	-	-	-
Pemphigus	1	33.3	-	-	1	33.3	-	-	1	33.3	-	-
Pemphigoid	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	1	100.0	-	-	-	-	-	-

Epidermolysis Bullosa	1	100.0	-	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-
Skin and joint conditions	5	45.5	3	27.3	1	9.1	-	-	2	18.2	-	-
The app offers information on the social impact of skin conditions											
Psoriasis	85	52.8	44	27.3	22	13.7	7	4.3	3	1.9	-	-
Ichthyosis	23	41.1	20	35.7	8	14.3	3	5.4	2	3.6	-	-
Multiple conditions	14	48.3	8	27.6	5	17.2	2	6.9	-	-	-	-
Eczema	8	44.4	5	27.8	4	22.2	-	-	1	5.6	-	-
Vitiligo	5	55.6	3	33.3	1	11.1	-	-	-	-	-	-
Hidradenitis Suppurativa	23	69.7	9	27.3	1	3.0	-	-	-	-	-	-
Lichen Sclerosus	14	41.2	13	38.2	2	5.9	3	8.8	2	5.9	-	-
Acne	1	50.0	-	-	1	50.0	-	-	-	-	-	-
Lupus Erythematosus	-	-	1	33.3	2	66.7		-	-	-	-	-

Pachyonychia Congenita	1	33.3	-	-	-	-	1	33.3	1	33.3	-	-
Pemphigus	2	66.7	1	33.3	-	-	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	1	100.0	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	5	45.5	2	18.2	2	18.2	-	-	2	18.2	-	-
The app offers tips for managing social interactions												
Psoriasis	69	42.9	48	29.8	25	15.5	11	6.8	8	5.0	-	-
Ichthyosis	20	35.7	21	37.5	11	19.6	2	3.6	2	3.6	-	-
Multiple conditions	11	37.9	6	20.7	7	24.1	4	13.8	1	3.4	-	-
Eczema	8	44.4	3	16.7	4	22.2	2	11.1	1	5.6	-	-
Vitiligo	5	55.6	3	33.3	1	11.1	-	-	-	-	-	-

Hidradenitis Suppurativa	20	60.6	9	27.3	3	9.1	-	-	1	3.0	-	-
Lichen Sclerosus	12	35.3	13	38.2	2	5.9	3	8.8	4	11.8	-	-
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	-	-	2	66.7	1	33.3	-	-	-	-
Pachyonychia Congenita	1	33.3	-	-	1	33.3	-	-	1	33.3	-	-
Pemphigus	2	66.7	-	-	1	33.3	-	-	-	-	-	-
Pemphigoid	-	-	-	-	1	50.0	-	-	1	50.0	-	-
Rosacea	-	-	-	-	1	100.0	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	1	100.0	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	5	45.5	4	36.4	1	9.1	-	-	1	9.1	-	-

The app offers tip for managing social anxiety												
Psoriasis	75	46.6	47	29.2	22	13.7	6	3.7	10	6.2	1	0.6
Ichthyosis	22	39.3	15	26.8	11	19.6	4	7.1	3	5.4	1	1.8
Multiple conditions	11	37.9	5	17.2	7	24.1	4	13.8	1	3.4	1	3.4
Eczema	6	33.3	5	27.8	4	22.2	3	16.7	-	-	-	-
Vitiligo	5	55.6	3	33.3	1	11.1	-	-	-	-	-	-
Hidradenitis Suppurativa	24	72.7	7	21.2	1	3.0	1	3.0	-	-	-	-
Lichen Sclerosus	12	35.3	10	29.4	4	11.8	3	8.8	4	11.8	1	2.9
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	-	-	2	66.7	1	33.3	-	-	-	-
Pachyonychia Congenita	1	33.3	-	-	-	-	1	33.3	1	33.3	-	-
Pemphigus	2	66.7	-	-	1	33.3	-	-	-	-	-	-
Pemphigoid	-	-	-	-	1	50.0	-	-	1	50.0	-	-
Rosacea	-	-	-	-	1	100.0	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	1	100.0	-	-	-	-	-	-

Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	6	54.5	3	27.3	-	-	1	9.1	1	9.1	-	-
The app offers information on how having a skin condition(s) can impact mood												
Psoriasis	87	54.0	45	28.0	22	13.7	3	1.9	3	1.9	1	0.6
Ichthyosis	27	48.2	14	25.0	10	17.9	5	8.9	-	-	-	-
Multiple conditions	17	58.6	12	41.4	-	-	-	-	-	-	-	-
Eczema	8	44.4	6	33.3	4	22.2	-	-	-	-	-	-
Vitiligo	4	44.4	3	33.3	2	22.2	-	-	-	-	-	-
Hidradenitis Suppurativa	27	81.8	5	15.2	1	3.0	-	-	-	-	-	-
Lichen Sclerosus	16	47.1	10	29.4	3	8.8	3	8.8	2	5.9	-	-
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	2	66.7	1	33.3	-	-	-	-	-	-

Pachyonychia Congenita	1	33.3	1	33.3	1	33.3	-	-	-	-	-	-
Pemphigus	3	100.0	-	-	-	-	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	1	100.0	-	-	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	1	100.0	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	7	63.6	2	18.2	-	-	1	9.1	1	9.1	-	-
The app offers tips for managing mood												
Psoriasis	107	66.5	33	20.5	9	5.6	7	4.3	4	2.5	1	0.6
Ichthyosis	34	60.7	11	19.6	8	14.3	2	3.6	1	1.8	-	-
Multiple conditions	20	69.0	7	24.1	-	-	1	3.4	1	3.4	-	-
Eczema	11	61.1	4	22.2	2	11.1	1	5.6	-	-	-	-
Vitiligo	5	55.6	3	33.3	1	11.1	-	-	-	-	-	-

Hidradenitis Suppurativa	27	81.8	5	15.2	-	-	1	3.0	-	-	-	-
Lichen Sclerosus	21	61.8	7	20.6	2	5.9	2	5.9	2	5.9	-	-
Acne	1	50.0	-	-	1	50.0	-	-	-	-	-	-
Lupus Erythematosus	-	-	2	66.7	1	33.3	-	-	-	-	-	-
Pachyonychia Congenita	2	66.7	-	-	-	-	1	33.3	-	-	-	-
Pemphigus	3	100.0	-	-	-	-	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	1	100.0	-	-	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	9	81.8	1	9.1	-	-	-	-	1	9.1	-	-

The app offers information on how diet can impact the skin												
Psoriasis	102	63.4	38	23.6	19	11.8	2	1.2	-	-	-	-
Ichthyosis	28	50.0	19	33.9	9	16.1	-	-	-	-	-	-
Multiple conditions	15	51.7	12	41.4	1	3.4	-	-	1	3.4	-	-
Eczema	9	50.0	4	22.2	2	11.1	2	11.1	1	5.6	-	-
Vitiligo	4	44.4	3	33.3	2	22.2	-	-	-	-	-	-
Hidradenitis Suppurativa	24	72.7	8	24.2	1	3.0	-	-	-	-	-	-
Lichen Sclerosus	17	50.0	12	35.3	3	8.8	1	2.9	1	2.9	-	-
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	2	66.7	1	33.3	-	-	-	-	-	-
Pachyonychia Congenita	1	33.3	1	33.3	1	33.3	-	-	-	-	-	-
Pemphigus	2	66.7	1	33.3	-	-	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-	-	-

Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	-	-	-	-	-	-	1	100.0	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	6	54.5	4	36.4	-	-	-	-	1	9.1	-	-
The app offers tips for eating a healthy diet												
Psoriasis	84	52.2	44	27.3	17	10.6	11	6.8	5	3.1	-	-
Ichthyosis	15	26.8	17	30.4	18	32.1	3	5.4	3	5.4	-	-
Multiple conditions	10	34.5	11	37.9	5	17.2	1	3.4	2	6.9	-	-
Eczema	7	38.9	4	22.2	4	22.2	-	-	3	16.7	-	-
Vitiligo	3	33.3	2	22.2	3	33.3	-	-	1	11.1	-	-
Hidradenitis Suppurativa	19	57.6	11	33.3	2	6.1	1	3.0	-	-	-	-
Lichen Sclerosus	11	32.4	12	35.3	4	11.8	5	14.7	2	5.9	-	-
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	1	33.3	2	66.7	-	-	-	-	-	-

Pachyonychia Congenita	1	33.3	-	-	1	33.3	-	-	1	33.3	-	-
Pemphigus	2	66.7	-	-	1	33.3	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	5	45.5	3	27.3	2	18.2	-	-	1	9.1	-	-
The app offers information on how physical activity can impact the skin												
Psoriasis	98	60.9	47	29.2	15	9.3	-	-	1	0.6	-	-
Ichthyosis	26	46.4	19	33.9	11	19.6	-	-	-	-	-	-
Multiple conditions	15	51.7	10	34.5	2	6.9	2	6.9	-	-	-	-
Eczema	7	38.9	6	33.3	3	16.7	1	5.6	1	5.6	-	-
Vitiligo	3	33.3	4	44.4	2	22.2	-	-	-	-	-	-

Hidradenitis Suppurativa	23	69.7	9	27.3	-	-	1	3.0	-	-	-	-
Lichen Sclerosus	18	52.9	13	38.2	2	5.9	-	-	1	2.9	-	-
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	2	66.7	1	33.3	-	-	-	-	-	-
Pachyonychia Congenita	2	66.7	-	-	-	-	-	-	1	33.3	-	-
Pemphigus	2	66.7	1	33.3	-	-	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	5	45.5	4	36.4	1	9.1	-	-	1	9.1	-	-

The app offers tips for keeping physically active												
Psoriasis	91	56.5	51	31.7	8	5.0	6	3.7	4	2.5	1	0.6
Ichthyosis	26	46.4	17	30.4	11	19.6	1	1.8	1	1.8	-	-
Multiple conditions	18	62.1	7	24.1	2	6.9	2	6.9	-	-	-	-
Eczema	8	44.4	5	27.8	4	22.2	-	-	1	5.6	-	-
Vitiligo	3	33.3	2	22.2	4	44.4	-	-	-	-	-	-
Hidradenitis Suppurativa	23	69.7	8	24.2	2	6.1	-	-	-	-	-	-
Lichen Sclerosus	23	67.6	7	20.6	3	8.8	-	-	1	2.9	-	-
Acne	1	50.0	-	-	1	50.0	-	-	-	-	-	-
Lupus Erythematosus	-	-	2	66.7	1	33.3	-	-	-	-	-	-
Pachyonychia Congenita	1	33.3	-	-	1	33.3	-	-	1	33.3	-	-
Pemphigus	2	66.7	-	-	1	33.3	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-	-	-

Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	8	72.7	2	18.2	-	-	-	-	1	9.1	-	-
The app offers information on how smoking can impact the skin												
Psoriasis	74	46.0	29	18.0	20	12.4	8	5.0	30	18.6	-	-
Ichthyosis	13	23.2	10	17.9	16	28.6	3	5.4	14	25.0	-	-
Multiple conditions	11	37.9	7	24.1	4	13.8	2	6.9	5	17.2	-	-
Eczema	6	33.3	1	5.6	3	16.7	4	22.2	4	22.2	-	-
Vitiligo	2	22.2	5	55.6	2	22.2	-	-	-	-	-	-
Hidradenitis Suppurativa	17	51.5	11	33.3	3	9.1	2	6.1	-	-	-	-
Lichen Sclerosus	8	23.5	8	23.5	6	17.6	4	11.8	7	20.6	1	2.9
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	1	33.3	1	33.3	1	33.3	-	-	-	-

Pachyonychia Congenita	1	33.3	-	-	-	-	-	-	2	66.7	-	-
Pemphigus	2	66.7	-	-	-	-	-	-	1	33.3	-	-
Pemphigoid	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	1	100.0	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	3	27.3	2	18.2	2	18.2	1	9.1	3	27.3	-	-
The app offers tips for quitting smoking												
Psoriasis	60	37.3	34	21.1	17	10.6	15	9.3	35	21.7	-	-
Ichthyosis	12	21.4	7	12.5	18	32.1	3	5.4	16	28.6	-	-
Multiple conditions	9	31.0	5	17.2	6	20.7	-	-	9	31.0	-	-
Eczema	1	5.6	7	38.9	4	22.2	2	11.1	4	22.2	-	-
Vitiligo	-	-	4	44.4	2	22.2	2	22.2	1	11.1	-	-

Hidradenitis Suppurativa	21	63.6	5	15.2	3	9.1	1	3.0	3	9.1	-	-
Lichen Sclerosus	6	17.6	10	29.4	4	11.8	2	5.9	12	35.3	-	-
Acne	1	50.0	-	-	1	50.0	-	-	-	-	-	-
Lupus Erythematosus	-	-	1	33.3	1	33.3	1	33.3	-	-	-	-
Pachyonychia Congenita	-	-	-	-	-	-	-	-	3	100.0	-	-
Pemphigus	2	66.7	-	-	-	-	-	-	1	33.3	-	-
Pemphigoid	-	-	-	-	-	-	-	-	2	100.0	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	-	-	-	-	1	100.0	-	-
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	3	27.3	2	18.2	2	18.2	1	9.1	3	27.3		

The app offers information on how alcohol consumption can impact the skin												
Psoriasis	78	48.4	38	23.6	20	12.4	9	5.6	16	9.9	-	-
Ichthyosis	14	25.0	12	21.4	16	28.6	5	8.9	9	16.1	-	-
Multiple conditions	11	37.9	7	24.1	5	17.2	2	6.9	4	13.8	-	-
Eczema	5	27.8	2	11.1	5	27.8	2	11.1	4	22.2	-	-
Vitiligo	3	33.3	3	33.3	3	33.3	-	-	-	-	-	-
Hidradenitis Suppurativa	17	51.5	11	33.3	3	9.1	2	6.1	-	-	-	-
Lichen Sclerosus	9	26.5	12	35.3	6	17.6	4	11.8	3	8.8	-	-
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	1	33.3	1	33.3	1	33.3	-	-	-	-
Pachyonychia Congenita	1	33.3	-	-	-	-	-	-	2	66.7	-	-
Pemphigus	2	66.7	-	-	-	-	-	-	1	33.3	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	1	100.0	-	-	-	-	-	-	-	-

Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	--	-	-	-	-	-
Skin and joint conditions	3	27.3	3	27.3	1	9.1	1	9.1	3	27.3	-	-
The app offers tips for reducing alcohol intake												
Psoriasis	60	37.3	33	20.5	24	14.9	16	9.9	28	17.4	-	-
Ichthyosis	10	17.9	12	21.4	17	30.4	4	7.1	13	23.2	-	-
Multiple conditions	9	31.0	5	17.2	5	17.2	2	6.9	8	27.6	-	-
Eczema	-	-	6	33.3	6	33.3	1	5.6	5	27.8	-	-
Vitiligo	1	11.1	3	33.3	3	33.3	1	11.1	1	11.1	-	-
Hidradenitis Suppurativa	19	57.6	7	21.2	4	12.1	3	9.1	-	-	-	-
Lichen Sclerosus	5	14.7	12	35.3	5	14.7	4	11.8	8	23.5	-	-
Acne	1	50.0	-	-	1	50.0	-	-	-	-	-	-
Lupus Erythematosus	-	-	-	-	2	66.7	1	33.3	-	-	-	-

Pachyonychia Congenita	-	-	-	-	-	-	-	-	3	100.0	-	-
Pemphigus	2	66.7	-	-	-	-	-	-	1	33.3	-	-
Pemphigoid	-	-	-	-	-	-	-	-	2	100.0	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	-	-	1	100.0	-	-	-	-
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	3	27.3	2	18.2	3	27.3	-	-	3	27.3	-	-
The app offers information on how sleep can impact the skin												
Psoriasis	91	56.5	41	25.5	20	12.4	5	3.1	2	1.2	2	1.2
Ichthyosis	17	30.4	19	33.9	16	28.6	2	3.6	2	3.6	-	-
Multiple conditions	14	48.3	10	34.5	5	17.2	-	-	-	-	-	-
Eczema	9	50.0	3	16.7	4	22.2	1	5.6	1	5.6	-	-
Vitiligo	3	33.3	4	44.4	2	22.2	-	-	-	-	-	-

Hidradenitis Suppurativa	22	66.7	8	24.2	3	9.1	-	-	-	-	-	-
Lichen Sclerosus	13	38.2	12	35.5	6	17.6	1	2.9	2	5.9	-	-
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	1	33.3	2	66.7	-	-	-	-	-	-
Pachyonychia Congenita	1	33.3	-	-	1	33.3	-	-	1	33.3	-	-
Pemphigus	2	66.7	1	33.3	-	-	-	-	-	-	-	--
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	5	45.5	3	27.3	2	18.2	-	-	1	9.1	-	-

The app offers tips for improving sleep quality												
Psoriasis	94	58.4	52	32.3	6	3.7	6	3.7	3	1.9	-	-
Ichthyosis	22	39.3	20	35.7	11	19.6	2	3.6	1	1.8	-	-
Multiple conditions	17	58.6	7	24.1	4	13.8	1	3.4	-	-	-	-
Eczema	8	44.4	7	38.9	2	11.1	-	-	1	5.6	-	-
Vitiligo	2	22.2	4	44.4	3	33.3	-	-	-	-	-	-
Hidradenitis Suppurativa	23	69.7	6	18.2	3	9.1	-	-	-	-	1	3.0
Lichen Sclerosus	19	55.9	9	26.5	4	11.8	1	2.9	1	2.9	-	-
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	2	66.7	1	33.3	-	-	-	-	-	-
Pachyonychia Congenita	1	33.3	-	-	1	33.3	-	-	1	33.3	-	-
Pemphigus	2	66.7	1	33.3	-	-	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-	-	-

Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	9	81.8	1	9.1	-	-	-	-	1	9.1	-	-
The app offers tips for coping well with a skin condition(s)												
Psoriasis	124	77.0	28	17.4	8	5.0	-	-	-	-	1	0.6
Ichthyosis	38	67.9	12	21.4	6	10.7	-	-	-	-	-	-
Multiple conditions	23	79.3	6	20.7	-	-	-	-	-	-	-	-
Eczema	13	72.2	2	11.1	2	11.1	1	5.6	-	-	-	-
Vitiligo	5	55.6	3	33.3	1	11.1	-	-	-	-	-	-
Hidradenitis Suppurativa	27	81.8	6	18.2	-	-	-	-	-	-	-	-
Lichen Sclerosus	26	76.5	5	14.7	2	5.9	-	-	1	2.9	-	-
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	1	33.3	2	66.7	-	-	-	-	-	-

Pachyonychia Congenita	1	33.3	-	-	1	33.3	-	-	1	33.3	-	-
Pemphigus	2	66.7	1	33.3	-	-	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	1	100.0	-	-	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	9	81.8	-	-	-	-	-	-	2	18.2	-	-
The app offer tips for keeping motivated												
Psoriasis	72	44.7	51	31.7	24	14.9	6	3.7	8	5.0	-	-
Ichthyosis	18	32.1	16	28.6	13	23.2	5	8.9	4	7.1	-	-
Multiple conditions	9	31.0	9	31.0	9	31.0	1	3.4	-	-	1	3.4
Eczema	7	38.9	6	33.3	2	11.1	1	5.6	2	11.1	-	-
Vitiligo	3	33.3	2	22.2	4	44.4	-	-	-	-	-	-

Hidradenitis Suppurativa	21	63.6	9	27.3	3	9.1	-	-	-	-	-	-
Lichen Sclerosus	12	35.3	13	38.2	4	11.8	4	11.8	1	2.9	-	-
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	1	33.3	2	66.7	-	-	-	-	-	-
Pachyonychia Congenita	1	33.3	-	-	2	66.7	-	-	-	-	-	-
Pemphigus	2	66.7	1	33.3	-	-	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	-	-	-	-	1	100.0	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	1	100.0	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	6	54.5	3	27.3	1	9.1	-	-	1	9.1	-	-

The app offers tips for managing itch												
Psoriasis	124	77.0	27	16.8	7	4.3	2	1.2	1	0.6	-	-
Ichthyosis	29	51.8	15	26.8	9	16.1	1	1.8	2	3.6	-	-
Multiple conditions	22	75.9	7	24.1	-	-	-	-	-	-	-	-
Eczema	13	72.2	3	16.7	2	11.1	-	-	-	-	-	-
Vitiligo	1	11.1	3	33.3	2	22.2	2	22.2	1	11.1	-	-
Hidradenitis Suppurativa	25	75.8	6	18.2	1	3.0	1	3.0	-	-	-	-
Lichen Sclerosus	27	79.4	5	14.7	-	-	1	2.9	1	2.9	-	-
Acne	2	100.0	-	-	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	-	-	3	100.0	-	-	-	-	-	-
Pachyonychia Congenita	1	33.3	-	-	1	33.3	-	-	1	33.3	-	-
Pemphigus	2	66.7	1	33.3	-	-	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	1	100.0	-	-	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-	-	-

Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	9	81.8	1	9.1	-	-	-	-	1	9.1	-	-
The app offers tips for taking medication as prescribed												
Psoriasis	95	59.0	38	23.6	18	11.2	8	5.0	2	1.2	-	-
Ichthyosis	17	30.4	13	23.2	15	28.6	4	7.1	6	10.7	-	-
Multiple conditions	18	62.1	8	27.6	2	6.9	-	-	1	3.4	-	-
Eczema	8	44.4	1	5.6	4	22.2	3	16.7	2	11.1	-	-
Vitiligo	1	11.1	5	55.6	2	22.2	1	11.1	-	-	-	-
Hidradenitis Suppurativa	22	66.7	8	24.2	3	9.1	-	-	-	-	-	-
Lichen Sclerosus	26	76.5	5	14.7	1	2.9	1	2.9	1	2.9	-	-
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	1	33.3	-	-	2	66.7	-	-	-	-	-	-

Pachyonychia Congenita	1	33.3	-	-	1	33.3	-	-	1	33.3	-	-
Pemphigus	2	66.7	-	-	1	33.3	-	-	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	1	100.0	-	-	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	-	-	1	100.0	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	-	-	1	100.0	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	5	45.5	3	27.3	1	9.1	1	9.1	1	9.1	-	-
The app gives users a sense of control												
Psoriasis	94	58.4	49	30.4	11	6.8	4	2.5	2	1.2	1	0.6
Ichthyosis	26	46.4	14	25.0	13	23.2	2	3.6	-	-	1	1.8
Multiple conditions	14	50.0	9	32.1	3	10.7	2	7.1	-	-	1	3.4
Eczema	13	72.2	2	11.1	3	16.7	-	-	-	-	-	-
Vitiligo	5	55.6	2	22.2	2	22.2	-	-	-	-	-	-

Hidradenitis Suppurativa	27	81.8	4	12.1	2	6.1	-	-	-	-	-	-
Lichen Sclerosus	22	64.7	8	23.5	3	8.8	-	-	1	2.9	-	-
Acne	2	100	-	-	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	1	33.3	2	66.7	-	-	-	-	-	-
Pachyonychia Congenita	1	33.3	1	33.3	-	-	-	-	1	33.3	-	-
Pemphigus	2	66.7	-	-	-	-	1	33.3	-	-	-	-
Pemphigoid	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	1	100.0	-	-	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	6	54.5	2	18.2	2	18.2	-	-	1	9.1	-	-

The app gives users a sense of continuity of care												
Psoriasis	86	53.4	41	25.5	20	12.4	8	5.0	5	3.1	1	0.6
Ichthyosis	22	39.3	19	33.9	10	17.9	5	8.9	-	-	-	-
Multiple conditions	17	58.6	7	24.1	4	13.8	1	3.4	-	-	-	-
Eczema	10	55.6	3	16.7	5	27.8	-	-	-	-	-	-
Vitiligo	4	44.4	3	33.3	2	22.2	-	-	-	-	-	-
Hidradenitis Suppurativa	24	72.7	7	21.2	2	6.1	-	-	-	-	-	-
Lichen Sclerosus	17	50.0	11	32.4	4	11.8	1	2.9	1	2.9	-	-
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	1	33.3	2	66.7	-	-	-	-	-	-
Pachyonychia Congenita	1	33.3	-	-	1	33.3	-	-	1	33.3	-	-
Pemphigus	2	66.7	-	-	-	-	-	-	1	33.3	-	-
Pemphigoid	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Rosacea	-	-	-	-	1	100.0	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	1	100.0	-	-	-	-	-	-	-	-

Epidermolysis Bullosa	1	100.0	-	-	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	6	54.5	2	18.2	2	18.2	-	-	1	9.1	-	-
The app increases peoples' awareness of skin condition(s)												
Psoriasis	93	57.8	44	27.3	19	11.8	3	1.9	2	1.2	-	-
Ichthyosis	26	46.4	13	23.2	13	23.2	1	1.8	2	3.6	1	1.8
Multiple conditions	17	58.6	8	27.6	4	13.8	-	-	-	-	-	-
Eczema	11	61.1	4	22.2	3	16.7	-	-	-	-	-	-
Vitiligo	5	55.6	2	22.2	2	22.2	-	-	-	-	-	-
Hidradenitis Suppurativa	27	81.8	6	18.2	-	-	-	-	-	-	-	-
Lichen Sclerosus	22	64.7	9	26.5	-	-	2	5.9	1	2.9	-	-
Acne	1	50.0	1	50.0	-	-	-	-	-	-	-	-
Lupus Erythematosus	-	-	1	33.3	1	33.3	1	33.3	-	-	-	-

Pachyonychia Congenita	1	33.3	1	33.3	1	33.3	-	-	-	-	-	-
Pemphigus	1	33.3	-	-	1	33.3	1	33.3	-	-	-	-
Pemphigoid	2	100.0	-	-	-	-	-	-	-	-	-	-
Rosacea	-	-	1	100.0	-	-	-	-	-	-	-	-
Lichen Planus	1	100.0	-	-	-	-	-	-	-	-	-	-
Aktinic Keratosis	-	-	1	100.0	-	-	-	-	-	-	-	-
Epidermolysis Bullosa	-	-	1	100.0	-	-	-	-	-	-	-	-
Loss of pigment	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and mental health conditions	1	100.0	-	-	-	-	-	-	-	-	-	-
Skin and joint conditions	5	45.5	4	36.4	1	9.1	-	-	1	9.1	-	-

Appendix 48: Free-text responses from survey respondents

#	Theme	Quote
1	The impact of skin conditions	*"It impacts every part of my life" (Epidermolytic Ichthyosis, female, 60 years, white, England).* *"It just knocks u back in life" (HS, female, 36 years, white, Ireland).* *"When it's at its worst I can't do much with my hands, and I'm not allowed to work and I feel crappy physically, then I can't sleep because I itch so much." (Multiple skin conditions, female, 35 years, England)* *"It's a constant issue in my life that causes massive emotional stress. In any situation that is the first thing I have to consider, and it's really tiring." (Psoriasis, male, 33 years, Wales)* *"Awareness of condition is constant and there is no distraction - it in fact distracts me while I'm trying to concentrate on other things." (Lichen Sclerosus, female, 56 years, white, New Zealand)* *"You never know when it will flare which causes anxiety" (Bullous Pemphigoid, female, 66 years, white, US)* *"I just hope a pray that I have taken this for the team, that my kids don't get it and have to suffer" (Psoriasis, male, 40 years, white, Scotland)*

“I worry about long term effects on my health from the medications I take” (Psoriasis, female, 58 years, white, England)

“destroys self-confidence and self-esteem” (Multiple skin conditions, female, 63 years, white, England)

“The way I feel today will be totally different another day due to the highs and lows of having a skin condition.” (HS, male, 36 years, white, Republic of Ireland)

“It effects on what clothes I can wear as I get paranoid people are staring if I don't cover up my psoriasis as it is red and scaly. So covering up makes me feel more secure.” (Psoriasis and Osteoarthritis, female, 51 years, white, UK)

“I am on biologics and my psoriasis is nearly in remission but I have lasting psychological symptoms. I have zero body confidence and I absolutely hate the way I look. […] I have problems with my weight, and I am undiagnosed with an eating disorder, I binge eat and I am bulimic, which I am currently struggling with.” (Psoriasis, female, 25 years, white, England)

“Can cause waves of anxiety and depression when the symptoms increase or the condition progresses.” (Lichen sclerosus, female, 35 years, white, England)

“My romantic relationships are affected by the trails of skin cells I leave” (Ichthyosis Vulgaris, female, 54 years, white, USA).

		“Kids point it out and ask about it, adults stare at it and just can’t help but give you advice. What gives them the right to do this. Would they tell a guy in a wheelchair tips on how to use his chair?” (Psoriasis, male, 40 years, white, Scotland) *“I have good days and bad days, its comments made by strangers that are hurtful and annoying.” (Autosomal recessive congenital ichthyosis, male, 61 years, white, Scotland)* *“Being a mother. Trying to hug your children when you're either slathered in greasy steroid creams or in pain from the dry cracking skin. Or when you leave your flaking skin on them. It's awful. They like to stroke my arms but won't because of psoriasis. They look concerned when it bleeds. This is just a fraction of the pain it causes.” (Psoriasis, female, 33 years, white, England)* *“I dropped out of med school because my contact dermatitis was misdiagnosed for an extended amount of time […] I basically cannot work in a place where I do not have control of my exposure to allergens.” (Contact Dermatitis, female, 40 years, East Asian, Canada)* *“I would have liked to be a Nurse, not possible as my skin is so dry and applying cream to my hands so often.” (Ichthyosis, female, 71 years, white, Scotland)*
2	*The burden of self-management*	“hard to manage” (Scalp psoriasis and Seborrheic Dermatitis, female, 42 years, Southeast Asian, England)

“It can be very hard when dealing with mental health conditions to stay positive and keep going with treating it, as it can easily seem like a chore and an endless cycle and almost feel undeserving of it being healed.” (Psoriasis, female, 29 years, white, England)

“It compounds anything else that happens to my body. For example side effects of depression medicine, which are necessary to tolerate, yet become 'harder' to function with.” (Pemphigus Herpetiformis, female, 36 years, white, US)

“Tending to Eczema doesn't just impact your life. It dominates it. Most decisions are based on "Will this cause more flaring? Will that hurt?" Etc.” (Eczema, male, 29 years, white, Wales)

“Having psoriasis and managing the symptoms affects the time that I need to get up in the morning for work. It takes up to 20 minutes extra time to apply creams and lotions, which impacts on the amount of time I have to sleep.” (Psoriasis, female, 57 years, England)

“Can impact holidays because of the importance of protecting our skin in the sun.” (Vitiligo, female, 39 years, multiracial, England)

“I have to make hard choices on what additional therapies I can afford to pay for and receive. I have to ask and pay for help. I have to buy expensive clothes that do not exacerbate my skin condition” (Psoriasis and Psoriatic Arthritis, female, 51 years, white, Canada)

		"The ability to be independent because a lot of the time you need help and support with changing dressings or getting dressed if it really bad so your identity and dignity is gone as well." (Hidradenitis Suppurativa and Psoriasis, female, 30 years, white, Ireland)
3	Helpful and unhelpful coping strategies	*"Reading books such as The Hidden Plague. Doing an elimination diet and trying to figure out what food triggers the boils/make them worse." (Hidradenitis Suppurative, female, 40 years, white, Ireland)* *"Sport, hiking, friends, family, pets, living life." (Lamellar Ichthyosis, female, 33 years, white, Belgium)* *"I have movement disorders which affect my quality of life more than my skin condition does. This puts my lichen sclerosus in some perspective." (Lichen Sclerosus and Granuloma Annulare, female, 64 years, white, US)* *"As my condition is rare, I find comfort in speaking to others with my condition about issues that plague me. I feel the opinions of people with non-visible differences are hollow, although well-meaning, they do not fully understand." (Epidermolytic Ichthyosis, female, 25 years, white, Wales)* *"I have been journaling my thoughts a lot over the past few years. It is nice to read back and see something that were really frustrating and upsetting me weren't a big deal and how far I've come." (Guttate psoriasis, male, 23 years, white, England)* *"I smoke cannabis to help with stress." (Hidradenitis Suppurativa, female, 39 years, white, Ireland)*

		“I've been using chocolate, sweets cake etc to help me get through it.” (Eczema, female, 41 years, white, England) *“Occasional short stints in a sunbed as find helps” (Psoriasis, female, 34 years, white, Scotland)* *“I avoid some situations where I would find it physically difficult to manage.” (Lichen Sclerosus, female, 59 years, white, England)* *“It has been a journey. I have had vitiligo for 20 years. If you’d asked me these questions even 5 years ago the answers would be different as I was not coping with it very well at all and had not come to terms with it. I have now, thanks to therapy and time.” (Vitiligo, male 37 years, white, England)* *“My condition is life long and inherited from my Nan and then father so has affected me differently to those with acquired conditions as I have had a chance to get used to it (the time it takes and the stares it brings) growing up, and had a strong family support network with strong knowledge of the condition already.” (Bullous ichthyosis, female, 25 years, white, England)*
4	Inadequacies in existing support	*“how awkward they [skin conditions] are to manage and the struggle of getting medical help.” (HS, non-binary, 30 years, white, Ireland)* *“Waiting to see the dermatologist but due to covid circumstances they've cancelled my appointments so now longer to wait to be seen and its affected me badly” (Psoriasis, female, 36 years, white, UK)*

“Since moving to Ireland from the UK I’ve not had any medical help as its too expensive for any treatment here.” (HS, female, 32 years, white, Ireland)

“It's difficult, and made more difficult by the separation of functions within the NHS, the concept of MDT's is good, however they really don’t work.” (Psoriasis, male, 43 years, white, England)

“There isn't much help out there in general...treat the skin problem and goodbye.” (Pemphigus Vulgaris, female, 54 years, white, US)

“GP training doesn't even cover basic dermatology, I sat with an st3 who was reading as we went along and had zero experience with eczema which for such a common condition is disgusting.” (Eczema, female, 41 years, white, England)

“When you tell a new G.P. that you suffer from X-linked ichthyosis, they have NEVER heard if it but STILL do not look it up during your appointment.” (X-Linked Ichthyosis, male, 63 years, white, England)

“Drs are useless especially the 'specialists' don't bother going now unless I need antibiotics or a topical for it. My GP is actually alright.” (Multiple skin conditions, female, 35 years, white, England)

“it is extremely difficult to get any emotional support as those around you don't understand the sheer irritation and pain you go through every day.” (Eczema, male, 29 years, white, Wales)

“My parents feel extremely guilty that I have this condition […] If I try and get support from them it usually turns around that I’m supporting them not to feel guilty […] but can make me feel

		unseen/unheard as usually it ends up them talking about their feelings…" (Bullous ichthyosis, female, 40 years, white, England) *"There is simply no psychological support for this in my region. I've wanted to see a mental health specialist for ages, but I've been told me and my condition aren't a priority, despite it having severe mental consequences on my health." (Psoriasis and Psoriatic Arthritis, male, 33 years, white, Wales)* *"I've been on a very restrictive diet and supplementation protocol for the past 2 years overseen by a private holistic healthcare professional. It has improved my skin about 80% and improved a lot of other health problems I was suffering with which I am very pleased about!" (Psoriasis, male, 23, white, England)* *"I have found the Facebook groups for my condition to be extremely helpful. I also participated on Stuff That Works for my condition, however I find the knowledge level is not as advanced in those communities. The American Contact Dermatitis Society has also been an important resource as well as an allergy page on Facebook…" (Contact Dermatitis, female, 40 years, East Asian, Canada)* *"Sometimes it would be nice for someone else's perspective. I find the GPs increasingly unhelpful. Sometimes you just need a little support and some advice" (Ichthyosis, female, 43 years, white, Wales)*
5	*Perceptions and ideas on MiDerm*	*"I think more needs to be done to support emotional/psychological impact of skin conditions so if it does that it would be good." (Bullous Ichthyosis, female, 40 years, white, England)*

"in today's technology-based environment such apps need to be considered" (Ichthyosis, male, 64 years, white, UK)

"Information and knowledge is power, this needs to happen to help people like me who are struggling to cope." (Psoriasis, male, 43 years, white, England)

"Good as a mechanism for sharing latest research (global), foods or drinks which causes flare ups, study groups/research projects to join, details of the latest drugs/medications etc. what does not work for most - save time/money etc. […] I don't smoke and am a moderate drinker, however, details on how giving up/cutting down will help most people" (Palmoplantar Psoriasis, male, 47 years, white, England)

"There is little support around reducing steroid medication during fertility treatment and pregnancy, when this condition especially is flared up via procedures." (Psoriasis, female, 30 years, white, England)

"The last thing I would like is an app that preaches the crap that healthcare professionals yap at us. Lose weight, stop smoking, stopping drinking, exercise more. We know all this. We have been preached at for years. There are people who are thin, don't smoke/drink, eat healthy and still have this curse. At the first sign of preaching I turn off" (HS and Rosacea, female, 43 years, white, Ireland)

“Not blaming, I've had plenty of rude Drs & nurses over the years. I don't need lecturing on not eating, not drinking, not exercising, not meditating, being overweight. That's going to make me feel down & hate myself more.” (Ichthyosis, female, 44 years, white, Wales)

“Advice, or info on who to contact or where to go if struggling like a lot of people do mentally with skin conditions.” (Psoriasis, female, 27 years, white, England)

“To track ALL appointments and treatments and add symptom side effects as well as mental awareness questions to answer...but not these check off things...that's not good enough. It has to be open ended questions and the ability to express the actual answers.” (Pemphigus Vulgaris, female, 54 years, white, US)

“The danger of this type of App is that the condition becomes a focus of your life if you are continually referring to it. The goal should be to forget the condition in your daily life and get on with living, an app may make you continually worry about the condition” (Lamellar ichthyosis, male, 68 years, white, England)

“I think if you can talk or relate to some one that has it or some understanding of it would be a great help in more ways than one.” (Epidermolytic Ichthyosis, female, 60 years, white, England)

“no idea if it [app] would be helpful for me or not until I see it” (Nonbullous Congenital Ichthyosiform Erythroderma, 58 years, female, white, Northern Ireland)

“It would have to be all encompassing as I feel skin conditions can be dramatically different from each other” (Hidradenitis Suppurativa, female, 42 years, white, Ireland).

“probably useful to newbies” (Multiple skin conditions, female, 35 years, white, England)

“… I think it can’t be assumed that these issues will all be solved by an app that provides support and advice and if this is to be presented to NHS commissioners it should be as an addition to medical support not in place of or as a first option. […] An app won’t replace the need for sufficient medical support.” (Psoriasis, female, 30 years, white, England)

“I do not have a 'smart' phone and today everything is 'app' this and 'app' that. It would ok if the 'app' was not everything.” (Congenital Ichthyosis, male, 56 years, white, England)

“I am in my 60’s and do not have a smartphone or am very IT minded.” (Multiple skin conditions, female, 63 years, white, England)

“I spend most of my working day in front of a screen so I try to avoid screen time outside of this time.” (Psoriasis, female, 59 years, white, England)

“As many skin conditions can impact skin and touchscreen a web-based version may be more accessible or very easy to manage use with skin that makes mobile use painful or needs to be short time use or have audio voice control or link with Alexa etc?” (Psoriasis, female, 51 years, white, England)

	“fun, simple to use, not distressing” (Ichthyosis, female, 44 years, white, Wales). *“I’d love to have an app that I can go to that I know contains trusted information. Too many websites have conflicting information on management and treatment.” (Psoriasis, female, 41 years, white, England)* *“The need for support will encourage acceptance in an individual, making his living enjoyable though with the disease” (Eczema, male, 22 years, black, England).* *“This would be so beneficial to have between hospital appointments to keep records and stuff to be able to speak to doctors better.” (HS and Psoriasis, female, 30 years, white, Ireland)*

G, Group; HS, Hidradenitis Suppurativa

Appendix 49: Summary of main results from online survey and group interview studies

Quantitative survey results	**Qualitative survey results**	**Qualitative group interview findings**
Impact		
Life impact of skin conditions, especially the time and effort required for self-management, followed by the psychological, physical and social impact.	Impact of skin conditions and the burden of self-management.	Life impact of skin conditions and their management plus cumulative life course impairment. The degree of impact changed across the life span. Impact greater for adults with late condition onset, who had not fully adjusted to their condition, and children and young people who were already experiencing physical, psychological and social changes during these transitional life stages. These sub-groups, and women, were perceived to be at great risk of cumulative life course impairment.
	Demonstrates the link between cognitive, emotional, behavioural and social responses to skin conditions.	Further evidence and examples of the link between cognitive, emotional, behavioural and social responses to skin conditions.
Personal control		

Over 60% of participants believed their actions could, to some extent, influence the progression of their skin condition.		Participants sought control amid the uncertainty and unpredictability of their skin condition. An improved understanding of skin conditions and their management, acceptance and proactively approaching self-management all helped to increase personal control. However, trial and error approaches to self-management could reduce personal control and self-efficacy.
An app that increases users' personal sense of control was extremely important to approximately 60% of participants.		
Existing support		
General lack of support for adults living with skin conditions.	General lack of support for adults with skin conditions, which was often attributed to poor awareness and understanding of skin conditions, particularly rarer types. Desire for additional support.	General lack of appropriate support for adults with skin conditions. Poor support was attributed to poor awareness and understanding, particularly of rarer skin conditions, among the medical community and the public. Some adults lack understanding of the causes and particularly

		the psychological consequences of their skin condition also.
Over half the sample reported receiving support from health professionals occasionally or rarely.	Limitations, inadequacies and inequities in medical care and treatments, which were made worse by the SARS-CoV-2 pandemic. Dissatisfaction at the lack of inter-disciplinary approaches to condition management and attitudes of health professionals.	Biomedical model in dermatology and the burden of existing models of patient care (stepped treatment approach and reactive). Issues in the way health professionals communicated with people about their skin condition (e.g., breaking bad news, dismissing concerns and lack of shared decision-making). Poor access to timely medical care, especially during the SARS-CoV-2 pandemic.
Approximately three quarters of the sample had never received psychological support.	Lack of psychological support in dermatology services was attributed to poor awareness of the psychological impact of skin conditions.	Psychological support was generally limited. Nine participants shared experiences of psychological support they had received, including cognitive, emotional and behavioural benefits, as well as barriers (inaccurate perceptions of skin conditions and psychological support, avoidant and emotion-focused coping strategies, cost of

		private care, lack of specialist support dedicated to skin conditions, dualism between physical and psychological health care.
Social support was variable.	Disadvantages of social support – lack of understanding and relatedness.	Social support is important but limited. Benefits and disadvantages of receiving support from friends and family who have no lived experience of skin conditions.
Over 60% had never accessed support from a dedicated patient organisation. More participants reported seeking peer support online, but 30% never received this type of support.	Preference for support from people living with the same skin condition. Reliance on online support groups for informational, practical and emotional support.	Peer support appears to be a form of psychological support in its own right, but there are also disadvantages, particularly to online peer support. These include a lack of safe and evidence-based information from credible sources, poor regulation and moderation leading to increased psychological burden. Emphasises, in broader context of little support, that people have no choice but to rely on the information available online and may adopt such guidance out of desperation.

Preference for digital over written self-help materials.		
Most used prescribed medications for condition management, but the frequency of use varied.	Issues with medical treatments, including cost, side effects, limited efficacy, discontinuation, and inequities in availability depending on geographical location.	Issues with medical treatments (limited choice, efficacy, access and availability, plus cost and geographical inequities) added to the existing burden.
Coping		
Evidence of dysfunctional, problem and emotion focused coping strategies, plus health-protective behaviours and some, but limited, evidence for health-threatening behaviours.	Ability to cope was dependent on the number of years lived with a skin condition and extent of adjustment.	Ability to cope was dependent on the number of years lived with a skin condition and extent of adjustment, plus competence and confidence that individuals develop through their careers and hobbies as they get older.
Common dysfunctional coping strategies included self-criticism, self-distraction and behavioural disengagement. Denial and venting were less common.	Avoidant behaviour was reported by some.	
Common problem-focused coping strategies included active coping, planning and seeking	The burden of self-management, which generally dominated daily living and required	The burden of self-management, including the time, effort and planning involved, as

informational support, although 30% reported never seeking or receiving informational support.	a substantial amount of time, effort and planning.	well as the pressure to adhere to personal routines to control symptoms.
	Individuals reported carrying out their own research on their skin condition and searching for information on the internet to improve understanding.	Some evidence to suggest people with skin conditions lack understanding of skin conditions and their management, plus poor awareness of their life impact. Personal online research was common, as were trial and errors approaches to self-management.
Common emotion-focused coping strategies included acceptance and, to some extent, seeking emotional support, although 30-40% said they never sought or received this. Religion, humour and positive reframing were employed less frequently as coping strategies.	Seeking emotional support online from other people living with the same skin condition. Some participants reported expressing emotion through journalling.	Seeking emotional support from online patient support groups.
	Use of downward social comparisons as a helpful coping strategy.	Use of downward social comparisons as a helpful coping strategy, but may be a barrier to adults seeking appropriate support.
	Acceptance was described as a journey and pivotal for successful adjustment.	Acceptance was seen as a way to take back personal control and was deemed necessary for successful adjustment and interrupting CLCI.

A range of health-protective behaviours were employed to cope with skin conditions, but over half of the sample reported rarely or never trying to keep physically active and self-reported treatment adherence varied.	A range of health-protective behaviours were reported and said to help increase physical, psychological and social well-being. Responses mainly related to physical activity and diet, including vegan and elimination diets plus time-restricted eating.	Experiences of changing diet to identify potential triggers. Participants reported trying juicing and elimination diets usually with little success.
Most participants tried to prioritise getting enough sleep to some degree.	Self-management routines disturbed sleeping patterns and contributed to physical and psychological fatigue.	
Health-threatening behaviours – most participants reported not smoking or using substances, including drugs and alcohol, but a small percentage (6-10%) reported using these strategies often.	A couple of participants explained using recreational drugs and comfort eating to cope with emotions and stress related to their condition. One participant reported occasional sun bed use to improve their physical symptoms.	
Hiding was frequently employed as a coping strategy. Approximately one fifth of the sample reported never hiding the skin.	Hiding the skin was common but the terms 'hide' and 'cover' were used interchangeably making it difficult to determine the usefulness of this strategy.	
Perceptions and ideas for the MiDerm app		

Most participants reported the idea of the MiDerm app was acceptable.	Positive attitudes and perceived benefits for users, especially young people and adults with late condition onset. Appropriate in the context of modern society where use of digital technologies, including apps, is normalised.	Positive attitudes given the limitations associated with existing face-to-face and online support. The app was seen as a convenient resource for locating and storing information tailored to skin conditions and the individual user, helping to alleviate psychological burden. It was considered beneficial for children and young people, and particularly in societies, and among younger generations, in which use of apps is normalised. Ideas for the app related to the key concepts of STD (ref): • Competence – understanding skin conditions and approaches to management. • Autonomy – need for tools and techniques to manage independently. • Relatedness – support from others living with skin conditions.

Approximately 15% of participants were unsure whether the idea of the app was acceptable to them.	Some uncertainty around what the app would offer, plus concerns about it giving false hope, catering for different skin conditions, and being a replacement rather than an adjunct to face to face psychological support.	Concerns about how the app would differ from existing apps and cater for a range of skin conditions and different levels of psychological need.
A few participants deemed the MiDerm app slightly unacceptable or not acceptable.	Perceived barriers to use – physical symptoms, skills to use app, current screentime, poor access to smartphones, and personal preferences.	Perceived barriers to use: • Physical symptoms. • Inaccurate beliefs, avoidant coping and self-stigma. • Lacking skills and self-efficacy to use digital technology. • Industry involvement. • Language. • Poor awareness of the app. • Cost. • Limited access to a smartphone or the internet. • Fluctuating motivation.
	Flexible use was important for engagement.	Perceived enablers to app use:

		- Avoid manually entering lots of data and include basic questions and responses. - Simple interface for ease of use. - Lay language. - Translation into different languages. - Visual as well as written content. - Appropriate marketing. - Endorsement from key stakeholders. - Available on different digital mediums. - Downloadable resources. - Personal choice and autonomy, including option to register anonymously.
Over half of the sample reported it was extremely important that the app gives users a sense of continued care.	The app was perceived to be a useful adjunct to standard care that would provide a sense of continued care in between consultations.	The app was viewed as a way to provide continuity of care between consultations and across life stages, as well as a useful tool for consultations.

Co-developing the app with key stakeholders was important.		
Endorsement from key stakeholders, including health professionals followed by patient organisations and health authorities, was a priority.		Endorsement from health professionals and providers and patient organisations was important for disseminating the app.
An app that increases peoples' awareness of skin conditions was important. There was a desire for the provision of information on the links between skin conditions and psychological and social consequences. The percentage of participants who rated the following topics as *extremely* important are presented below (highest to lowest): • Diet (57.8%) • Physical activity (55.7%) • Mood (54.9%) • Social impact (50.3%)	Willingness to learn about skin conditions, cost-effective treatments, dealing with itch and condition management, including health behaviours.	Potential for helping individuals to recognise and address the psychological impact of skin conditions, dispel common myths. Signposting users to existing resources was suggested as a way to educate people about skin conditions, comorbidities and treatments.
	The app was perceived to be a convenient and credible source of tailored information.	Desire for evidence-based information that is specific to skin conditions rather than generic.
	Lack of information for women on skin conditions and reproductive health, specifically pregnancy and menopause.	Additional uncertainty for women around the impact of skin conditions on reproductive health and vice versa. Lack of support and

• Sleep (49.7%) • Alcohol (40%) • Smoking (38.4%)		guidance and support for women on reproductive health and skin conditions.
		Concerns among male and female participants about the implications of skin condition and treatments for family planning and offspring.
	The language used to communicate information and guidance on health behaviours is important.	Mixed opinions on mindfulness, mainly because they are instructional.
Including practical tips for coping and self-management were important. The percentage of participants who rated the following topics as *extremely* important are presented below from the highest to the lowest percentage: • Coping well in general (74.6%) • Managing itch (70.5%) • Managing low mood (66.8%) • Keeping physically active (56.8%) • Improving sleep quality (55.1%)	One participant believed the app could facilitate acceptance and improve psychological well-being and quality of life. Another felt the app could support people to cope and self-manage effectively.	Desire for practical tips for labelling, processing and regulating emotions, especially in social situations.
		Perceived benefits of the app included supporting habit formation (treatment adherence).

• Treatment adherence (54.9%) • Managing social anxiety (45.4%) • Healthy eating (44.3%) • Staying motivated (42.4%) • Managing social interaction (42.4%) • Quitting smoking (31.9%) • Reducing alcohol consumption (30.5%)		
Features that the participants deemed *extremely* important for the app included: • Free access (81.6%) • Tailored to users (50.3%) • Tracking physical symptoms (50%) • Tracking psychological processes (47.8%) • Option to connect with other users (40%)	A tracking feature was desirable for monitoring symptoms and triggers and logging medical information. Drawbacks to a tracking feature – increased psychological burden.	Desire for tracking feature to recognise psychological triggers, direct goals for self-management and reinforce positive behaviours. However, tracking could increase the emotional burden on users by reducing motivation, increasing pressure and heightening healthy anxiety.
	Cost	Free to access, or a small subscription fee to deter people with ulterior motives. Available on prescription.

• Interactive activities (38.1%) • Visual feedback on progress (36.2%) • Optional reminders (32.7%) • Support with goal setting and action planning (32.2%) • Virtual points or rewards (22.7%)		Push notifications serving as reminders for app use. Importance of language and frequency of delivery.
	Connection and communication with other users was desirable.	Desire for the app to offer peer support and facilitate connection between users in person. Synchronous peer support via an app was seen to require additional resource (cost, time and moderation) and the provision of patient stories was viewed as an acceptable alternative.
	Fun to use.	Enjoyable to use.
		App design: • Soft, calming colours (shades of blue or green) that resemble existing health and well-being apps. • Avoid a ‘clinical’ feel.

Appendix 50: Definition of MiDerm according to the Template for Intervention Description and Replication (TIDieR) checklist and guide (Hoffmann et al. 2014)

	TIDieR item	Description
1	Brief name	Intervention name: MiDerm Intervention description: MiDerm is a complex digital behaviour change intervention that supports the self-management of skin conditions.
2	Why	Rationale: The psychological impact of skin conditions is profound, yet there is a widespread and persisting lack of psychological support, including behaviour change, within dermatology service provision and patients often must self-manage their condition with little or no support. Many adults living with skin conditions have expressed both a need and a desire for additional support to be able to deal with the psychological consequences of their condition more effectively. Digital technologies, including smartphone apps, can support the self-management of long-term health conditions. Digitally delivered interventions in dermatology can improve some clinical and health outcomes, but new digital interventions offering behaviour change support for a range of common and rare skin conditions are needed. MiDerm was theoretically informed by the: CSM (Leventhal et al. 1984); COM-B Model (Michie et al. 2011b); PBA to intervention development (Yardley et al. 2015b); TFA (Sekhon et al. 2017). Main intervention components: Educational material, behaviour change support, peer support, signposting.

		Potential mechanisms of action to investigate in future: condition-specific knowledge; self-efficacy; self-acceptance; degree of adaptation.
3	What – materials	A full list of content included in the MiDerm app is presented in Table X. In brief, the MiDerm app includes written information on: • Psychological processes (cognitions, emotions and behaviour) and the skin. • Health behaviour change support. • Signposting to existing support for self-management. • Push notifications, including motivational messages. It also contains 'patient stories' representing the lived experiences of five adults who were part of the original PPI group and helped to co-develop the MiDerm app. The patient stories are in video format for users to watch and listen to. The skin conditions represented include psoriasis (x2), eczema, rosacea and acne/scarring.
4	What – procedures	Intervention processes: N/A at this stage of intervention development. Intervention activities: Below is a list of activities that are included within the MiDerm app. All activities are optional. • Set up personal user profile. • Read written content in the library. • Watch/listen to patient stories. • Add notes.

		- Diary entry. - Be your own psychologist. - Goal setting. - Action planning - Implementation intentions or 'if-then' plans. - Reflect on key learnings of each section in notes section.
5	Intervention provider	None, as this is a digital intervention designed to support the self-management of skin conditions. The intervention was developed by a trainee health psychologist under the supervision of a qualified health psychologist and academic psychologist and with support from a research assistant specialised in health psychology. The intervention was developed in collaboration with an external software development company and a group of ten PPI contributors.
6	How	The intervention was aimed at adults (18≥ years) living with skin conditions and was intended for individual use. MiDerm was delivered digitally via a new smartphone application.
7	Where	The intervention was developed for digital delivery via a smartphone app. The intention is to make the app widely available via the app store. This will mean that individuals have the flexibility and autonomy to choose when and where they access the intervention, providing they have a smartphone and download the MiDerm app.
8	When and how much	MiDerm was designed to be used flexibly to suit the individual user. Users can choose when they access the app as well as how often (frequency) and how long (duration) they use it for. Include details of push notifications

9	Tailoring	All activities within the app are optional, meaning users can select those that are most relevant to them.
10	Modifications	N/A at this stage of intervention development.
11	How well (planned)	N/A at this stage of intervention development.
12	How well (actual)	N/A at this stage of intervention development.

CSM, Common Sense Model of Self-Regulation; COM-B, Capability Opportunity Motivation – Behaviour; PBA, Person-Based Approach; TFA, Theoretical Framework of Acceptability; TBC, To be confirmed; PPI, Patient and Public Involvement; N/A, not applicable.

Appendix 51: List of issues, needs and perceived barriers plus facilitators, potential solutions and perceived benefits of MiDerm

	Issues, needs and perceived barriers	**Perceived facilitators, potential solutions and advantages**
1.	Lack of psychological support.	App could help to increase provision of psychological support.
2.	Personal experiences and level of need varies.	Signposting to existing types of psychological support.
3.	Poor clinical communication and management of skin conditions.	App could support communication between patients and health professionals.
4.	Poor understanding of skin conditions and their impact.	• Self-monitoring function. • Provision of evidence-based information from credible sources.
5.	Low personal control.	Provision of education for adults with skin conditions.
6.	Patient health and safety online.	Provision of evidence-based information from credible sources.
7.	Information seeking and recall increase cognitive burden.	App could provide a convenient and safe space for locating new information and recording personal history.
8.	Difficulty managing emotions and alexithymia.	Provision of techniques for emotion regulation.
9.	Low self-esteem and poor self-image.	Support people to accept their skin condition.
10.	Peer support	• Provision of patient stories. • App could facilitate communication between adults with skin conditions.
11.	Low digital literacy	• App has a simple interface.

		• Prioritise questions with basic response options and rating scales.
	Manually entering information is time consuming and effortful.	Prioritise questions with basic response options and rating scales.
	Low digital self-efficacy	None stated.
12.	Limited or no access to digital technology.	Ability to use offline.
13.	Poor awareness of app.	Promotion by credible sources.
14.	Skepticism towards pharmaceutical companies.	Endorsement from credible sources.
15.	English language only.	Translate into different languages.
16.	Cost.	App is free to access.
	App has a clinical design and feel.	• Refer to branding of other companies in the health, fitness and well-being industry. • Colour scheme: focus on blues and greens.
17.	Health literacy.	Use simple language.
18.	Low reflective motivation (continued engagement).	• Gather and incorporate feedback from prospective users. • Provision of personalised feedback on progress. • Update app content. • Push notifications including positive affirmations and quotes. • Allow users to decide the frequency and duration of app use, choose the content they engage with, and personalise functions of the app to suit their preferences.

		- Ability to use app flexibly. - Virtual rewards and affirmations.
19.	Privacy and data protection	- Data handler is credible. - Follow protocol for data protection (i.e., GDPR). - Transparency around data use and storage. - Give users the option to register anonymously/with a username.
19.	Public and self-stigma related to seeking psychological support.	None stated.
20.	Perceptions of psychological health and well-being.	None stated.
21.	Avoidant coping strategies.	None stated.

Appendix 52: Guiding principles for MiDerm

# Key issues and needs	Descriptive summary of key issues and needs	Guiding principles	
		Intervention objective	Intervention features
1 Lack of psychological support. 3 Poor clinical communication and management of skin conditions. 6 Patient health and safety online. 7 Information seeking and recall increase cognitive burden.	Lack of dedicated, specialist and free psychological support for adults with skin conditions and especially behaviour change support. Typically, patients are not prepared to self-manage all aspects of their skin condition and seek advice from online sources that are often unregulated, unqualified and, potentially, unsafe.	Increase adults' capability for self-management by providing an opportunity to access free psychological support from trustworthy and expert sources that are tailored to skin conditions and focus on health behaviour change wherever possible.	• Intervention is developed, endorsed and promoted by credible sources (e.g., universities and patient organisations). • Optional activities designed to support health behaviour change and maintenance, including goal setting, action planning and forming implementation intentions. • Diary section for self-monitoring physical and psychological symptoms and personal reflection. • Notes section for general note taking and reflections on learning.

2 Personal experiences and level of psychological need varies. 8 Difficulty managing emotions and alexithymia. 9 Low self-esteem and poor self-image.	The psychological impact of skin conditions is often the most challenging to manage, but personal experiences/level of need will vary. Self-acceptance is important for successfully adapting to having a visible skin condition. Supporting self-esteem (thoughts and feelings about the self, skin condition and personal appearance) could help adults to come to terms with, and see themselves beyond, their skin condition.	Increase adults' capability (skills) to self-manage difficult beliefs and emotions, health behaviours and facilitate self-acceptance.	• Diary section for self-monitoring physical and psychological symptoms and personal reflection. • Signpost to existing resources, interventions and services, as well as peer and organizational support (online and in person). • Optional activities designed to support health behaviour change and maintenance, including goal setting, action planning and forming implementation intentions.
4 Poor understanding of skin conditions and their impact. 5 Low personal control.	Poor understanding of skin conditions, triggers and their impact contributes to a low sense of personal control and is a potential barrier to effective self-management.	Increase adults' capability (knowledge) for self-management, focusing on the role of psychological processes, particularly health behaviours.	• Provision of evidence-based information on the common impacts across skin conditions. • Signpost to existing resources, scientific literature and clinical guidance for management.

20 Perceptions of psychological health and well-being .			• Provision of evidence-based information on the skin and psychological mechanisms, focusing on health behaviours (sleep, physical activity, diet, smoking, alcohol, treatment adherence, itch and scratching). • Diary section for self-monitoring physical and psychological symptoms and personal reflections.
10 Peer support	Peer support offers a valuable opportunity for adults to make new social connections, feel less isolated, normalise their skin condition, become more self-confident, as well as to learn from and be inspired by similar others.	Increase social opportunity and capability through the provision of stories of adults' experiences of living with and managing all aspects of skin conditions.	• Inclusion of patient story videos to model how similar others self-manage effectively. • Signpost to websites of existing organisations representing people with skin conditions.
11 Low digital literacy/self-efficacy.	Barriers to accessing and engaging with smartphone apps	Increase physical opportunity by minimising barriers to accessing	• App is free to download.

12 Limited or no access to digital technology. 13 Poor awareness of app. 14 Skepticism towards pharmaceutical companies. 15 Language. 16 Cost. 17 Health literacy. 18 Reflective motivation/ behaviour change maintenance. 19 Public and self- stigma surrounding seeking psychological support. 21 Existing avoidant coping strategies.	exist, including: cost, having limited or no access to digital technology, low digital literacy/self-efficacy, and physical symptoms (e.g., pain, impaired vision) and psychological processes, specifically (reflective) motivation and preconceptions of what psychological support entails and who it is intended for.	and engaging with the digital intervention overtime. Focus on increasing reflective **motivation**, self-efficacy, and supporting personal autonomy.	• App content can be downloaded/printed for use offline wherever possible. • Clear and simple interface, language and navigation procedures. • Inclusion of simple question and answer formats and click responses where possible. • Optional push notifications including motivational messages. • State purpose and benefits of psychological support delivered via a smartphone app. • Section for gathering user feedback. • Sections/activities within app are all optional.

Appendix 53: Percentage of survey respondents who perceived the provision of information and tips on health behaviours to be of at least some importance

Educational material		Practical tips	
Topic	**%**	**Topic**	**%**
Physical activity	97.5	Itch and scratching	96.1
Diet	96.7	Sleep	94.9
Sleep	94.6	Physical activity	94.6
Drinking alcohol	81.7	Treatment adherence	91.4
Smoking	74.8	Healthy eating	89.4
		Reducing alcohol intake	71.4
		Quitting smoking	68.3

Appendix 54: Matrix of links between COM-B and interventions functions adapted from Michie at al. (2014) for MiDerm

COM-B construct	Intervention functions								
	Education	Persuasion	Incentivisation	Coercion	Training	Restriction	Environmental restructuring	Modelling	Enablement
Physical capability					▨				▨
Psychological capability	▨ ✓				▨ ✓				▨ ✓
Physical opportunity					▨	▨	▨		▨ ✓
Social opportunity						▨	▨	▨	▨ ✓
Automatic motivation		▨	▨	▨	▨		▨	▨	▨
Reflective motivation	▨ ✓	▨	▨	▨					

Appendix 55: Description of links between COM-B constructs and interventions functions for MiDerm

COM-B component	COM-B construct	Intervention function	Description of link to MiDerm
Capability	Psychological capability	Education	Educate adults on how skin conditions are linked to psychological processes.
			Increase adults’ awareness of approaches and strategies for self-management and coping that other adults with skin conditions use and their understanding of why these are effective.
		Training	Explain to adults the practical techniques (i.e., goal setting, action planning, implementation intentions) that they can use to change health behaviour.
			Give adults an opportunity to practice the techniques described to support behaviour change.
		Enablement	The provision of a diary for self-monitoring as a means of increasing adults’ psychological capability for condition self-management.
Opportunity	Physical opportunity	Enablement / Environmental restructuring	Pooling existing resources, services and interventions designed to support psychological health and well-being that could support adults to self-manage skin conditions more effectively.

	Social opportunity	Enablement	The provision of ‘patient stories’ demonstrating how other adults self-manage skin conditions as a way to encourage and socially influence behaviour change.
Motivation	Reflective motivation	Environmental restructuring	Push notifications including motivating messages written by people with lived experiences of skin conditions that can be delivered to adults who MiDerm to prompt them to engage with the app.

Appendix 56: MiDerm guiding principles, components and behaviour change techniques

Guiding principles for intervention		Intervention component	Target construct (COM-B Model)	Intervention function (BCW)	BCT taxonomy grouping	BCT
Intervention objective	Intervention feature					
Increase adults' capability for self-management by providing an opportunity to access free psychological support from trustworthy and expert sources that are tailored to skin conditions and focus on health behaviour change wherever possible.	Links to existing resources, scientific literature, clinical guidance for management and patient organisations.	Signposting	Physical opportunity	Enablement	Not relevant	Not relevant

Increase adults' capability (knowledge) for self-management, focusing on the role of psychological processes, particularly health behaviours.	Evidence-based information on: (1) Common impacts and (2) skin conditions and psychological processes, including health and lifestyle behaviours.	Library	Psychological capability	Education	4) Shaping knowledge	4.2 Information about antecedents
					5) Natural consequences	5.1 Information about health consequences
						5.3 Information about social and environmental consequences
						5.6 Information about emotional consequences
Increase social opportunity and capability through the provision of stories of adults' experiences of living with and managing	Patient story videos focusing on how others cope with and manage skin conditions effectively.	Patient Stories	Psychological capability Social opportunity	Education Enablement/ Modelling	3) Social support	3.1 Social support (unspecified)
					6) Comparison of behaviour	6.2 Social comparison
					9) Comparison of outcomes	9.1 Credible source

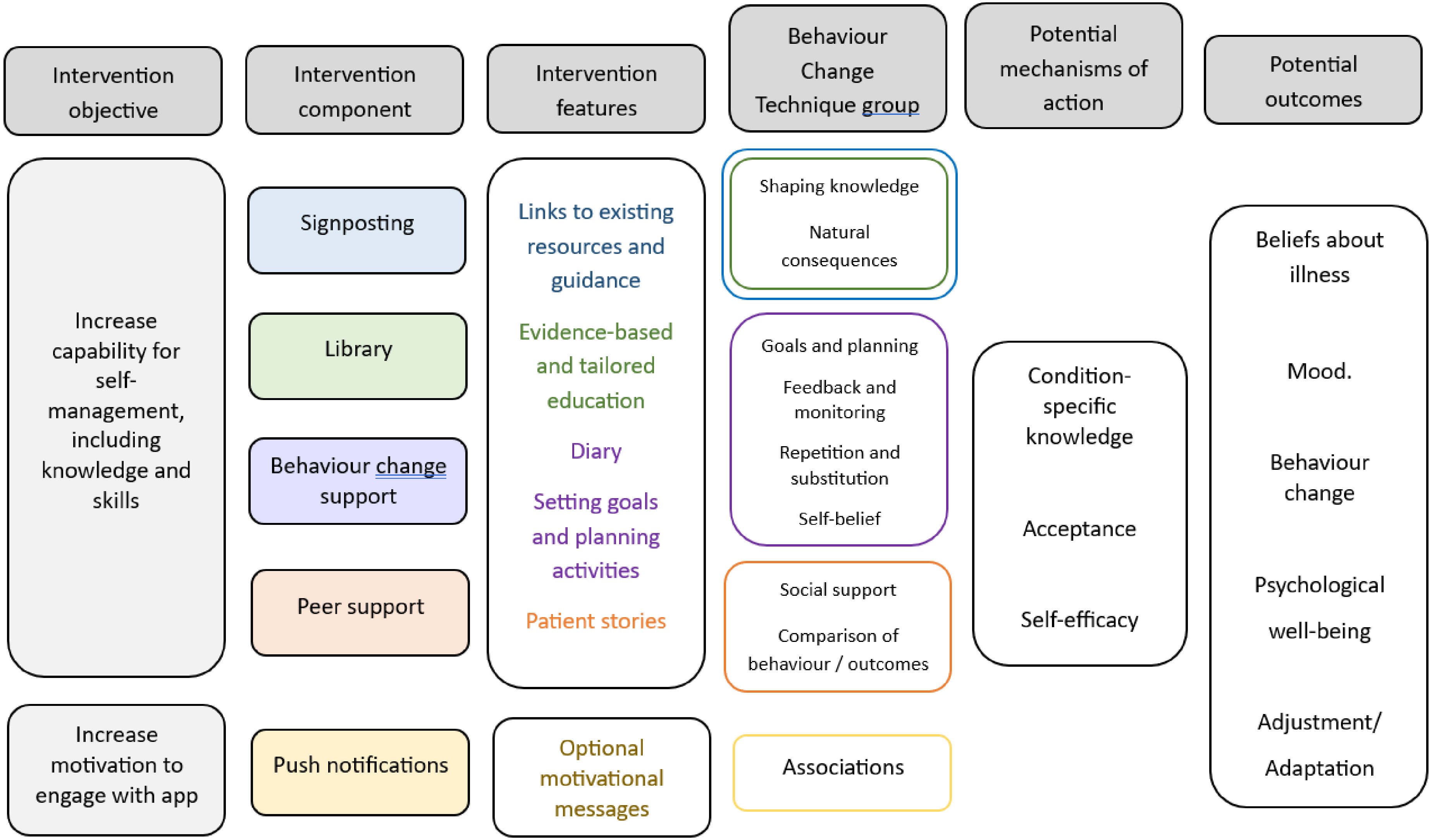
all aspects of skin conditions.	Links to websites of existing patient organisations					
Increase adults' capability (skills) to self-manage difficult beliefs and emotions, health behaviours and facilitate self-acceptance.	Diary section for self-monitoring of physical and psychological symptoms and noting personal reflections	Diary	Psychological capability	Enablement	2) Feedback and monitoring	2.3 Self-monitoring of behaviour
						2.4 Self-monitoring of outcome(s) of behaviour
Increase adults' capability (skills) to self-manage difficult beliefs and emotions, health behaviours and facilitate self-acceptance.	Optional activities designed to support health behaviour change and maintenance, including goal setting, action planning and forming implementation intentions.	Behaviour change support	Psychological capability	Education Training	1) Goals and planning	1.1 Goal setting behaviour 1.2 Problem solving 1.3 Goal setting (outcome)

						1.4 Action planning 1.7 Review outcome goal(s)
					2) Feedback and monitoring	2.3 Self-monitoring of behaviour
					8) Repetition and substitution	8.2 Behavioural substitution 8.3 Habit formation 8.4 Habit reversal
					15) Self-belief	15.3 Focus on past success
Behaviour: accessing app repeatedly						

Increase physical opportunity by minimising barriers to accessing and engaging with the digital intervention overtime. Focus on increasing reflective motivation, self-efficacy, and supporting personal autonomy.	Optional push notifications including motivational messages.	Push notifications	Reflective motivation	Environmental restructuring	7) Associations	7.1 Prompts and cues

COM-B, Capability Opportunity Motivation – Behaviour; BCW, Behaviour Change Wheel; BCT, Behaviour Change Technique

Appendix 57: Logic model for MiDerm



Appendix 58: Potential names for the research project, intervention and smartphone app

Name	**Trademark Checked?**	**Status**
Dermablues	Yes	Available
MindTheSkin	Yes	Available
SkinClear	Yes	Available
DermApp	Yes	Available
SkinEase	Yes	Available
Patchwork	Yes	Registered
MySkin	Yes	Registered
SkinWell	Yes	Registered
WellSkin	Yes	Dead (Previously registered)
eSkin	Yes	Registered
SkinLink	Yes	Available
SkinSmart	Yes	Available
My Skin and I	Yes	Available
Skin and Me	Yes	Registered
Skinhale	Yes	Available
Skintelligence	Yes	Available
Skintellect	Yes	Available
Skin halo	Yes	Withdrawn
Live	Yes	Registered
Free	Yes	Registered
Wise skin	Yes	Available
MiDerm	Yes	Available
MiSkin	Yes	Registered
Easy Skin	Yes	Registered
SkinWise	Yes	Registered
SkinWizz	Yes	Available
Confidence	Yes	Registered

Skinory	Yes	Available
Help	Yes	Registered
CME	Yes	Registered
Natural	Yes	Registered

Appendix 59: Written content produced for MiDerm

Content for MiDerm App – Welcome and Profile

Welcome

Welcome to MiDerm. Build your own profile and get tailored content by answering some questions about your skin condition, or jump right in and start gaining new knowledge and skills to be able to manage key aspects of your condition.

Main menu

- Profile
- Library
- Goals and plans
- Diary
- Existing support
- Help

My profile

Tell us a bit about you, your skin condition(s) and what you want from the app.

About me

First name
Last name
What do you like to be called?

About my skin condition

What is the name of your skin condition?
How many years have you lived with your skin condition?
When was your skin condition identified? [childhood, adolescence, adulthood]
Was your skin condition diagnosed by a doctor [Yes/No]

[+ skin condition]

My app preferences

Dark mode

App notifications

Motivational messages

Content for MiDerm App – Library

Library

In this section, you will learn about:

- The link between how you think, feel and act (psychology) and your skin.
- Psychological processes (thoughts, feelings and behaviour links) that are common across skin conditions.
- An evidence-based model of behaviour change called the COM-B Model.
- What habits are, how we form and sustain them.

Psychology and the skin

We all know that skin conditions can impact on well-being.

But did you know…

- Thoughts, feelings and behaviours are what we call psychological ‘processes.’
- How you think and feel about your skin condition can influence how you respond to it and the symptoms you have.
- The psychological impact is common across a range of skin conditions. Often people think that their experience is unique, but our research on the impact of skin conditions has shown that most people experience similar feelings (e.g., embarrassment, shame, disgust, worry, distress etc.) whether they have a common or rare skin condition. The same is true for the physical, social, financial and daily impact of skin conditions. Read our paper here.

The link between thoughts, feelings and behaviour

Everyone has **thoughts** about their skin condition relating to:

- Symptoms.
- Causes and triggers.
- Control over it, your beliefs about treatments and ways of self-managing.
- Its duration (acute/short-term or chronic/long-term).
- Its impact on you and your life.

People often hold untrue or unhelpful thoughts about their skin condition, for example:

"My skin condition is a curse."

"There is nothing I can do to stop it."

"My skin rules my life."

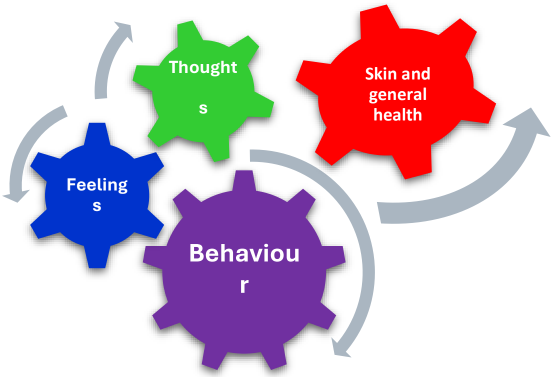
These thoughts commonly lead to negative **feelings**, such as:

- Shame and embarrassment.
- A loss of control.
- Helplessness and hopelessness.
- Feeling low, anxious or depressed.

These thoughts and feelings can influence **behaviour** and what people do to cope with their skin condition. We call these behavioural 'strategies' for coping with negative thoughts and feelings. Some behaviours may be helpful in the short or immediate term but are harmful in the longer term because they reinforce negative thoughts and feelings, keeping the person trapped in a negative cycle. For example:

- People try to stop thinking about their skin condition, but often end up focusing on it more, which can be frustrating and tiring.
- People stop seeing friends and family to avoid feeling self-conscious and embarrassed, but this can lead to feelings of loneliness and isolation.

People use unhealthy ways (e.g., drinking lots of alcohol and comfort eating) to escape their reality, but these health-threatening behaviours can cause skin flares, worsen symptoms and can be bad for our general health and well-being.



Health behaviour

We all know that the actions we take to influence our health and well-being can be either good for our health (health-protective) or bad for our health (health-threatening).

But did you know…

- Many skin conditions, such as acne, psoriasis and eczema, involve inflammation.
- Inflammation occurs when your immune system is trying to protect you against something it thinks could be harmful and cause infection or illness. But sometimes it can mistake your healthy skin cells for foreign cells. The removal of these foreign cells and rapid production of new skin cells often shows as visible symptoms on the surface of your skin (e.g., raised and thick plaques or red and very dry skin).
- Health-threatening behaviours can increase the level of inflammation in the body, which can:
    - Trigger some skin conditions.
    - Worsen symptoms.
    - Increase the risk of other serious long-term health conditions (e.g., heart disease and weight gain) that are related to some skin conditions. Weight gain also increases inflammation causing a vicious cycle, hence the need to stay lean.

We know most people do not receive professional support or advice they need to make appropriate and lasting changes to their lifestyle, hence the MiDerm app was developed.

The COM-B Model of behaviour change (Michie et al., 2011)

The COM-B Model is an evidence-based model in psychology that explains three key drivers of behaviour. COM-B stands for: **C**apability, **O**pportunity, **M**otivation – **B**ehaviour.

Capability means your ***physical*** and ***psychological*** capacity to perform a behaviour.

- Physical capability – physical strength and stamina.
- Psychological capability – knowledge and skills.

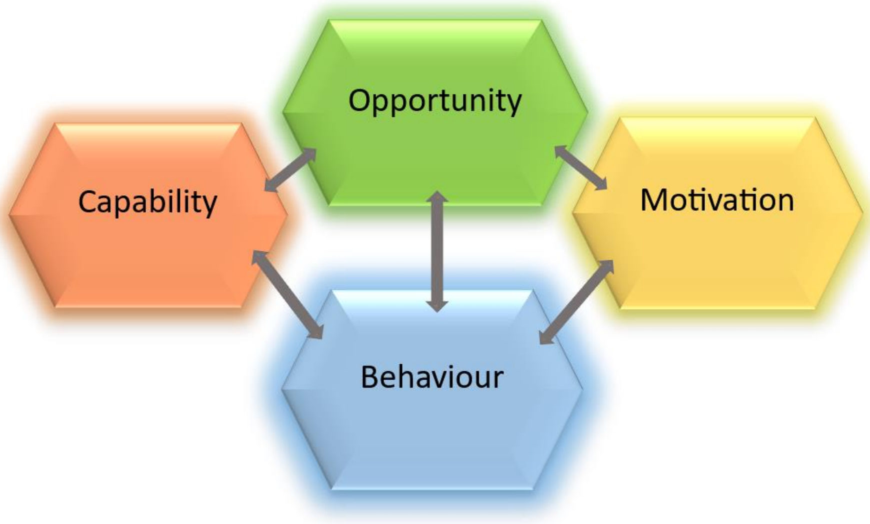
Opportunity relates to the external ***physical*** and ***social*** factors that can affect behaviour.

- Physical opportunity – factors in your environment, such as time, money and location, that influence your ability to perform a behaviour.
- Social opportunity – social factors, such as social and cultural norms, can affect your ability to enact a behaviour.

Motivation is the internal processes that occur within the brain which influence your decisions and actions. Motivation can be divided into:

- Reflexive motivation – consciously thinking about, planning and evaluating a behaviour (or situation) before you engage in it.
- Automatic motivation – you engage in behaviour automatically due to your desires and impulses.

The components of the COM-B model can all influence one another. People are more likely to change their behaviour if they feel they have the ability, opportunity and motivation to do so.



Habits

We all know that…

- Changing your behaviour can be difficult.
- Breaking old habits and forming new ones takes time, effort and energy.
- Lapsing back into old patterns of behaviour is usual.

But did you know…

- Habits are automatic *processes* that are prompted by cues in our environment. They typically involve a series of smaller actions that lead to the desired behaviour. For example, you might think of making a cup of coffee as one action when in fact a sequence of actions (e.g., filling and boiling the kettle and getting milk from the fridge) needs to occur to make the coffee.
- The time it takes to form a habit varies from person to person, but behaviours that are consistently and frequently repeated (e.g., at the same time every day) are more likely to become strong automatic habits.
- A 'lapse' or 'slip' is different to a 'relapse.' Lapses or slips in your behaviour occur because the cues in our environment prompt you to enact the behaviour even if we intend not to do it. The automatic process overrides our conscious intention. Behavioural slips may be a one-off or temporary, whereas a relapse is a full return to the initial behaviour.

Be your own psychologist….

- **Assess** what behaviour you want to do more or less of (e.g., I want to get better at applying my emollients).
- **Think** about:
    - How can I make it easy (in your mind's eye, visualise yourself doing the task)
    - Make the cues in your environment work for you, they could prompt you to act (e.g., being able to visibly see the bottle of cream instead of it being in my drawer).
    - Focus on the best reasons for making a change (e.g., help to make my skin less dry and itchy; I will feel more in control of my skin condition; I won't have to lie to my doctor anymore about using the cream).
- **Plan** how you will form or break the habit:
    - Set a specific goal (e.g., I will apply my emollient once per day).

    - Create an action plan (e.g., I will place the bottle of emollient on the floor next to the shower and apply the cream immediately after my morning shower).
    - Create an 'if-then' plan to help cope with and overcome lapses. For example: **If…** I forget to apply my emollient in the morning, **then…** I will not beat myself up and I will think of the next best time to apply the cream (e.g., when I get ready for bed).
- **Evaluate** your progress. Focus on what worked well and what you could do better (e.g., my plan works well when I am at home, but not so well on the mornings I get up early to go the gym because I forget to put my cream in my bag. In future I will buy another bottle of emollient and keep it in my bag to use after showering at the gym).

Pause – what did you learn in this section?

Consider taking a moment to reflect and note down the 3 key learning points from this section in your notes. What was the most helpful thing?

Content for MiDerm App – Patient Stories

Patient Stories

When developing MiDerm we spoke with a range of people to find out about their experiences of living with skin a condition.

In this section, you will learn:

- How other people manage all aspects of their skin condition, mainly the psychological impact.
- Tips and strategies for living well with a skin condition.

Martin's story

Martin has psoriasis. Listen to how he copes with psoriasis.

Neesha's story

Neesha has acne and scarring. Listen to how she lives well with acne.

Amie's story

Amie has eczema. Listen to how Amie came to accept and live well with eczema.

Sue's story

Sue has psoriasis. Listen to how she manages psoriasis effectively.

Lex's story

Lex has rosacea. Listen to how she copes effectively with rosacea.

Lex has a blog all about living with Rosacea. You can visit Lex's blog here.

Pause – what did you learn in this section?

Consider taking a moment to reflect on what you have learned in this section and note down the 3 key learning points in your notes. What was the most helpful thing?

Content for the MiDerm App – Diet

Diet

In this section, you will learn:

- The basic principles of a healthy, balanced diet.
- How your diet can affect your health generally and specifically your skin.
- Common myths about diet and the skin.
- Foods that are beneficial for the skin, including the Mediterranean diet and SkinFood approach.
- Tips for maintaining a healthy, balanced diet.

What do we mean by a balanced diet?

The term ‘diet’ means the food you eat. To eat a healthy diet means to get a balance of the following food groups:

- Protein.
- Carbohydrates.
- Fats.
- Fruit and vegetables, which contain key vitamins and minerals.

Everyone will need different amounts of these foods depending on their health and lifestyle.

No foods are ‘bad,’ but some foods can lead to poor health, if eaten regularly or in large amounts, and need to be eaten in moderation. This typically includes foods that are:

- **Processed**. This means the food is altered in some way when it is being prepared, usually to make it tastier or last longer. Usually, the more steps in the process the less healthy the food.
- **High in saturated fat**. It is important to include some fat in your diet because fat is a source of energy and helps to protect your organs, balance your hormones and absorb vitamins A, D and E. The mainstream thinking is that foods that are high in saturated fat should only be eaten in small amounts because they can lead to high cholesterol and increase the risk of heart disease, but some researchers and

clinicians argue that carbohydrates are worse for you than fat, hence it is important to eat everything in moderation.

- **High in refined sugar**. Sugar is naturally found in many foods, but when sugar is processed, it is 'refined' and becomes more concentrated, contains less nutrients and is higher in calories. Foods that contain refined sugars cause a rapid rise in blood sugar levels and give you a burst of energy. The energy from these foods is released and burned off quickly and this can leads to an energy 'slump' where you feel tired and your body craves more food. You should always think about reducing your sugar intake, you don't need extra sugar beyond that which your carbohydrate intake gives you.

Why is eating a healthy, balanced diet important for people living with skin conditions?

We all know… What you eat and drink is important for our general health. Eating a balanced diet can help to prevent weight gain and serious health conditions, such as:

- Obesity.
- Type II diabetes.
- Heart disease.

But did you know…. The food you eat can also affect our skin health. Generally, foods that are processed and high in saturated fat and sugar increase inflammation, which can trigger and worsen some skin conditions (e.g., psoriasis, rosacea and acne).

However, the links between certain foods and skin conditions are not yet fully understood by researchers and people report different experiences; some say their diet effects their skin, but others do not.

Myths about diet and skin conditions

With limited evidence available, there are some myths about the role that some foods play in common skin conditions. The table below summarises some common diet myths against the scientific evidence:

Skin and diet myths	What the science says

“I have acne, I can’t eat dairy”	**Skimmed** cow’s milk can make acne worse for some people. People with acne might want to consider limit how much skimmed milk they drink, but it is not necessary to cut out diary and it is fine to eat other dairy products (e.g., cheese and yoghurt) in small amounts.
“I have rosacea, I shouldn’t drink tea or coffee”	Caffeine found in tea and coffee does not cause rosacea flares. Research shows that people experience less redness when they leave their tea and coffee to cool down before drinking. It is, therefore, the temperature of hot drinks that people with rosacea need to be mindful of to avoid triggering the skin.
“I have rosacea, I can’t drink alcohol”	Alcoholic drinks should always be consumed in moderation. Some alcoholic drinks, including (mainly red) wine and beer, contain histamines, which can cause redness and flushing. People with rosacea do <u>not</u> need to stop drinking alcohol completely, but they might want to limit or avoid some alcoholic drinks that trigger symptoms.
“I have psoriasis, I need to go gluten-free”	Research shows that gluten-free diets are only beneficial for people with psoriasis who have been diagnosed with coeliac disease (an inflammatory condition). People with psoriasis should <u>not</u> go gluten-free unless they have been diagnosed with coeliac disease and a gluten-free diet has been recommended by a doctor.

What should I eat when living with a skin condition?

The Mediterranean Diet

The Mediterranean diet is <u>rich</u> in:

- Fruit and vegetables.
- Oily fish.

- Pulses.
- Wholegrains.
- Olive oil.

The Mediterranean diet is low in:

- Red meat.
- Processed foods, including foods high in refined sugars.

The Mediterranean diet reduces inflammation in the body and has been linked to living longer. Researchers based in London are currently testing whether the Mediterranean diet can improve psoriasis. Find out more about this research here.

The SkinFood approach

SkinFood is a new, flexible and science-based approach to eating for healthy skin, which focuses on eating foods that lower inflammation (anti-inflammatory). SkinFood was founded by Dr Thivi Maruthappu, a consultant dermatologist, nutritionist and researcher based in London, UK. The four key principles of the SkinFood approach are outlined in the table below. Learn more about Dr Thivi's work and new book 'SkinFood' on her website.

The basic principles of the SkinFood approach			
	Principle	**Explanation**	**Examples**
1	Eat to **GLOW**		
	Greens	Fruit and vegetables (of all colours) contain nutrients called antioxidants, which lower inflammation, fight skin damage and ageing.	Spinach, broccoli, carrots, sweet potatoes, tomatoes, pineapple, blueberries, beetroot, plus many more!
	Lean proteins	Protein contains amino acids which helps your muscles, organs and cells to grow and repair.	Fish, meat, eggs and dairy. Plant-based proteins include soya products (e.g., tofu), quinoa, nuts and seeds, lentils and beans.
	Oils & healthy fats	Are high in unsaturated fats, which help to balance blood sugar levels and keep you full. They contain Omega-3 (a type of unsaturated fat) which lowers inflammation and moisturises and brighten the skin.	Olive oil and some other types of oil (e.g., rapeseed). Nuts and seeds (e.g., almonds and walnuts)

			Oily fish (e.g., salmon and mackerel) are high in Omega-3.
	Wholegrains	Are ‘complex’ carbohydrates which have a low glycaemic index (GI). This means they release energy slowly, which helps stabilise blood sugar levels and keeps you full for longer. They are a source of fibre which supports good gut health and functioning.	Wholegrain breads, pasta and oats. Brown rice, quinoa and bulgur wheat.
2	Eat **pre** and **pro**biotics		
	Prebiotics	Contain ‘gut-friendly’ bacteria.	Some fruits – apples and bananas. Some veg – onions, garlic, leeks. Nuts – cashews and hazelnuts. Wholegrains – rye and barley.
	Probiotics	Are types of fibre that the body cannot digest. They support the growth of good bacteria in the gut.	Live yoghurt, kombucha and fermented foods, such as kefir and sauerkraut.
3	Include **spices** in your diet	Spices can lower inflammation.	Turmeric.
4	Limit refined sugars and alcohol	Refined sugars are defined above. Foods that contain refined sugars and alcoholic beverages increase inflammation. Reducing the intake of these can help to stop skin flares.	Refined sugars – table sugar. Alcohol – beer, cider, wine, spirits.

General tips for eating a healthy, balanced diet that can also support healthy skin:

- Eat all foods in moderation. There is no need to avoid or cut out any foods from your diet unless you have a specific allergy or intolerance and have been advised to do so by a doctor.
- Try to include some protein, low amounts of wholegrain carbohydrates, unsaturated fats and fruit/vegetables in every main meal.
- Eat at least five portions of fruit and veg each day.
- Try to vary the types and colours of the fruit and veg that you eat to support gut health.
- Use spices in your cooking.

- Stay hydrated – aim to drink eight glasses (2 litres) of water per day.
- Limit the amount of alcohol you drink.
- Limit the amount of processed food, especially refined sugars, that you eat.

Learn more about diet and skin conditions:

- Diet in dermatological conditions (melanoma, chronic urticaria and psoriasis).
- A systematic review of diet and acne.
- A review of diet and acne.
- Dietary factors in acne.
- Impact of diet on acne and treatments.
- Lifestyle factors, including diet, in hidradenitis suppurativa.
- The effect of dietary modifications in people with hidradenitis suppurativa.
- Nutrition and the Mediterranean diet in people with hidradenitis suppurativa.
- The impact of diet on psoriasis.
- Dietary habits in people with and without psoriasis.
- The Diet and Psoriasis Project (DIEPP).
- Protective effect of the Mediterranean diet against inflammation and long-term conditions.
- The cost-effectiveness of the Mediterranean diet.
- The Mediterranean diet and skin health.
- Psoriasis and the Mediterranean diet.
- The Mediterranean diet reduces the risk of in men with androgenic alopecia.
- The role of diet as a useful adjunct to standard treatments for non-scarring alopecia.
- Protective effect of the Mediterranean diet in people with cutaneous melanoma.
- Inflammation and diet in women with skin conditions.

Pause – what did you learn in this section?

Consider taking a moment to reflect on this section and write down the 3 key learning points in your notes. What was the most helpful thing?

Content for MiDerm app – Alcohol

Drinking alcohol

In this section, you will learn:

- How drinking alcohol can affect your health generally and specifically the skin.
- The current recommendations for drinking alcohol.
- Tips for drinking less alcohol.

Why is drinking less alcohol important when living with a skin condition?

We all know… drinking lots of alcohol, especially binge drinking, is bad for your health and can cause serious health conditions, such as:

- Liver disease.
- Heart disease.
- Strokes.
- Some types of cancer.

Did you know…

- People with skin conditions often drink more alcohol than people without skin conditions. High levels of alcohol use disorder have also been seen in people with skin conditions, such as psoriasis.
- Drinking too much alcohol can have physical, psychological and social consequences for people living with skin and conditions.

Physical impact:

- Drinking more than the recommended amount of alcohol increases the risk of developing psoriasis in people who may have that genetic tendency.
- Drinking alcohol can worsen symptoms of skin conditions in different ways:
    - Alcohol is dehydrating; it can dry out the skin and make conditions like psoriasis worse.
    - Drinking alcohol can weaken the skin barrier. This can cause the skin to lose moisture and become dry. The skin is also less protected from chemicals,

allergens and irritants in the environment that can trigger some skin conditions or worsen symptoms.

  - Alcohol increases inflammation in the body, which can worsen symptoms of inflammatory skin conditions, such as psoriasis and acne.
  - Drinking too much alcohol stops our immune system from working well. This means that wounds caused by skin conditions, or scratching the skin, can take longer to heal and may become infected.
  - Alcohol causes blood vessels to get bigger, which can increase the risk of rosacea and worsen symptoms of redness and flushing.
  - Drinking too much alcohol can cause liver disease, which can make the skin itchy.
  - Alcohol is made from natural starch and sugar and contains calories. Some alcoholic drinks, such as cider, have a high calorific content. Mixer drinks (e.g., tonic water) also contain calories. Drinking lots of high-calorie alcoholic and mixer drinks can increase the risk of obesity, which can cause some skin conditions and make skin symptoms worse (e.g., psoriasis).
  - If you drink less alcohol, levels of inflammation in the body are lower and your immune systems works better, which can improve skin and general health.

Impact on treatment:

Drinking alcohol can make medications for skin conditions less effective. People with psoriasis, for example, should not drink alcohol when taking Methotrexate because both can cause liver damage.

Psychological impact:

Some people drink alcohol as a way of coping with their skin condition and the difficult feelings associated with it. Many people say that drinking alcohol helps to relive stress and anxiety. This is because alcohol is a ‘depressant’ and slows down the chemical messengers (neurotransmitters) in the brain which influences how you think, feel and behave. However, these effects are temporary and drinking alcohol can result in even lower mood, depression and anxiety in the long term.

Social impact:

People with skin conditions often report feeling embarrassed, ashamed or self-conscious of their skin condition and feel anxious around others or in social situations.

We know that drinking alcohol can make people feel more self-confident in the short term. This is because alcohol slows the part of the brain which controls our impulses, which can make you feel more relaxed and more likely to say or do things that we usually would not. Whilst drinking alcohol might give some people the confidence to interact socially, it can make social anxiety worse and can cause some people to become aggressive or violent.

Guidance on drinking alcohol

It is recommended to drink no more than 14 units of alcohol (e.g., six pints of beer or six medium glasses of wine) per week and to spread alcoholic drinks out evenly across 3 or more days.

Drinking heavily over a short period of time is known as ‘binge’ drinking and is not recommended. Drinking over 8 units in a day for men, or 6 units for women, is considered to be binge drinking.

Small amounts of some types of alcohol are better for your health than others clear spirits, like vodka, are lower in calories (kcal) per gram than beer.

We used to think that drinking red wine in small quantities (e.g., 3 to 4 small glasses per week) may have some health benefits, such as reducing blood pressure. This is because red wine contains nutrients called ‘antioxidants’ which stop the production of harmful molecules called ‘Free Radicals’ that can damage cells, increase inflammation and cause skin ageing and some serious health conditions (e.g., cancer). However, we now know that the antioxidants in red wine would only decrease inflammation if several glasses a day were consumed, which would be detrimental to health overall due to calorie and alcohol content.

Tips for cutting down on drinking alcohol:

Be your own psychologist…

- **Assess** when you are more likely to drink alcohol (e.g., when feeling anxious about socialising).

- **Think** about:
    - Why you drink alcohol.
    - Your reasons for drinking less alcohol.
    - How you can make it easier to reduce your alcohol intake (visualise the benefits of drinking less alcohol)
- **Plan** to cut down gradually and stop:
    - Think of something you could do instead of drinking alcohol and create an action plan.
    - Create an 'if-then' plan to help cope with cravings, triggers, difficult feelings and during social events. For example: **If…** I feel low because of my skin condition, **then…** I will call a friend instead of pouring a drink.
- **Evaluate** your progress. Focus on what worked well and what could be done better.

Seek support:

- Speak to a professional, such as your GP, for support in cutting down.
- Let your family, friends and colleagues know that you intend to cut down on drinking alcohol so that they can support you.

Other things to consider:

- Set a limit for how much alcohol you can drink each week.
- Set a budget for how much you want to spend on alcohol each week.
- Be selective about the type of alcohol you drink.

Learn more about drinking alcohol and skin conditions:

- The effect of drinking excess alcohol on the skin.
- The relationship between alcohol and psoriasis severity
- The effect of drinking alcohol and other lifestyle factors on inflammatory skin conditions, such as acne.
- Alcohol increases the risk of developing rosacea.
- Alcohol reduces the effectiveness of some medications for psoriasis.
- Are mindfulness-based therapies effective at reducing alcohol consumption?
- Can Acceptance and Commitment Therapy help reduce alcohol use?

Pause – what did you learn in this section?

Consider taking a moment to reflect and note down the 3 key learning points in your notes.

What was the most helpful thing?

Content for MiDerm App – Smoking

Smoking

In this section, you will learn:

- How smoking cigarettes can affect skin conditions.
- Strategies for stopping smoking.

Why is stopping smoking important when living with a skin condition?

We all know that smoking cigarettes is bad for health and can cause:

- Serious health conditions (e.g., heart disease and different types of cancers).
- Early death. On average, non-smokers live 10 years longer than smokers.

But did you know…

- Smoking is specifically linked to some skin conditions. People who smoke, for example, are at higher risk of developing psoriasis, hand eczema, androgenetic alopecia. Smokers with psoriasis and hidradenitis suppurativa (HS) are also likely to experience more severe symptoms than non-smokers.
- Cigarettes contain additive chemicals (i.e., nicotine) and harmful substances (e.g., tar) that can cause inflammation, which can trigger and worsen some skin conditions (e.g., psoriasis, eczema).
- Smoking can weaken the skin barrier. When this happens, the skin loses moisture and becomes dry. The skin is also less protected from things in the environment (e.g., pollen, soaps) that can irritate the skin and trigger or make eczema symptoms worse.
- Smoking can affect how some skin treatments work and make them less effective.
- Stopping smoking is one of the most helpful things you can do to improve skin health by reducing inflammation and other health risk factors. Make the decision today!

Tips for stopping smoking:

- Be your own psychologist:
  - **Assess** when you are more likely to smoke (e.g., when you are stressed or socialising, or when you see cues such as an ash tray or cup of coffee or tea).

    - **Think about:** what, if anything, you like about smoking but also why it is important to you to stop. You can have both feelings; it's important to understand your specific reasons for smoking and stopping. Visualise the benefits of not smoking.
    - **Plan** to cut down gradually and stop:
        - Think of something you could do instead of smoking and create an action plan.
        - Create an 'if-then' plan to help you overcome cravings, triggers and difficult feelings. For example: **If…** my colleagues invite me outside for a cigarette break, **then…** I will go for a 5-minute walk to avoid the temptation and help improve my mood.
    - **Evaluate** your progress. Focus on what worked well and what could be done better.

- Seek support from others…
    - Think about *who* can support you and *how* they can support you with your goal.
    - Once you have set your goal and made a plan, you might want to tell your family, friends and colleagues and let them know how they can best support you to achieve your goal.
    - Ask your GP for help and advice.
    - Find your local stop smoking service.

Learn more about smoking and skin conditions:

- The effect of smoking on skin.
- Being a smoker and overweight can worsen symptoms of androgenetic alopecia.
- Cigarette smoking is a risk factor for psoriasis.
- Smoking can weaken the skin barrier and make it more sensitive to irritants.
- The effect of smoking on inflammation in skin conditions.
- The association between cigarette smoking and eczema.
- The impact of smoking on treatments for eczema.
- Can mindfulness help people to stop smoking?

- Does one-to-one counselling help people to stop smoking?
- Can exercise help people to stop smoking?
- Sleep disturbances and smoking.

Pause – what did you learn in this section?

Consider taking a moment to reflect and note down the 3 key learning points in your notes.

What was the most helpful thing?

Content for MiDerm app – Physical Activity

Physical Activity

In this section, you will learn:

- How physical activity and exercise can benefit your skin and general health.
- What stops people with skin conditions from taking regular exercise.
- Tips for getting more active.

What do we mean by physical activity and exercise?

Physical activity is any movement that makes your muscles use energy. Exercise is planned activity to improve or maintain your health and well-being.

Why is being physically active important when living with a skin condition?

We all know that moving our body is essential for our physical and mental health.

But did you know keeping physically active can also benefit the skin, and help people to overcome some of the psychological and social challenges of having a skin condition:

Physical benefits

- Reduce inflammation and the risk of early death and serious health conditions (e.g., heart disease and type II diabetes), which in some people are related to some skin conditions.
- Strengthen and protect bones and joints, lowering the risk of inflammatory joint conditions that are linked to skin conditions (e.g., psoriatic arthritis), and other conditions, such as osteoarthritis (bone disease).
- Improve mobility, which is sometimes limited by some skin conditions (e.g., Pachyonychia Congenita).
- Support weight management. Being overweight can increase inflammation and the risk of serious health conditions, including some skin conditions (e.g., psoriasis). Keeping active while eating well can prevent weight gain, which helps to control levels of inflammation and reduce the risk of developing some skin and other health conditions. Keeping active can also support fat loss in people who are overweight, which can lower inflammation and improve psoriasis severity.

Psychological benefits

- Exercise can boost your mood and reduce stress through the release of chemicals called 'endorphins' and chemical messengers (neurotransmitters) called 'serotonin,' both are involved with your reward system and help you to feel good.
- Prevent common mental health conditions, such as depression and anxiety, by lowering inflammation.
- Improve sleep quality by resetting the body's sleep-wake cycle (circadian rhythm).
- Improve self-esteem and confidence.

Social benefits

- Keeping you socially active; this is known to reduce stress and off-set feelings of loneliness and social isolation.

How much activity is enough?

Physical activity guidelines recommend how much, how often and how hard activity should be performed. This includes a mix of activities that help to reduce sitting time and improve our:

- Strength (e.g., lifting weights or resistance training, where you push or pull against an object or use your own body weight).
- Overall conditioning:
    - Aerobic activities (e.g., walking, swimming, running and cycling) that increase heart and lung health.
    - Activities that stretch your muscles (e.g., yoga) and strengthen your core (e.g., pilates), which help to improve joint health and mobility.

Research in this area is ongoing and new findings may show different results to the current advice. A recent study, for example, found that taking part in moderate and vigorous physical activity lowers the risk of serious health conditions (e.g., heart disease) whether people spread their activity out over a week or take a 'weekend warrior' approach and complete their activity in two days.

Often adults do not meet these recommendations and lead inactive lifestyles. Adults with long-term health conditions are less likely to be physically active than people without health constraints. People with psoriasis, for example, exercise less often and at lower intensity than people without psoriasis. Those who have more severe psoriasis exercise even less than people with mild psoriasis.

Why don’t people with skin conditions take part in physical activity?

- Physical symptoms (e.g., pain, itch, fatigue and poor mobility) caused by their skin condition or comorbidities (e.g., inflammatory skin and joint conditions such as psoriasis and psoriatic arthritis).
- Thinking or fearing that exercise will make symptoms worse (e.g., itch, pain).
- Feeling embarrassed about their skin condition and worry about being judged or excluded by others in public spaces (e.g., being asked to leave the swimming pool because of their skin).
- Low motivation to exercise.
- Having to structure exercise around their skin condition (e.g., having to go for a run early in the morning or later in the evening to avoid sun exposure).
- Inappropriate clothing (e.g., clothes are too tight, revealing, or are made of materials that irritate the skin).

Tips for keeping physically active:

- Any form of movement is good – movement that makes you out of breath but able to hold a conversation is especially good – so find something you enjoy.
- Find a place where you feel psychologically ‘safe’, for example not being judged, and physically comfortable to move your body.
- If you are unsure, consider asking a professional for help and support.

Be your own psychologist…

- **Assess** when you are more or less likely to take part in physical activity or exercise.
- **Think** about why you want to be more physically active. Visualise yourself taking part in an activity.
- **Plan** to be more physically active:

    - Think of an activity or type of exercise that you want to do and create an action plan.
    - Create an ‘if-then’ plan to help keep physically active when challenges arise. For example: **If…** I feel too tired to go for the run I planned, **then…** I will go for a long walk instead.
- **Evaluate** your progress. Focus on what worked well and what could be done better.

Monitor your progress:

    - Set a goal to work towards – start small and build up gradually.
    - Make a specific plan to follow that you can build into your daily routine.
    - Think about what might make it hard to reach your goal and create an ‘if-then’ plan for how you will overcome these challenges.
    - Reflect on your progress focus on what you are doing well (try to avoid comparing yourself to others), celebrate your achievements and reward yourself.

Learn more about goal setting, action planning and ‘if-then’ plans here.

To stay motivated, consider:

- Finding a buddy to exercise with or work with a professional.
- Trying different activities to avoid getting bored and keep challenging yourself.
- Getting your clothes, trainers or any specific equipment ready beforehand – being prepared will make you more likely to do what you planned.
- Joining a team, group or take part in a class.

Learn more about skin conditions and physical activity:

- Evidence on physical activity and exercise in people with psoriasis.
- How more intense types of physical activity can help to reduce the risk of psoriasis.
- The link between keeping active and a lower risk of heart disease in people with psoriasis.
- A new group walking programme that researchers at the University of Manchester are developing for people with psoriasis.

- The benefits of resistance training for people with psoriatic arthritis.

Pause – what did you learn in this section?

Consider taking a moment to reflect and note down the 3 key learning points in your notes.

What was the most helpful thing?

Content for MiDerm App – Sleep

Sleep

In this section, you will learn about:

- The importance of sleep for our general health and skin conditions.
- Factors that influence sleep.
- Things you can do to improve your sleep.

Why is getting enough quality sleep important when living with a skin condition?

We all know that… getting enough sleep is important for overall health. Sleeping enough and sleeping well can help to reduce your risk of developing serious long-term health conditions, such as:

- High blood pressure.
- Type-2 diabetes.
- Heart disease.
- Obesity.

We all know that… getting enough and good quality sleep is important for daily functioning. Not getting enough sleep, or having poor quality sleep, can have a negative impact on:

- Thinking or cognitive functioning – poor sleep can lead to poor concentration, memory and processing of information and affects your ability to make decisions.
- Emotions – poor sleep can lead to low mood, which can make some skin conditions worse. It can also increase the risk of some psychological conditions (e.g., anxiety and depression). Poor sleep leads to low mood and low mood leads to poor sleep.
- Behaviour – poor sleep leaves you feeling tired and fatigued. When tired, you tend to exercise less and crave more food. The body craves more unhealthy foods that are high in salt, sugar and saturated fat because they cause a spike in blood sugar levels and give you a quick but short energy boost. However, unhealthy, sugar filled processed foods can increase inflammation and may worsen symptoms of some skin conditions.

Not getting enough sleep, or having poor quality sleep, also has physical consequences and can affect the skin by:

- Dehydrating the skin, which leads to dryness and worsens some skin conditions, such as eczema.
- Weakening the immune system, which means that wounds caused by a skin condition, or scratching, may take longer to heal.
- Increasing inflammation, which can trigger and worsen the symptoms of inflammatory conditions (e.g., psoriasis).

How much sleep is enough?

Did you know… the NHS recommends sleeping 7 to 9 hours each night. You may get away with less than that in the short-term but over time it creates a sleep deficit which cannot easily be made up and leads to more sleeplessness.

Getting enough sleep is important for the management of skin conditions, but many people struggle to fall asleep, or wake up during the night or early in the morning, because of discomfort caused by painful and itchy skin. This often causes people to feel sleepy in the daytime.

Why do people with skin conditions struggle to sleep?

There are many reasons why people with skin conditions struggle to get enough quality sleep:

- The skins barrier naturally becomes weaker overnight, which means that irritants, such as dust, or materials in clothing or bedding, are more likely to trigger itch.
- The immune system performs at its lowest overnight, which can mean itching becomes worse when trying to sleep.
- The body releases heat at nighttime, which helps you fall asleep. In some skin conditions, such as psoriasis, the skin doesn't release heat very well, and this can make it more difficult to fall asleep.
- Sweating occurs because of increased body temperature. Sweating during the night can make itch worse, which causes people to wake up and/or scratch their skin

periodically without even realising it. This interrupts the sleep cycle called the REM cycle, leading to sleep deficits.

- People often report feeling stressed because of their skin condition and stress can impact how well and how long we sleep for.
- There are three parts to sleep that can be affected, getting off to sleep, staying asleep and waking too early and different factors affect each stage.

Tips for improving sleep:

Be your own psychologist…

- **Assess** when you are more likely to sleep badly, identify any triggers to each stage above.
- **Think about:**
    a. Why you sleep badly, remembering that sometimes there is not an obvious reason.
    b. What helps you to sleep better.
- **Plan** how you will improve your sleep. See the list of tips below for inspiration.
- **Evaluate** your progress. Reflect on what is working well and what could be improved.

General tips for sleeping well:

- Look after you skin:
    - Take any medications for your skin condition as prescribed by your doctor.
    - Use a moisturiser before you go to bed to help with itching overnight.
    - If you continue having trouble sleeping, speak to your pharmacist or GP who may be able to recommend short-term medications or CBT therapy to help you sleep better.
- Consider your sleeping environment:
    - Keep your bedroom dark, cool and quiet.
    - Make sure your mattress, pillows and covers are made of materials that do not trigger itching. Many people report that natural cottons, satin or silk (if you can afford it) are most comfortable on their skin.
- Consider your behaviour:
    - Think about what you eat and drink and when:

        - Only drink caffeinated drinks (e.g., tea and coffee) in the morning. Caffeine is a stimulant which can cause you to stay awake for longer. Caffeine can stay in your system for up to 12 hours after drinking, so it is best to avoid drinking caffeinated drinks in the afternoon and evening to improve sleep.
        - Drinking alcohol can have a negative impact on sleep quality by reducing the amount of time that you spend less in deep, restorative sleep called Repetitive Eye Movement (REM) sleep cycles. Getting enough REM cycles is important because it helps our brain and body to recover and can help to lower the risk of serious health conditions, such as heart disease. Drinking less alcohol could help to improve the quality of your sleep and general health.
        - Avoid eating big meals late at night, as this can increase body temperature and cause slow digestion, which can make it more difficult to fall asleep.
    - Keep physically active. Exercising regularly can help to improve self-reported sleep quality, insomnia severity and daytime sleepiness. This is because exercise builds our ‘homeostatic sleep drive’, which is the drive to rest that builds up in your body the longer that you stay awake. Exercise can also relieve stress, which can impact the quality of your sleep.
    - If you smoke, consider quitting. Nicotine is a chemical in tobacco and is a stimulant, and so some people may find that stopping smoking can improve sleep. Smoking cigarettes and being overweight is associated with some sleep disorders, such as sleep apnoea.
    - Form a new routine:
        - Form a bedtime routine that you do consistently and involves relaxing activities that help you to fall asleep more easily and improves your general well-being (e.g., journalling, reading and meditating).
        - Reduce screentime before bed. Put your phone down at least one hour before you go to bed and use the time to relax instead.
        - Go to bed and wake up at the same time each day.

Learn more about sleep and skin conditions:

- Sleep disturbance in people with eczema.
- People’s experience of psoriasis and sleep disturbance.
- Factors that predict poor sleep in people living with psoriasis.
- Skin conditions and sleep in adults.
- Factors affecting sleep in people with long-term inflammatory skin conditions.
- The burden of poor sleep and fatigue in people with eczema.
- Why do some people with long-term skin conditions struggle to sleep?
- Long and short term consequences of poor sleep quality.

Pause – what did you learn in this section?

Consider taking a moment to reflect and summarise the 3 key learning points in your notes.

What was the most helpful thing?

Content for MiDerm App – Fatigue

Fatigue

In this section, you will learn:

- What is fatigue?
- How fatigue can affect people living with skin conditions.
- Tips for managing fatigue.

What is fatigue?

In 1996, two scientists, Krupp and Pollina, described fatigue as "an overwhelming sense of tiredness, lack of energy, and a feeling of exhaustion."

Fatigue can affect people physically and psychologically. Fatigue can be:

- Physical – "my body feels sluggish" or "my leg muscles ache after my exercise class."
- Cognitive – "my brain is tired after that exam" or "I can't think straight"
- Emotional – "I feel emotionally drained after a therapy session."

Fatigue is not a health behaviour, but fatigue affects many health behaviours and vice versa.

What is known about fatigue and skin conditions?

We know that…

- Fatigue is common in people living with skin conditions. However, research has, so far, focused mainly on fatigue in people with inflammatory conditions, including eczema, psoriasis and psoriatic arthritis, an inflammatory joint condition that is linked to psoriasis.
- Fatigue can have a major impact on everyday life. Fatigue often stops people from doing daily, social and leisure activities, including work and studying.

But did you know…

- Fatigue is often described as one of, if not, the most troubling symptom of these long-term conditions.
- People who have psoriasis and psoriatic arthritis tend to report higher levels of fatigue than people who have psoriasis alone, or no existing health condition.

- Pain, sleep disturbance and depression all affect fatigue. Evidence suggests genetics may play a role and fatigue may occur because of our bodies immune and stress responses. However, research on this topic is limited and, therefore, the exact causes and best treatment of fatigue are still unknown.
- Disease activity (the spread of symptoms) and severity (how bad symptoms are) are not always related to fatigue. Some people with rheumatoid arthritis, for example, report high levels of pain and fatigue even though their condition is less active and levels of inflammation are low. However, studies have found different results and more research is needed.
- Some treatments, including Biologic drugs, have been found to help ease fatigue in people with psoriasis.

Tips for managing fatigue:

Be you own psychologist…

- **Assess** when you experience fatigue.
- **Think about** why you feel fatigued. Try to weigh up if it’s mainly physical, emotional or cognitive fatigue (sometimes it’s all three, or not possible to separate them).
- **Plan** how you will cope with feelings of fatigue.
- **Evaluate** your progress. Reflect on what is working well and what could be improved.

Seek support from others, including:

- A qualified psychologist, therapist or counsellor can help you to talk about and cope with psychological factors linked to fatigue, such as stress, anxiety and low mood.
- Your GP or other specialist medical professionals. Speak to a doctor who can advise on treatments that could help to manage your fatigue and other symptoms.

Keep physically active:

- Doing physical activity or exercise makes your body release chemicals called ‘endorphins,’ which improve your energy levels. Pace yourself, doing too much in one day may cause rebound and have a heavy impact the next day. Gradually building up is a better plan.

- Taking part in regular activity can help with weight loss and people who carry less body weight generally report having more energy than people who are overweight or obese. If you are overweight, losing weight could help you to feel more energised. You may want to seek professional support to make sure weight loss is suitable, safe and effective for you.
- Exercise reduces stress and improves mood, which could also help to lessen fatigue.

Stay hydrated. You often feel fatigued when your body is dehydrated. Drinking water regularly throughout the day will help to prevent dehydration and support your energy levels.

Consider what you eat and when. The types of foods we eat and when we eat in the day can affect our energy levels.

- Eating foods with a high glycemic index (GI) or that are high in refined sugar can cause a ‘spike’ in your blood sugar levels and give you a sudden burst of energy. However, you quickly burn the energy from these foods, leading to energy ‘slumps.’ It is, therefore, important to eat these foods in small amounts and instead try to eat low GI foods, including ‘complex’ carbohydrates, which release energy slowly, to avoid the energy spike-slump cycle.
- Eating a healthy, balanced breakfast can stabilise your blood sugar levels across the day, which helps to avoid the energy spike-slump cycle.
- People often feel tired after eating a big meal, especially meals with lots of carbohydrates. Eating 3-4 smaller/lighter meals across the day might help to avoid this.
- Remember, there is no single perfect diet, we are all different and different things suit us differently. When you seek advice about your diet make sure it is from someone qualified and experienced in dealing with long-term health conditions. There is a lot of misinformation around, especially on the internet.

Prioritise sleep. Try to sleep for 7-8 hours per night to reduce feelings of fatigue during the daytime.

Limit the amount of alcohol you drink. Drinking alcohol can have a negative impact on how much and how well you sleep. Drinking a lot of alcohol in a short period of time can also lead to a ‘hangover’ where people commonly experience headaches, tiredness, nausea and increased or decreased appetite. Limiting how much alcohol you drink can help to improve the quality of your sleep and avoid dreaded hangovers!

Reduce your caffeine intake. Caffeine is commonly found in drinks such as coffee, tea and energy drinks. It might sound counterintuitive, but *slowly* reducing how much caffeine you consume overtime might help you to feel less tired and more energised in the long-term.

Learn more about fatigue and skin conditions:

- Rates of fatigue in people with skin conditions.
- Fatigue and psoriasis.
- Fatigue in psoriatic arthritis.
- Fatigue in people with hidradenitis suppurativa.
- Sleep disturbance and fatigue in people with eczema.
- A call for more research on fatigue in people with psoriasis.

Pause – what did you learn in this section?

Consider taking a moment to reflect and write down the 3 key learning points in your notes. What was the most helpful thing?

Content for MiDerm App – Itch and Scratching

Itch and scratching

In this section, you will learn about:

- The factors that commonly affect itch.
- The itch-scratch cycle.
- Evidence-based approaches for managing itch.
- Tips for managing itch and scratching.

We all know that… itch is a common symptom of some skin conditions.

Did you know…

- 'Pruritis' is the medical term for itch.
- Chronic (or long-term) pruritis is a medical condition in itself where itchy skin is the main symptom and lasts more than six weeks.

Factors that can affect itch

People with skin conditions often report a range of environmental, physical and psychological factors that can trigger or worsen itch.

Environmental factors:

- Natural fabrics (e.g., wool) and materials that are made in factories (e.g., nylon), including fabrics that trap heat and do not let the skin 'breathe' (e.g., polyester).
- Metals (e.g., nickel) which are used to make accessories, including jewellery and glasses.
- Chemicals in some household, skin care and make up products, as well as chlorine in swimming pools.

Physical factors:

- Symptoms associated with skin conditions, including dry skin.
- Scratching the skin can also lead to wounds on the skin that release cells that promote healing, but also cause more itching – this is the itch-scratch cycle.

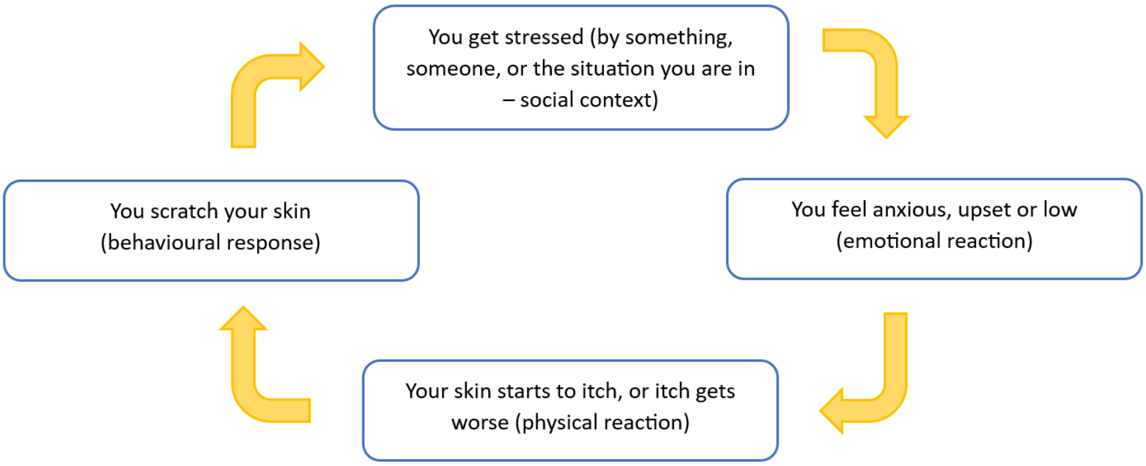
Psychological processes:

Thinking a lot, or thinking negatively, about itch, or worrying about having itchy skin, draws your attention to the sensation which can increase the urge to scratch the skin.

Many people say that itch gets worse when they feel stressed by daily hassles and negative life events. Stress occurs when a person believes they are unable to cope with the situation they are in. Stress affects people physically and psychologically (how they think, feel and behave). The more you itch the more you form the scratch habit.

The itch-scratch cycle

The itch-scratch cycle shows how physical, psychological and social factors are linked:



Evidence-based approaches for managing itch

There are some evidence-based approaches and techniques that can help to ease itch by changing people’s thoughts, feelings and behaviours that might make itch worse. For example:

- **Cognitive Behavioural Therapy** aims to change the way people think about itch in order to change how they behave when their skin gets itchy.
- **Habit reversal training** aims to break unhelpful habits (e.g., scratching) and replace them with neutral or positive actions, such as gently pressing or rubbing the skin to alter the sensation.
- **Relaxation techniques** can be used to help manage stress, which worsens itch.

  - ***Progressive Muscle Relaxation*** is one technique that involves short periods of tensing and relaxing muscles.
  - ***Autogenic training*** is another technique that gets people to focus on and say out loud how parts of their body feel (e.g., “my skin feels calm”), which can reduce feelings of stress and anxiety.
- **Mindfulness** means to be present in the moment and notice what is happening without making any judgement. Mindfulness-based training may help people to change the way they think and feel about itch.

Tips for managing itch and scratching:

Be your own psychologist…

- **Assess** when your skin feels most itchy and you get the urge to scratch. You might find it helpful to keep a written record of the times your skin gets itchy and any factors you think might have contributed.
- **Think** about the reasons why your skin gets itchy.
- **Plan** how you manage your itch and avoid scratching your skin. Do things that you enjoy and support your mental health and well-being.
- **Evaluate** your progress. Think about what is working well and what could be improved.

Seek support from others…

- Find a qualified psychologist, therapist or counsellor who can help you to break the itch-scratch cycle and cope well with your skin condition(s).
- Work with your doctor or dermatologist to find skin care products (e.g., moisturisers) and treatments that can help to reduce itch, which are most suitable for you.

Learn more about itch and scratching

- A review of biological, social and psychological factors in people with skin conditions.
- Causes of itch in atopic dermatitis.
- Effectiveness of a multidisciplinary itch-coping training programme in adults with atopic dermatitis.
- Psychological processes and itch in psoriasis.

- An educational website called ITCH RELIEF to improve itch-related quality of life in adults with eczema, psoriasis and chronic itch.
- The process of habit-reversal therapy for itch.
- A review of psychological therapies for itch.
- The impact of itch on people living with psoriasis.
- Effectiveness of mindfulness in managing itch.

Pause – what did you learn in this section?

Consider taking a moment to reflect and write down the 3 key learning points in your notes. What was the most helpful thing?

Content for MiDerm App – Using treatments

Using treatments

In this section, you will learn:

- How using prescribed treatments correctly can affect skin conditions.
- Strategies for sticking to treatment plans.

Why is it important to use treatments consistently when living with a skin condition?

We all know that using treatments as prescribed by the doctor is important because it gives the treatment the best chance of being effective and controlling or improving symptoms, which can help to improve quality of life.

But did you know…

- ‘Treatment adherence’ means using a treatment exactly as prescribed, at the prescribed time, dose and frequency. Not taking or using treatments as prescribed is known as ‘treatment non-adherence’.
- Having a better understanding of your skin conditions, and how treatments might affect it, will make it more likely that you will stick to a treatment plan.
- What you think about treatments and how you feel about them can determine whether you use them correctly.
- Your mood, and mental health conditions, such as anxiety and depression, can influence how likely you are to stick to a treatment plan. Your mood will fluctuate over time and this might affect your motivation to engage in self-care activities.
- Not taking treatments as prescribed can make symptoms worse and increase the chance of experiencing negative side effects, which may lower your quality of life.
- Support from family and friends can improve treatment adherence, for example, your partner might help you to apply topical treatments, or you may ask your friends to remind you to take your medication at a certain time.
- ‘Shared decision making’ refers to working together with your doctor to discuss and make joint decisions on the best treatment for your skin condition. If you have an open, trusting relationship with your doctor, in which your thoughts and feelings

about treatments are considered, the more likely it is that you will use the treatment prescribed for you.

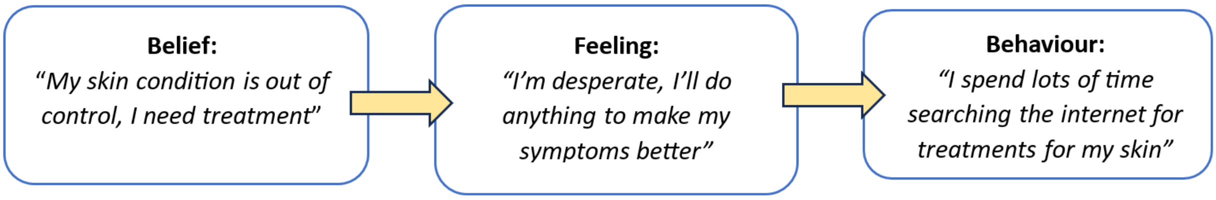
The role of personal beliefs

What you think about your skin condition can influence how you feel and how you respond to it.

Beliefs about skin conditions

What you believe about your skin condition can influence how you manage it. Examples of key beliefs can be found in the ‘Psychology and the skin’ section.

Your thoughts impact your feelings about your skin condition, which can then affect how you behave towards it, including how you use treatments.



Belief:
“My skin condition is out of control, I need treatment”

Feeling:
“I’m desperate, I’ll do anything to make my symptoms better”

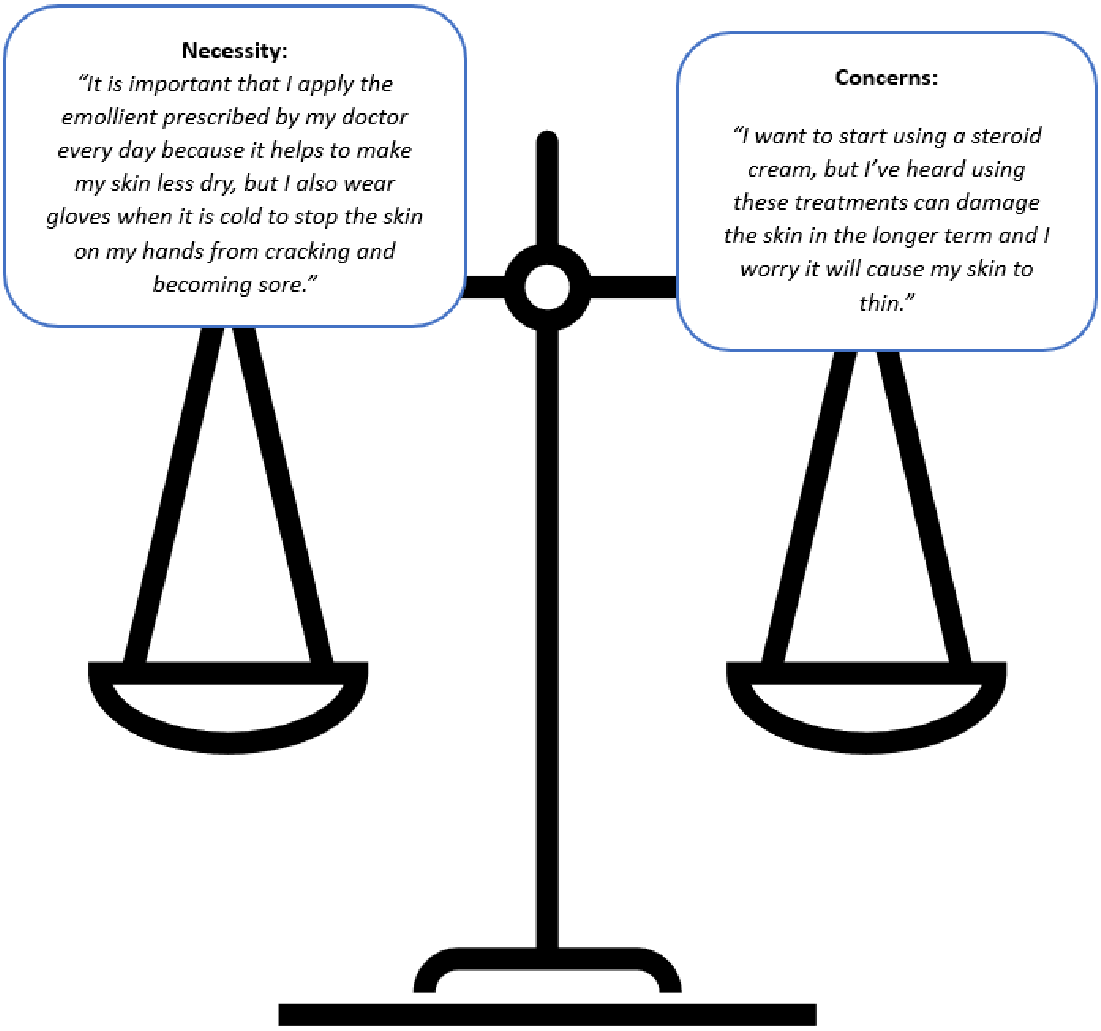
Behaviour:
“I spend lots of time searching the internet for treatments for my skin”

Beliefs about treatments

What you believe about treatments can influence the likelihood that you use treatments as prescribed.

Psychologists explain beliefs about treatments impact how people take their medications. The ‘Necessity-Concerns Framework’ explains that people weigh up how ***necessary*** they believe a treatment to be (e.g., to control our symptoms), against any ***concerns*** that they have about taking the treatment (e.g., about potential side effects).

- If you believe a treatment is necessary and have no concerns about it, the more likely you are to use it. However, if you don’t believe treatment is necessary and have strong concerns, the less likely you are to adhere.
- For example, a woman living with acne may believe that taking isotretinoin (Roaccutane) medication is necessary to control her symptoms, and therefore, avoid negative feelings, but also have concerns over how Roaccutane treatment may affect her fertility.



Necessity:
"It is important that I apply the emollient prescribed by my doctor every day because it helps to make my skin less dry, but I also wear gloves when it is cold to stop the skin on my hands from cracking and becoming sore."

Concerns:

"I want to start using a steroid cream, but I've heard using these treatments can damage the skin in the longer term and I worry it will cause my skin to thin."

Barriers to treatment use

- Some people choose not to take their treatment as prescribed. There are many reasons why people may decide against using their treatments as prescribed, including worries about side effects, believing that the treatment isn't working, or disliking how the treatment looks or feels.
- Some people also choose to change the dose of treatment that they use, for example, they up their dosage because they think this might bring quicker results.
- Understandably, a skin condition is part of, but should not be a dominant part, of life. Some people might unintentionally not take treatments as prescribed because they forget, or do not understand how to take their treatment.

Tips for sticking to your treatment plan:

- Be your own psychologist:
    - **Assess** when you are more likely to become inconsistent with your treatment (e.g., when you feel tired at the end of a long day, or when you are away from home).
    - **Think about** why you might stop your treatment and why it is important to you to be consistent.
    - **Plan** to stick to your treatment schedule:
        - Think of situations when you might choose to stop, or forget to use, your treatments and create an action plan to avoid those pitfalls.
        - Set a specific goal using the PACT acronym.
        - Create an 'if-then' plan to help you stick to your treatment plan. For example: **If…** I am going on holiday **then…** I will ensure I take my treatments with me and will set a reminder on my phone to use them.
    - **Evaluate** your progress. Focus on what worked well and what could be done better.

- Seek support from others…
    - Think about *who* can support you and *how* they can support you with your goal.
    - Once you have set your goal and made a plan.
    - Studies show if you share your goals with someone you are more likely to stick to the plan so you might want to tell your family, friends and colleagues and let them know how they can best support you to achieve your goal.
    - Ask your GP for help and advice if relevant. Health professionals can provide advice and guidance on a range of evidence-based treatments and support you to identify the treatment that is most suitable for you.
    - During medical consultations, your doctor should always take into account your needs, concerns and preferences when it comes to deciding the best treatment for you. Don't be afraid to share your views with your doctor and

    explain to them what you think would help you to stick to your treatment plan, and what might prevent you from sticking to it.
  - Patients from our research have suggested preparing for consultations by writing a list of questions or topics you would like to cover beforehand to make sure your goals for the meeting are taken into account. They also suggested being open and honest about what you want to get out of the consultation, and how you feel about any treatments that are discussed.

- Be cautious…
  - There is a wealth of information available online and this can be overwhelming, confusing and sometimes just incorrect when trying to identify a suitable treatment.
  - There are people online selling treatments that they claim will 'cure' skin conditions. These products often have no scientific backing and are unlikely to be effective and could even be harmful to you.
  - Health authorities and dermatology organisations, such as the National Institute of Care Excellence (NICE), the British Association of Dermatologists (BAD) and the NHS, offer the latest evidence-based guidance and recommendations on treatments. The websites of these organisations are a good place to start to find out about the treatments available for your skin condition.

Learn more about treatment use and skin conditions:

- The impact of treatment use on the severity of psoriasis symptoms.
- Factors that affect use of acne treatments.
- Factors that affect treatment use in all skin conditions.
- Methods of improving treatment use for those with psoriasis.
- Methods of improving treatment use for those with atopic dermatitis.
- Methods of improving treatment use for those with acne.
- Interventions that can improve treatment use for all skin conditions.
- The impact of psychological health on treatment use.
- How beliefs about medicines impact how we use them.

Pause – what did you learn in this section?

Consider taking a moment to reflect and note down the 3 key learning points in your notes.

What was the most helpful thing?

Content for MiDerm App – Signposting to existing support

Existing support for people with skin conditions

In this section, you will learn about existing types of support that could help you to live well with your skin condition(s).

All the resources, services and organisations listed in this section have been recommended by experts in dermatology, psychology and psychodermatology. Our research team have reviewed and approved the resources to the best of our ability, but we can’t always endorse externally developed content. We recommend you always check out the organisations who promote content and give priority to professional ones such as the British Association of Dermatologists (BAD) or National Health Service (NHS) for example.

Psychological support for people with skin conditions

Find existing services that offer psychological support for people with skin conditions.

- ***Changing Faces***

  Online information and advice on living with a visible difference, including skin conditions. Includes patient stories, an online community support forum, a skin camouflage service and offers one-to-one counselling.

- ***Skin Support***

  A website offering emotional support for people with skin conditions.

- ***FaceIT@Home***

  Online support for people with visible differences. Educational sessions and online peer support (registration required) and quizzes on coping, worry about others, understanding the self, negative thoughts.

- ***IMPARTS***

  Online self-help resources and activities including: condition-specific guidance on living with psoriasis, hidradenitis suppurativa and vulvodynia; scratch monitoring and habit reversal for reducing scratching; and guided meditation for people experiencing itch, psoriasis and Hidradenitis Suppurativa. IMPARTS is recommended by the BAD.

- ***Mindfulness meditation for people with psoriasis***

A 30-minute mindfulness meditation programme for psoriasis that is available to buy online.

- ***Psychodermatology UK***

Information on existing psychodermatology services plus links to other useful resources for people with skin conditions.

- ***Outlook Patient Information (North Bristol NHS Trust)***

A specialist psychological service for people with appearance-related concerns. Referral required.

Support groups and organisations for people with skin conditions

Patient organisations offer support to people living with skin conditions. We worked with the leaders and members of the following nine patient organisations to carry out the research which MiDerm is based on:

1. The Psoriasis Association.
2. The International Alliance of Dermatology Patient Organisations (also known as Global Skin).
3. Skin Care Cymru.
4. Eczema Outreach Support.
5. The British Skin Foundation.
6. HS Ireland.
7. The Vitiligo Society.
8. Ichthyosis Support Group.
9. Alopecia UK.

Learn more about each of these organisations below.

Support for people living with different dermatological conditions

- ***The International Alliance of Dermatology Patient Organisations (IADPO)*** **[INSERT LOGO]**

The International Alliance of Dermatology Patient Organisations (also known as GlobalSkin) is a unique global alliance, committed to improving the lives of skin patients worldwide. They aim to nurture relationships with members, partners and all involved in healthcare – building dialogue with decision-makers around the globe to promote patient-centered healthcare. GlobalSkin works to empower its more than 235 patient association members – located in 67 countries representing more than 57 disease areas – to reach more patients, and provide them with greater support, education, and advocacy.

- ***The British Skin Foundation (BSF)*** **[INSERT LOGO]**

The BSF is the only UK charity that raises money to fund research into all types of skin diseases, including skin cancer. The BSF raises money for vital research to help find cures and treatments for common skin conditions like eczema or acne, through to potential killers like malignant melanoma.

- ***Skin Care Cymru*** **[INSERT LOGO]**

Skin Care Cymru is a charity which seeks to promote the interests of all those with skin conditions within Wales. They look to inform the general public on skin related issues, such as their successful ‘Don't Be A Lobster’ campaign, and are represented on various bodies to advance the cause of dermatology patients. They also provide funding for medical professionals, through their Barry Statham awards, to assist with matters such as travel to conferences, purchasing dermatascopes and so on.

- ***British Association of Dermatology***

Providing advice on living with a skin condition, including: condition-specific information and downloadable patient information leaflets; patient support groups; and skin and well-being.

Support for people living with psoriasis and psoriatic arthritis

- ***The Psoriasis Association*** **[INSERT LOGO]**

The Psoriasis Association is the leading national charity and membership organisation for people affected by psoriasis in the UK. Through their work, they are able to provide help, information and support for people whose lives are affected by psoriasis and psoriatic arthritis, raise awareness and fund and promote research into the causes, nature and care of people with psoriasis.

- ***Psoriasis and Psoriatic Arthritis Alliance (PAPAA)***

A UK-based charity offering evidence-based self-help information for people with psoriasis and psoriatic arthritis, including tips for coping.

- ***National Psoriasis Foundation***

This organisation provides information and research on psoriasis, as well as social and community events for people living with psoriasis in the USA.

- ***Coping with psoriasis***

A website offering tips on coping with psoriasis by a psychologist living with psoriasis.

- ***The Skin I'm In***

A short YouTube film on the psychological impact of psoriasis that was produced as part of the 'See Psoriasis: Look Deeper' campaign.

- ***Informatree***

A website that includes evidence-based resources designed to help people to live well with psoriatic arthritis.

- ***Health Talk***

A website offering information on psoriasis and video depicting people's experiences of psoriasis.

- ***Everyday Health***

Article on sleep and psoriasis.

Support for people with eczema

- ***Eczema Outreach Support*** **[INSERT LOGO]**

Eczema Outreach Support is the only charity providing free direct practical advice for children and young people with the painful skin condition eczema. They provide emotional support to the whole family through resources, calls, events and workshops; empowering young people to take back control of their health, breaking the isolation.

- ***National Eczema Society***

A UK charity that offers support to people living with eczema, including downloadable resources on eczema and how to live well with eczema.

- ***Eczema Care Online***

An evidence-based website offering information on eczema triggers, treatments and dealing with the psychological, physical, financial and daily consequences of eczema.

- ***Atopic Skin Disease***

An online community for people with eczema and practitioners involved in the management of eczema. Includes condition-specific information about eczema, treatments, tips and a behavioural approach to management.

- ***Health Talk***

Information on eczema and videos depicting people's lived experiences of eczema.

- ***Sleep Scotland***

Information on sleep and tips for sleeping well with eczema.

- ***The Eczema Solution***

Book by Sue Armstrong-Brow focused on increasing awareness of and reducing scratch, supporting personal control and using treatments effectively.

- ***WebMD***

Tips for sleeping better with eczema.

Support for people with vitiligo

- ***The Vitiligo Society*** **[INSERT LOGO]**

The Vitiligo Society is a national charity headquartered in London which supports those living with vitiligo across the UK. As an organisation, they are proud of their long heritage and their continued commitment to improve the lives of those diagnosed with vitiligo. Their mission is to beat vitiligo by eradicating the psychological, social and physical effects on people's lives and by finding effective treatments and a cure.

Support for people with alopecia

- ***Alopecia UK*** **[INSERT LOGO]**

Alopecia UK is a small UK charity working to improve the lives of those affected by alopecia through the aims of Support, Awareness and Research. They work to help adults, young people and children affected by alopecia, including those with the condition and their loved ones. Visit their website to find information, resources and signposting to their support groups and forums, as well as news about their events and research.

- ***Health Talk***

Online information on alopecia and video depicting people's lived experiences of alopecia.

Support for people with hidradenitis suppurativa (HS)

- ***HS Ireland (Hidradenitis Suppurativa Association)*** **[INSERT LOGO]**

The mission at HS Ireland is to empower people affected by HS to live life to their fullest potential through support, research, and representation.

- ***HS Connect***

Online information on HS (about, treatment, nutrition, mental health, parents/children), including latest research and studies and patient stories.

- ***Shine a Light on HS (by Novartis)***

Online information and a downloadable booklet on HS (about HS, causes, symptoms, treatments and impact), and opportunity to share your story.

- ***Hidradenitis Suppurativa Trust – Patient Support Group***

An open Facebook peer support group.

Support for people with ichthyoses

- ***Ichthyosis Support Group*** **[INSERT LOGO]**

The Ichthyosis Support Group (ISG) was formed in 1997 by a group of individuals affected by ichthyosis who wanted to create a network of parents, sufferers and medics. The ISG became a UK registered charity in 2001. They are committed to the ongoing provision of an information network and support structure for sufferers and families affected by ichthyosis; greater awareness and understanding within the medical profession; and lobbying for greater research into this distressing condition.

- ***FIRST***

Regional support networks for Ichthyosis in the US. The FIRST website includes tools and tips for living with ichthyosis, including environmental factors, mood, lifestyle behaviours (diet, physical activity) and social support.

- ***X-Linked Ichthyosis Community***

A private Facebook Support Group for patients and parents or carers.

- ***Netherlands Ichthyosis Network***

An online peer support network for those living with Ichthyoses in the Netherlands.

Support for people with acne

- ***Acne Care Online***

University of Southampton are developing a self-management support website for young people with acne (13 to 25 years).

- ***Acne support (by BAD)***

Online information on types and causes of acne, treatments, prevention and emotional impact.

- ***Health Talk***

Information on acne and a video depicting people’s lived experiences of acne.

Support for people with Pemphigus/Pemphigoid

- ***PEM Friends***

Online support for people with pemphigus and pemphigoid, their carers and clinicians. Condition-specific information (diagnosis, treatment, tips and nutrition), blog and patient stories.

Support for people with Lichen Sclerosus/Vulval Cancer

- ***Lichen sclerosus & vulval cancer UK awareness***

Online condition-specific information, peer support groups and patient stories.

Support for people with skin picking disorder (Dermatillomania)

- ***SkinPick app***

A fee app for monitoring skin picking behaviours. The SkinPick website includes information, blog posts and webinars about dermatillomania.

General Support for psychological wellbeing

Find services that provide support for improving psychological wellbeing in general.

- ***IAPT / NHS Talking Therapies***

Evidence based, NICE recommended talking therapies for depression and anxiety.

- ***iCope / NHS Talking Therapies***

Free support for psychological conditions.

- ***5 Steps to Mental Wellbeing***

Five tips for supporting mental well-being by the NHS (social connection, physical activity, mindfulness, giving to others, self-development).

- ***Feelings and Symptoms***

Information on feelings and symptoms associated with common mental health conditions by NHS.

- ***Centre for Mindfulness Research and Practice, Bangor University***

Free audio activities (body scans and breathing, seated meditation, mindful movement and yoga practices) which are available to download.

- ***Smiling Mind App***

Free evidence-based mindfulness app.

- ***Headspace App***

Evidence based meditation and mindfulness tools, activities, information. Also covers sleep and stress.

- ***Mindfulness: Finding peace in a frantic world***

Free meditations (body scan, breathing techniques, chocolate meditation).

- ***Get Some Headspace***

Book on mindfulness by Andy Puddicombe.

- ***MIND***

UK-based charity supporting mental health through the provision of information, advice and signposting to local services.

- ***Overcoming Low Self Esteem***

Book / self-help guide using cognitive behavioural techniques by Melanie Fennell.

- ***UK Council for Psychotherapy***

Website designed to help people find a qualified therapist.

- ***IMPARTS***

General guidance and self-help on living well with a long-term health condition.

- ***Noom Mood***

Educational content, personalized courses and (optional) coaching. Activities include mindfulness and daily mood monitoring.

- ***Self-compassion.org***

Website focused on self-compassion by Dr Kristin Neff. Information, research and free activities/practices.

Support for improving health behaviours

Find services offering support and guidance for health behaviour change.

- ***Find your local stop smoking service***

Search engine for local stop smoking services in the UK.

- ***Sleeping Problems, An NHS Self-Help Guide***

Free and downloadable guide designed to support understanding of sleep problems and how to sleep better.

- ***SkinFood***

Book on skin and diet by Dr Thivi Maruthappu, a leading dermatologist.

- ***The Pioppi Diet***

Book on the Mediterranean diet.

- ***British Heart Foundation***

Information on the Mediterranean diet.

Tips for making meals more Mediterranean.

Interactive activity including breakfast, lunch and dinner ideas that follow the Mediterranean diet.

- ***Diabetes UK***

Interactive: Make your meals Mediterranean - BHF.

- ***Noom***

A weight loss app – 4-week free trial. Educational content, personalized courses and (optional) coaching.

Includes free personality quiz and calorie and macro calculator.

- ***NHS***

  Information and tips for better sleep.

Support currently in development

Look through support services that are currently in development, and read the relevant publications.

- ***APPLE study meal plan***

  A meal plan specific to psoriasis that was produced as part of the APPLE study, which was funded by the Psoriasis Association UK and led by researchers at King's College London.

- ***Coach-led group walking sessions***

  An evidence-based, moderate-intensity physical activity intervention for people with psoriasis, involving two 60-minute, coach-led group walking sessions per week for ten weeks. This study is funded by The Psoriasis Association UK and is led by researchers at The University of Manchester.

- ***Expand your horizon***

  Online, one-week body functionality writing booklet intervention for people with appearance-altering conditions.

- ***Act it Out App***

  Acceptance and Commitment Therapy app for adults with appearance-altering conditions.

Content for MiDerm App – Goals and plans

My goals and plans

In this section, you will learn evidence-based strategies for changing and keeping up health-protective behaviour. It includes activities to support you to make and keep up positive changes to your lifestyle that could improve your health and well-being. Start small with changes that are easy.

To get the most out of this section, we encourage you to:

- Think of a behaviour you want to change.
- Set a goal and create an action plan for achieving this change.
- Use the diary to record and reflect on your progress.

Goal setting

We all know that a goal is something that you are aiming to do.

Did you know that setting a specific goal, and being clear about how you will achieve it, will help you to meet your goal?

Use the **PACT** acronym to help set your goal. PACT stands for:

- **P**urposeful – the goal is meaningful to you and matches your values.
- **A**ctionable – the goal is something you can act on now rather than in the future.
- **C**ontinuous – the goal involves something that you can do repeatedly without too much thinking or planning, and that you can learn from as you go.
- **T**rackable – the goal can be measured and you can track your effort and progress against it.

PACT goal example:

- To go for a 20-minute brisk walk every afternoon for one month.
- To get up and make my bed before breakfast.
- To play the piano for 10 minutes every day for two weeks.
- To speak to a family member or friend every week.

Be your own psychologist…

- **Assess** what do you want to change.
- **Think** about:
    - The reasons why it is important to you to make this change.
    - How ready you feel to make this change [Numeric rating scale from 0-10].
    - What would make it easy (visualise yourself making the change)
- **Set your goal.** Have a go at using the PACT acronym to help you set a goal.
- **Evaluate** your goal. Reflect on what is working well and what you could do to improve and meet your goal.

[+ new goal]

Action planning

We all know that setting goals can help us to make changes that are important to us.

But did you know… *"A goal without a plan is just a wish."* Planning how you will meet your goal will help to keep you accountable and motivated to keep working towards your goal over time.

My action plans:

- Short-term plans.
- Medium-term plans.
- Long-term plans.
- Completed plans.

Be your own psychologist…

- **Think** about how you could meet your goal. Visualise yourself achieving it.
- **Plan** how you will meet your goal. Use the five W's below to help you create a specific action plan for achieving your goal:
    - **What** will you do?
    - **Who** can help you achieve your goal?
    - **Where** will you do this?

    - **When** will you do this?
    - **How** long will you do this for?
- **Evaluate** your action plan. Reflect on what aspects of your action plan are working well and what you could do to improve it.

If-then plans

We all know that some things make it harder (barriers) or easier (enablers) to meet our goals.

Did you know '*if-then*' plans are a good strategy that can help you to deal with challenges and stay on track with your goal. For example:

If… I start to feel anxious, ***then…*** I will take ten deep breaths to calm myself.

If… I call my friend regularly, ***then…*** I won't feel awkward about seeing her if I am having a flare.

If… my friend suggests sharing a bottle of wine, ***then…*** I will say no and order one glass of wine.

Be your own psychologist…

- **Assess** when you are likely to work on your goal.
- **Think** about:
    - What could stop you from meeting your goal in that situation [+ barrier].
    - How you could overcome anything that might stop you from meeting your goal [+ enabler].
- **Plan** how you will overcome any barriers that you might face along the way and create an 'if-then' to help you.

If… _________ , ***then…*** __________ . [+ if-then plan]

Pause – what did you learn in this section?

Consider taking a moment to reflect and note down the 3 key learning points in your notes. What was the most helpful thing?

Appendix 60: Reflections on semi-structured interviews with PPI contributors

Amie's interview

Amie discussed relying on faith as a coping strategy, which was at odds with the researcher's personal beliefs about religion (atheism).

Amie described trialing an elimination diet to investigate whether certain foods triggered her eczema. The same topic was discussed by some group interview participants, who reported trialing different diets despite the lack of evidence-based guidance on their effectiveness for dermatological conditions. This, and the researcher's personal and largely negative experiences of trailing FODMAP diet, may have influenced how they approached these discussions and interpreted what Amie said.

Martin's interview

Martin discussed the change in his symptoms, and therefore their psychological impact, between present day and when he was a child and adolescent. This meant that a lot of retrospective thinking was required to identify how living with psoriasis has impacted Martin as a child, and therefore may not have been an accurate depiction of his psychological state during that period. Martin had not accessed any psychological support for his condition, and had very limited experiences with peer support. This meant that very little discussion could be had surrounding this, which led to a conflict on the researchers side due to their knowledge of the potential benefits of this type of support.

Sue's interview

Sue discussed her engagement in advocacy work, including taking part in the PPI group, contributing to a Psoriasis advocacy group, and giving educational sessions on the impact of Psoriasis to medical students. The researcher recognised the value of these activities, and Sue's positive experience of taking part in the PPI group, which may have caused the researcher to ask more questions during this part of the interview. In addition, Sue mentioned the importance of maintaining a positive outlook, which the researcher may have probed more than other coping strategies due to a personal agreement with this strategy.

Neesha's interview

Neesha discussed her journey to accept her acne and scarring over time, citing several coping strategies that the researcher knew to be often positive and helpful. Neesha also mentioned her perceived value of the ‘skin-acceptance’ movement and the increase of skin and body positivity on social media platforms such as Instagram. The researcher was conflicted over the inclusion of this, as from other interviews and personal experience they were aware of the disadvantages of such social media movements, such as vicarious trolling and obsession.

Lex’s interview

Lex advocates for people living with rosacea and described having a substantial presence on social media – it started out as a passion but became her occupation. Lex covered some useful tips for coping with skin conditions that had not been covered in other interviews (being honest about personal needs associated with a skin condition and identifying and learning to balance personal triggers). However, the researcher felt that some of Lex’s comments sounded rehearsed and this made the researcher questioned the authenticity of her words.

General reflections

The purpose of the patient stories interviews was to convey what strategies adults consider to be effective for self-managing skin conditions. Mention of avoidant coping strategies created cognitive dissonance; wanting to accurately represent the individual’s experience but also achieving the aim of the activity to convey approaches that are safe, healthy and effective. Therefore, the researcher may have focused and probed more into positive coping strategies, such as acceptance and engagement with peers, in comparison to avoidant coping methods mentioned, such as ignoring skin and stopping self-management all together, due to an awareness of the purpose of patient stories. This was felt across the interviews by both interviewees.

Appendix 61: PPI stories interview recordings – team discussion on topics and timestamps (round 1)

Participant	Topic Discussed	CSM concept	RH	CD	Discussion	Included?	Timestamps
Martin	Age of onset and condition progression.	Timeline	00:38 – 00:57		Decided it would be useful to include this as context, and gives description of timeline (CSM)	✓	00:38 – 00:57
	Social – responding to others. Coping – acceptance.	Consequences	02:31 – 02:51		Helpful as gives insight into his self-acceptance	✓	02:31 – 02:51
	Leisure – example of experience in swimming pool. Social – others' reactions. Psychological – embarrassment.	Consequences	07:25 – 08:50	07:35 – 8:50	Both agreed that this was a clear example of both social stigmatization and feelings of embarrassment	✓	07:25 – 08:50

Psychological – self-consciousness and embarrassment.	Consequences	09:13 – 09:32		Decided not to include this section as the concepts are described more concisely elsewhere in recording		
Societal perceptions. Life stages. Psychological – individual attitude change in relation to swimming pool example	Social context, timeline, consequences	10:36 – 10:57	10:25 – 10:58	Both considered this to be an important section, and agreed that most relevant part starts at (10:36)	✓	10:36 – 10:57
Coping – avoidant coping as a child/adolescent.	Consequences	12:42 – 13:38	12:40 – 13:40	Discussed the potential value of having a realistic view of coping, but decided that it is important not to advocate for		

				avoidant coping strategies		
Self-management		14:56 – 15:39 *15:30 – 15:39*		Both agreed that the end quote of this section about self-acceptance was important. Discussed whether statements around self-management should be included, and decided that this would be valued by users.	✓	14:56 – 15:39
Treatment control – drug/UV lamp trial	Controllability		17:20 – 18:11	CD included this as it spoke to the participants story, but after discussion it was decided that this was not		

					relevant as it took place a long time ago and had limited benefit.		
	Seeking others with the same condition – peer support group and positive influence of role model.	Consequences	24:56 - 25:30	24:55 – 25:30	Agreed that influence of role model was an important section to include. Decided that a short section introducing the support group should also be included to add context.	✓	23:06 – 23:12 24:56 – 25:30
	Advice to others, not letting the condition rule your life.		36:08 – 36:12	35:40 – 36:14	Discussed the section on advice, and decided that the short quote around not limiting	✓	36:08 – 36:12

					yourself was the most valuable to include		
Amie	Age of onset and condition progression – description of flare up		0:32 – 2:22	0:33 – 1:52	Discussed whether to keep in section including engagement with healthcare system – decided to keep this as it gives concise account	✓	0:32 – 2:22
	Psychological impact of eczema flare up as a result of withdrawal from school and sport	Consequences	2:39 – 3:15	2:41 – 3:08	General agreement for this section, decided to cut first few section for conciseness and extend to 3:15 to give full description of psychological impact	✓	02:41 – 3:15

Description of proactivity around self-management		3:24 – 3:52	3:22 – 3:52	Discussed whether to include mention of phototherapy and decided to include this as gives concise account of experience	✓	3:24 – 3:52
Self-isolation – distancing herself at sixth form			5:18 – 5:30	Decided that this was effectively covered elsewhere and so was removed for conciseness		
Description of how physical appearance and ability had mental health impacts		6:18 – 6:47	6:26 – 6:38	This was discussed as in important quote, and it was decided to keep the first few seconds in as it provides context	✓	6:18 – 6:47

Feelings of being punished and pressure from needing to stay on top of education		7:51 – 8:13	5:57-8:03	Extended this section to include mention of pressure to keep up with external expectations despite skin condition	✓	7:51 – 8:13
Depression and suicidal ideation		8:39 – 9:06	8:40 – 9:10	It was discussed whether this section was covered previously, but decided to keep in and review later	✓	8:39 – 9:06
Reliance on sleep medication and need for an 'escape'		9:19 – 10:21	9:36 – 10:05	Removed the first sentence explaining reliance on piriton as this is repeated, and extended to include description	✓	9:33 – 10:21

				of needing an escape		
Comments made by other people			13:17 – 13:24	It was decided not to include the comment given as an example because this did not reflect Amie's overall experience, it would seem out of context, and could potentially be triggering for others		
Description of positive framing and mind-skin connection		13:36 – 14:19	13:50 – 14:20	Agreed that this was a very important section to include. Decided to remove first few seconds giving	✓	13:50 – 14:19

				context of the flare up.		
Self-management behaviours (journalling and gratitude)		15:24 – 17:51	15:22 – 17:51	Agreed to add ‘journalling’ at beginning	✓	15:22 – 17:51
Visualisation methods			18:35 - 1842	It was decided not to include this section as it is described clearer elsewhere		
Impact of diet		19:58	19-58 – 20:08	Discussed benefits and disadvantages of including mentions of diet impacting skin. It was decided not to include this as mentions non evidence-based methods		

Impact of stress and dressing for comfort (cotton)		21:21-21:47	21:22-21:53	Discussed whether it would be useful to mention reducing stress, but decided not to include as this section does not specify methods of reducing stress		
Positive re-framing of thoughts		22:04 – 22:25		Decided not to include as this is mentioned clearer elsewhere		
Experience of seeking psychological support			23:16-23:32	Discussed the balance between reflecting real experiences and advocating for users seeking support. Decided		

				not to include for this reason.		
Experiences of phototherapy			24:54 – 26:21	Discussed the value of including this to provide context to Amie’s recovery. Decided to keep a short section and review on next round	✓	26:10 – 26:21
Positive experience of visiting nutritionist		27:32 – 28:28	27:38 – 28:38	Decided to take out first few seconds mentioning that it was private.	✓	27:38 – 28:38
Psychodermatology and improvement during waiting list		29:58 – 30:25	30:03 – 30:25	It was decided that this section had value in that it showed how self-management can lead to significant	✓	29:58 – 30:25

				improvements whilst on a waiting list		
Social/family support			31:01-31:11	Decided to include this for later review as this support was valued by Amie	✓	31:01-31:11
Advice for others – gratitude and taking care of mental health		37:30 – 39:04	37:36 – 39:04	Decided to keep in initial few seconds as context to question	✓	37:30 – 39:04
Routine – making self-management enjoyable		39:40 – 40:36		CD didn’t include as very specific to individual, but it was decided to include as describes making self-management routines enjoyable	✓	39:40 – 40:36

	Key messages		42:21 – 42:36		Discussed whether this was repetitive, but included as quote at the end was powerful	✓	42:21 – 42:36
Sue	Comorbidities, timeline		00:49-01:09/01:29 – 01:37/01:48 -01:52	00:49 – 02:30	Cut out pauses and repetition for clarity	✓	00:49-01:09 01:29-01:37 01:48-01:52
	Treatment experience, illness progression		02:19-02:43	02:30 – 05:51	Agreement	✓	02:19-02:43
	Treatment efficacy + concerns		03:39 – 04:21/04:38 -05:51	02:30 – 05:51	Cut out repetition on timeline of symptoms	✓	04:38-05:51
	Lack of negative comments/social impact		05:54 – 06:12	05:53-06:12	Cut extra second for conciseness	✓	05:54-06:12
	Impact on leisure + clothing choices		06:23 – 06:54	06:33 – 06:54	Included initial 10 seconds for context	✓	06:23-06:54

Treatment adherence + motivation		08:43-09:04/09:32 – 09:53	08:21-08:43	Decided to include mentions of adhering to medication for upcoming holiday as this will likely resonate with users	✓	08:34-09:04 09:32-09:53
Lack of clear cause			11:32 – 11:42	CD had question marked, decided to remove as not useful for the purpose of this analysis		
Treatment concerns			12:06 – 15:32	Removed as repetition		
Pressure		13:54 – 14:11		Discussed how feelings of needing to keep up despite condition would be	✓	13:54 – 14:11

				relatable and decided to keep in		
Leisure – self consciousness		14:18 – 14:33	14:00 – 15:32	Split this section into smaller chunks to avoid repetition and ensure clarity	✓	14:18 – 14:33
Comparing psychological impact to pituitary tumour		15:02 – 15:32	14:00 – 15:32	Discussed when quote about psychological impact started, agreed to keep in as emphasises psychological impact of skin conditions	✓	15:02 – 15:32
Visibility, covering up		15:50 – 16:12	15:50 – 16:12	Agreement	✓	15:50 – 16:12
Impact – no cumulative life course impairment		16:45 – 16:53	16:44 – 16:53	Both agreed on importance of this section	✓	16:45 – 16:53

Comparison to others/ comments + curiosity/social acceptance		17:12-17:40/17:45-18:42/19:11-19:23		Discussed each of these sections individually and took out middle section due to repetition	✓	18:21-18:33 19:11-19:23
Physical management			20:30 – 21:24	Removed this section as does not provide necessarily helpful information		
Impact of the sun			21:36-22:12	Both were unsure on this due to risks of sun exposure - discussed with CB and decided to remove from this section but potentially mention elsewhere		

Medication		23:26-23:39		Decided not to include as repetition/unclear		
Frustration/change in perception/acceptance		24 :37 – 25 :15		Cut out first and last few seconds for clarity but included as relatable	✓	24:51 – 25 :15
Medical support/treatment			26 :26-27 :07/27 :20-27 :44	Decided not to keep this section as medical treatment is covered more concisely elsewhere		
Pressure/management/time/effort		28 :20 – 28 :57	28 :21 – 29 :23	Cut into smaller sections for clarity	✓	28 :20 – 28 :57
Treatment regime		29 :03 – 29 :23		Decided to include disagreement with consultant as it speaks to a lack of	✓	29 :03 – 29 :23

					shared decision making		
	Contribution to medical education/advocacy		30:01 – 31:08/32:13 -33:08	30:29-31:19	Included second section as provides context and an example	✓	30:01–31:08 32:13-33:08
	Patient Panel		34:48 – 35:03/36:14 -36:28		Decided not to include as participant did not say this had benefitted much		
	Social support – unsolicited advice/comments		38:23 – 40:12		Removed as doesn't fit with flow of interview and is covered elsewhere		
	Acceptance		41:19 – 41:34	41:49 – 42:13	Agreement		
	Advice		41:49 -	42:16- 42:34/42:44	Discussed relevant parts of advice	✓	42:16-42:34 42:44-42:51

				-42:51/43:53-44:10	section and cut down		43:53-44:10
Neesha	Symptoms, timeline		00:21-00:29/00:35-00:43/00:46-01:11/01:25-01:43	00:21-00:46/00:59-01:48	Discussed repetition/less clear sections that could be cut out. Discussed whether it was valuable to include mentions of private healthcare.	✓	00:21-00:35 00:43-00:46 00:46-1:11
	Impact (specifically during 20s)		01:54-2:46	01:54-02:12	CD cut into sections	✓	01:54-2:46
	Scarring + acceptance		2:51 – 3:21	2:13 – 3:21	Overlap with previous sections, cutting our repetition	✓	2:51 – 3:21
	Symptoms – pain, flare ups			03:55-04:14/04:25-04:28	Repetition, main points already covered		

Camouflaging/feelings of shame		05:22-05:43	05:23-05:46	Cut final three seconds for conciseness	✓	05:22-05:43
Impact of stress		06:01-06:21	06:02-06:21	Decided to remove as no strategies for stress management and widely known contributing factor		
Mindset, cause/control		07:04-07:50	07:12-07:46	Cut out last part as repetition	✓	07:12-07:46
Social isolation and hurtful comments, ‘disgusting’		08:36-09:05/09:16-10:17	08:36-09:03/09:04-09:21	Including section that mentions term ‘disgusting’ as users may relate to this	✓	08:36-09:05 09:16-10:17
Isolation, covering skin		11:38-11:42/11:45-12:19/12:46-13:30	11:34-12:09/12:39-12:58/13:08-13:30	Decided to include caveat about how camouflaging/using makeup takes time	✓	11:34-11:42 11:45-12:09 12:46-13:30

ADD SECTION ON WORK HERE IF POSSIBLE						
Psychological Impact		14:12-14:31/14:36-15:12	14:12-15:02	Discussed whether there was repetition, but decided to keep as she implies that preoccupation with her skin lead to her feeling down	✓	14:12-14:31 14:36-15:02
-		15:45-16:23/17:31-17:56		Decided this section wasn't necessarily needed		
Skin acceptance and body positivity movement		19:30-20:45	19:49-20:46	The first 20 seconds give context about her age which may be motivational to younger people	✓	19:30-20:45
Physical symptoms		21:15-21:22		Out of place for flow of story		

Self-stigma/vanity		21:45-23:13	21:46-22:54	Final 20s includes advice that is not mentioned elsewhere	✓	21:45-23:13
		23:46-24:12		Repetition		
Societal attitudes/change in perceptions		24:40-24:56		Kept as useful addition of social context	✓	24:40-24:56
Body Positivity		25:11-25:33/26:13-26:30		Important to how this person copes with their condition	✓	25:11-25:33 26:13-26:30
Medical care		27:47-28:20	27:14-27:27/27:58-28:20	Removing repetition	✓	27:14-27:26
Dismissal in healthcare			29:13-29:49	Decided to cut as isn’t necessarily helpful and we don’t want to put people off seeking treatment		

Experiences with private healthcare		30:19-31:23	30:23-30:39/31:32-31:55/32:28-32:49	The usefulness of this was discussed, and decided to keep a short section as it is true to participants experience	✓	30:52-31:09
Self-management – skin patches		37:00-37:25	36:44-37:23	Removed as less useful than other sections		
Financial expense		40:41-41:20	39:55-40:12/40:47-41:21	Removed first section for clarity and succinctness	✓	40:41-41:20
Value of openness		42:59-43:33/43:43-44:50	43:04-43:49	Some repetition, cut out mentions of work as mentioned better elsewhere	✓	43:43-44:04
Advice		47:36-48:25/48:33-43:57	47:35-48:58	Removed mention about isolation as previously covered	✓	47:36-48:25 48:33-48:57

					and not recommended		
	Evidence Based Information in the app		51:48-51:59		Out of place		
	Impact on career – earlier if possible		57:57-59:04/59:55-1:01:11	57:59-59:04	Valuable but slightly out of place – ask logic if it can go earlier	✓	57:57-58:21 58:33-59:04 59:55-1:01:11
	Key Messages		1:01:09-1:01:36/1:01:51-1:02:02		Included as provides additional, succinct summary of points	✓	1:01:09-1:01:36 1:01:51-1:02:02
Lex	Symptom emergence/cause/experience with primary care/trial and error/methods of coping/change over time/blog		00:21-00:42 01:15-02:43 03:11 – 03:50 04:12-04:21 04:52-06:01 06:42-08:31	00:20-09:00	The first section covers a lot of context for further interview and includes many CSM concepts. Cut out part on genetics as	✓**	00:20-00:42 01:15-09:11

					covered more clearly later		
	Trial and error in self-management		09:19 – 09:53	09:53 – 10:26	Agreed that both sections contain valuable examples that may be useful	✓**	09:19-10:26
	Discussion of blog		10:28-14:05		Discussed that mentions of blog should be kept succinct as potentially limited in helpfulness		
	Cause/predisposition/genetics ‘ticking time bomb’		16:27-16:54 17:06 – 17:39	17:06-17:40	Included first section as section on genetics cut from beginning	✓	16:27 – 16:54 17:06 – 17:40
	Self-blame/ ‘early warning system’/ positive reframing		18:00-18:45 19:12 – 20:34	17:59 – 20:37	Important to include section on positive reframing	✓	17:59 – 18:45 18:50 – 20:37

				and examples of triggers are useful		
27-39 here if possible						
Psych impact/multifactorial treatment of rosacea		20:40-21:25	20:50-21:26	Repetition in beginning	✓	20:51 – 21:26
Impact of stress		21:45 – 22:11	21:45 – 22:11	Agreement	✓	21:45 – 22:11
Positive reframing/social support		22:49 – 23:19 23:52 – 24:51	22:50- 24:40	**review with later section on social support**		
Clarification on ‘punishing’ skin		27:53 – 28:30	27:39 – 28:31	***put after 20:37 if possible***		27:39 – 28:31
Lasting psychological impact		28:58 – 30:08	29:24 – 28:31	Included later section as summaries statement more clearly	✓	29:53 – 30:08
Social support/community		32:55 – 33:29		? repetition		

Experience of CBT			34:03-35:09	Not in enough detail to be valuable		
Positive affirmations		35:17 – 36:12	35:15-35:40/36:21-35:59/37:24-38:01/38:15-39:01	Kept in sections that gave practical examples of using affirmations in the face of negative automatic thoughts	✓	35:15-35:40/38:15-39:01
Re-training thoughts/positive reframing/coping strategies		40:59 – 41:53		Repetitive		
Constant management		43:09 – 43:32	42:03 – 44:53	Included shorter section for clarity	✓	43:09-43:32
Trigger management/exhaustion/time and effort/vigilance		43:46 – 44:20		Included as important context for coping	✓	43:46-44:34
Honesty with others		46:09 – 47:10	46:06-46:41 48:09-49:13	Including 'mental load' but remove	✓	46:06-47:11/48:18-49:13

		48:18 – 48:57		additional examples		
Raising awareness of rosacea		54:11 – 55:08		? value – normalisation, *review next time*	✓*	54:11 – 55:08
Personal trigger management		57:59-58:18 59:04 – 59:47	58:00-58:33 59:04 – 59:45	Including balance and personal management	✓	57:59 – 58:15 59:04 – 59:45
Working with skin		1:00:32 – 1:01:42	1:00:17-1:01:33	Context at the beginning is important	✓	1:00:17-1:01:43
Social/peer support		1:02:11-1:03:01	1:02:02-1:04:50	Cutting out repetition	✓	1:02:02-1:03:01/1:04:11-1:04:50
Honesty		1:06:47 – 1:07:31		Repetition		
Skin positivity/ skin functionality		1:09:19 – 1:11:21	1:09:07-1:11:21	Agreement	✓	1:09:11-1:11:21

	Positive influences/social support		1:11:55 – 1:12:28		Repetition		

Appendix 62: PPI stories interview recordings – team discussion on topics and timestamps (round 2)

Participant	Clip	Original timestamps	RH	CD	Discussion	Changed?	New timestamps
Martin	1	00:38 – 00:57	00:38-00:56	00:37-00:56	Included 1s at beginning for context and cut 1s at the end where participant runs into new sentence	ü	00:37-00:56
	2	02:31 – 02:51	02:31 – 02:52	02:31 – 02:52	Agreement – extend to finish sentence		02:31 – 02:52
	3	07:25 – 08:50	07:25 – 08:50	07:25 – 08:50	Agreement – No change needed		07:25 – 08:50
	4	10:36 – 10:57	10:36 – 10:57	10:36 – 10:57	Agreement – No change needed		10:36 – 10:57
	5	14:56 – 15:39	Removed 15:08 – 15:22	14:56 – 15:39	Discussed removing section about sunbathing, but decided to keep as it illustrates risks and benefits of sun exposure		14:56 – 15:39
	6	23:06 – 23:12	Removed	23:05 – 23:12	Include 1s at beginning for context – agreed that this section is redundant if clips cannot be	ü	23:05 – 23:12

					merged together as provides content for		
	7	24:56 – 25:30	24:56 – 25:30	24:56 – 25:30	Agreement – No change needed		24:56 – 25:30
	8	36:08 – 36:12	N/A	N/A	Extended by 22s at the beginning to include more of the advice Martin gave for others – some concern over encouraging avoidant coping but decided that this would not be evident to non-psychologists	ü	35: 56 – 36:12
Amie	1	0:32 – 2:22	0:32 – 2:22	0:32 – 2:12	Kept mention of HCS as gives context to self help		0:32 – 2:22
	2	02:41 – 3:15	02:41 – 3:15	02:41 – 3:15	Added 1s to finish sentence	ü	02:41 – 3:16
	3	3:24 – 3:52	3:24 – 3:52	Removed	Decided to include as gives concise summary of how Amie coped		3:24 – 3:52
	4	6:18 – 6:47	6:18 – 6:47	6:18 – 6:47	Agreement – No change needed		6:18 – 6:47
	5	7:51 – 8:13	7:51 – 8:13	7:51 – 8:13	Agreement – No change needed		7:51 – 8:13
	6	8:39 – 9:06	8:39 – 9:06	8:39 – 9:06	Discussed similarity to Clip 2, but decided they provide different		8:39 – 9:06

				explanations to suicidality (low mood and pain)		
7	9:33 – 10:21	9:33 – 10:21	9:33 – 10:21	Agreement – No change needed		9:33 – 10:21
8	13:50 – 14:19	13:50 – 14:19	13:50 – 14:19	Agreement – No change needed		13:50 – 14:19
9	15:22 – 17:51	15:22 – 17:52	15:22 – 17:51	Extend by 1s to finish sentence	ü	15:22 – 17:52
10	26:10 – 26:21	Removed	26:10 – 26:29	Decided to keep and extend to give benefits and drawbacks of phototherapy	ü	26:10 – 27:08
11	27:38 – 28:38	27:22 – 28:38	27:36 – 28:38	RH included context of question, but it was decided that including first second of answer gave context to nutritionist	ü	27:32 – 28:38
12	29:58 – 30:25	29:58 – 30:25	Removed	Include as shows self-help can work. Extend by 1s to finish sentence.	ü	29:58 – 30:26
13	31:01-31:11	Removed	31:00-31:11	Removed as doesn't add much – support from mum.	ü	~~31:01-31:11~~
14	37:30 – 39:04	37:30 – 39:04	37:30 – 39:04	Agreement – No change needed		37:30 – 39:04
15	39:40 – 40:36	39:40 – 40:36	39:40 – 40:36	Agreement – No change needed		39:40 – 40:36

	16	42:21 – 42:36	42:19 – 42:46	42:21 – 42:36	Decided to extend as important sections of clip were missing.	ü	42:19 – 42:46

Appendix 63: Existing support for people with skin conditions recommended by experts

Skin condition	Service, organization, intervention or resource	Description of support	Link
Psoriasis	Coping with psoriasis	Tips on coping with psoriasis by a psychologist with psoriasis	Coping With Psoriasis
	APPLE study meal plan*	A meal plan specific to psoriasis that was produced as part of the APPLE study, which was funded by the Psoriasis Association UK and led by researchers at King's College London.	Will be made available following completion of the study. Current Research (psoriasis-association.org.uk)
	Coach-led group walking sessions*	Evidence-based, moderate-intensity physical activity intervention for people with psoriasis, involving two 60-minute, coach-led group walking sessions per week for ten weeks. Study funded by The Psoriasis Association UK, led by researchers at The University of Manchester.	Developing an aerobic exercise intervention for patients with psoriasis to support lifestyle behaviour change and improve health outcomes | Clinical and Experimental Dermatology | Oxford Academic (oup.com)
	The Psoriasis Association (UK)	Condition-specific information, helpline and the latest research studies and findings.	Information & Support (psoriasis-association.org.uk)

		Leaflets and information sheets, including pregnancy and preparing for a virtual consultation.	Leaflets and information sheets (psoriasis-association.org.uk)
		Peer support.	Peer to peer support (psoriasis-association.org.uk)
	The Skin I’m In	Short film on YouTube produced as part of the ‘See Psoriasis: Look Deeper’ campaign. Focuses on psychological impact of psoriasis.	The Skin I'm In (Updated) - YouTube
	PAPAA	Evidence based self-help information for people with psoriasis and psoriatic arthritis.	Psoriasis and Psoriatic Arthritis Alliance (PAPAA)
		Information and tips on coping.	How can I learn to cope with psoriasis and psoriatic arthritis? (papaa.org)
		Information on diet and lifestyle.	Psoriasis and psoriatic arthritis: Can what you eat and do make any difference? (papaa.org)
		Fertility and pregnancy	Fertility and pregnancy with psoriasis or psoriatic arthritis (papaa.org)
		PAPAA TV; YouTube channel including seven videos on living with psoriasis and psoriatic arthritis.	PAPAA TV psoriasis and psoriatic arthritis YouTube Channel

	National Psoriasis Foundation (USA)	Condition-specific information, social and community events, research.	The National Psoriasis Foundation: National Psoriasis Foundation
		Webinars and podcasts on a range of topics related to psoriasis.	Watch & Listen - NPF Media: National Psoriasis Foundation
		Patient navigation center offering help and advice.	National Psoriasis Foundation Patient Navigation Center: National Psoriasis Foundation
	Health Talk	Information on psoriasis and video depicting people’s lived experiences of psoriasis.	Psoriasis (young people) - Overview (healthtalk.org)
	Mindfulness Meditation for People with Psoriasis	30-minute programme available to buy online.	Mindfulness Meditation for People with Psoriasis – Sounds True
	Everyday health	Article on psoriasis and sleep	How to Sleep Better With Psoriasis | Everyday Health
Eczema	National Eczema Society	Mental health support for people with eczema, including free, downloadable information on living with eczema, self-help strategies and managing stress.	Mental health support | National Eczema Society

		Free, downloadable information booklets specific to living with eczema during childhood, adolescence and adulthood.	Booklets | Eczema Information | Eczema.org
		Free, downloadable and evidence-based fact sheets on eczema, treatments and management.	Factsheets | Eczema Information | Eczema.org
		Article on sleep hygiene	Sleep and eczema | National Eczema Society
	Atopic Skin Disease	Online community for people with eczema and practitioners. Includes condition-specific information about eczema, treatments, tips, a behavioural approach to management.	Atopic Skin Disease
	Eczema Care Online	Information on eczema triggers, treatments and living well with eczema (stress, sleep, itch, work/study, financial).	Eczema Care Online
	Eczema Outreach Support	Eczema care and treatment plans for children aged <9 and ≥ 9 years old. Freely available to download. Developed with input from a health psychologist.	Healthcare Plans – Eczema Outreach Support (eos.org.uk)
		Tik Tok	
	Health Talk	Information on eczema and video depicting people’s lived experiences of eczema.	Eczema (young people) - Overview (healthtalk.org)

	The Eczema Solution	Book by Sue Armstrong-Brow focused on increasing awareness of and reducing scratch, supporting personal control and using treatments effectively.	
	Sleep Scotland	Information on sleep and tips for sleeping well with eczema.	Eczema-and-sleep-Sleep-Scotland-2021.pdf (eos.org.uk)
	WebMD	Tips for sleeping better with eczema	Tips for Better Sleep With Eczema (webmd.com)
Acne	Acne Care Online	University of Southampton are developing a self-management support website for young people with acne (13 to 25 years). 18-month NIHR funded research project.	Acne Care Online | Primary Care Research Centre | University of Southampton
	Acne support (by BAD)	Information on types and causes of acne, treatments and prevention, scarring.	Home - acne support
		Information on how to cover acne.	Covering Acne - acne support
		Information on emotional impact of acne and signposting to useful resources and support services.	Emotional Support - acne support
	Health Talk	Information on acne and video depicting people’s lived experiences of acne.	Acne (young people) - Overview (healthtalk.org)

Alopecia	Alopecia UK	Information on Alopecia, self-help materials (dealing with difficult situations, meeting new people and managing unhelpful thoughts), support groups (local, online and Facebook), appearance tips.	Alopecia UK
	Health Talk	Information on alopecia and video depicting people's lived experiences of alopecia.	Alopecia (young people) - Overview (healthtalk.org)
Hidradenitis Suppurativa	HS Connect	Information on HS (about, treatment, nutrition, mental health, parents/children), latest research and studies, patient stories.	Hidradenitis Suppurativa (HS) Support | HSConnect
		Find a dermatologist (UK, Canada, Australia, Belgium, The Netherlands)	Dermatologists for Adults & Pediatrics | HSConnect
	Shine a light on HS (by Novartis)	Information and downloadable booklet on HS (about HS, causes, symptoms, treatments and impact), and opportunity to share story.	Hidradenitis Suppurativa (HS) | Shine a Light on HS
		Sign up page for Driver's Seat guide (tools and resources) for patients.	Sign Up | Shine a Light on HS
	Hidradenitis Suppurativa Trust – Patient Support Group	Open Facebook peer support.	Hidradenitis Suppurativa Trust - Patient Support Group | Facebook

Ichthyoses	Ichthyosis Support Group UK	Patient helpline.	https://www.ichthyosis.org.uk/helpline
		Caring for ichthyosis: general and condition-specific information and information on genetics and inheritance, treatments, preparing for consultations and advice for parents.	Ichthyosis Support Group - People who care about ichthyosis
	FIRST	Regional support networks in the US.	https://www.firstskinfoundation.org/regional-support-network
		Tools and tips for living with ichthyosis, including environmental factors, mood, lifestyle behaviours (diet, physical activity) and social support	https://www.firstskinfoundation.org/tools-tips-for-living-with-ichthyosis
	Netherlands Ichthyosis Network		https://ichthyosisnetwerken.nl/
	X-Linked Ichthyosis Community	Private Facebook Support Group for patients and parents/carers.	X-Linked Ichthyosis Community | Facebook
Pemphigus / Pemphigoid	PEM Friends	Online support for people with pemphigus and pemphigoid, their carers and clinicians. Condition-specific information (diagnosis, treatment, tips and nutrition), blog and patient stories.	Help with Pemphigus and Pemphigoid | PemFriendsUK

Lichen sclerosus / vulval cancer	Lichen sclerosus & vulval cancer UK awareness	Condition-specific information, peer support groups and patient stories.	Lichen Sclerosus & Vulval cancer UK Awareness - Home Page (lsvcukawareness.co.uk)
Dermatillomania	SkinPick app	Free app for monitoring skin picking behaviours. Website includes information, blog and webinars about dermatillomania.	Dermatillomania APP – Monitor Your Picking Behavior | SkinPick.com
		Free self-guided 4-week program (habit reversal training) to stop skin picking.	Free Self-Guided Program to Stop Skin Picking | SkinPick.com
Not condition specific	BAD	Advice on living with a skin condition, including: condition-specific information and downloadable patient information leaflets; patient support groups; and skin and well-being.	Home - BAD Patient Hub (skinhealthinfo.org.uk)
	Changing Faces	Information and advice on living with a visible difference, patient stories.	Changing Faces | Visible Difference & Disfigurement Charity
		1:1 dedicated counselling support.	Counselling Support For Disfigurement | Changing Faces
		Support and information line.	Disfigurement Support & Information Line | Changing Faces

		Online community support forum.	Welcome to the Changing Faces Support Forum - Changing Faces (healthunlocked.com)
		Skin camouflage service. Information on camouflage and appointment request.	Skin Camouflage Services For Disfigurement | Changing Faces
	Face IT@home	Online support for people with visible differences. Educational sessions and online peer support (registration required) and quizzes on coping, worry about others, understanding the self, negative thoughts.	Face IT at home - Home (faceitonline.org.uk)
	Skin Support	Website offering emotional support for people with skin conditions.	Home | Skin Support
	IMPARTS	Self-help resources and activities including: Condition-specific guidance on living with psoriasis, hidradenitis suppurativa and vulvodynia; scratch monitoring and habit reversal for reducing scratching; and guided meditation for people experiencing itch, psoriasis and HS. Recommended by BAD.	Resources & Self-Help (imparts.org)

	Psychodermatology UK	Information on existing psychodermatology services plus links to other useful resources for people with skin conditions.	Home | psychodermatology-uk
	The British Skin Foundation	Blog containing ‘skin stories’.	Blog | British Skin Foundation
		Condition-specific information.	British Skin Foundation – Know your skin inside out
	Outlook Patient Information (North Bristol NHS Trust)	Specialist psychological service for people with appearance-related concerns. Referral required.	Outlook Patient Information | North Bristol NHS Trust (nbt.nhs.uk)
	Expand Your Horizon*	Online, one-week body functionality writing booklet intervention for people with appearance-altering conditions.	Expand-your-horizon-more-than-my-appearance.pdf
	Act It Out app*	Acceptance and Commitment Therapy app for adults with appearance-altering conditions.	JMIR Formative Research - Designing an mHealth Intervention for People With Visible Differences Based on Acceptance and Commitment Therapy: Participatory Study Gaining Stakeholders’ Input
Other/generic resources and activities			

IAPT / NHS Talking Therapies	Evidence based, NICE recommended talking therapies for depression and anxiety.	NHS England » NHS Talking Therapies, for anxiety and depression Find an NHS talking therapies services - NHS (www.nhs.uk)
iCope / NHS Talking Therapies	Free support for psychological conditions.	iCope | Free Help for Stress, Anxiety, Depression and Insomnia
5 Steps to Mental Well-Being	Five tips for supporting mental well-being by the NHS (social connection, physical activity, mindfulness, giving to others, self-development).	5 steps to mental wellbeing - NHS (www.nhs.uk)
Feelings and Symptoms	Information on feelings and symptoms associated with common mental health conditions by NHS.	Feelings and symptoms - NHS (www.nhs.uk)
Find your local stop smoking service	Search engine for local stop smoking services in the UK.	Find Your Local Stop Smoking Service (LSSS) - Better Health - NHS (www.nhs.uk)
Sleeping Problems, An NHS Self-Help Guide	Free and downloadable guide designed to support understanding of sleep problems and how to sleep better.	Sleeping Problems.pdf (ntw.nhs.uk)
Centre for Mindfulness Research and Practice, Bangor University	Free audio activities (body scans and breathing, seated meditation, mindful movement and yoga practices) which are available to download.	CMRP Audio downloads | Centre for Mindfulness Research and Practice | Bangor University

Smiling Mind app	Free evidence-based mindfulness app.	App — Smiling Mind
Headspace app	Evidence based meditation and mindfulness tools, activities, information. Also covers sleep and stress.	Meditation and Sleep Made Simple - Headspace
Mindfulness: Finding peace in a frantic world	App or book.	Mindfulness: Finding Peace in a Frantic World
	Free meditations (body scan, breathing techniques, chocolate meditation).	Free meditations from Mindfulness - Mindfulness: Finding Peace in a Frantic World | Mindfulness: Finding Peace in a Frantic World
Get Some Headspace	Book on mindfulness by Andy Puddicombe.	
MIND	UK-based charity supporting mental health through the provision of information, advice and signposting to local services.	Home - Mind
	Side by Side – online peer support.	Side by Side | A community platform by Mind
Overcoming Low Self-Esteem	Book / self-help guide using cognitive behavioural techniques by Melanie Fennell.	
UK Council for Psychotherapy	Website designed to help people find a qualified therapist.	Psychotherapy.org.uk
IMPARTS	General guidance and self-help on living well with a long-term health condition.	Resources & Self-Help (imparts.org)

SkinFood	Book on skin and diet by Dr Thivi Maruthappu	SkinFood – Your 4-Step Solution to Healthy, Happy Skin – Dr Thivi
The Pioppi Diet	Book on the Mediterranean diet by Dr Aseem Malhotra and Donal O'Neil.	
British Heart Foundation	Information on the Mediterranean diet.	Watch: What is the Mediterranean diet? - Heart Matters - BHF
	Tips for making meals more Mediterranean.	5 top tips for making your meals more Mediterranean - BHF
	Interactive activity including breakfast, lunch and dinner ideas that follow the Mediterranean diet.	Interactive: Make your meals Mediterranean - BHF
Diabetes UK	Information on the Mediterranean diet and a free, downloadable Mediterranean meal plan.	Mediterranean meal plan | Diabetes UK
Noom	A weight loss app – 4-week free trial. Educational content, personalized courses and (optional) coaching. Includes free personality quiz and calorie and macro calculator.	Noom: Stop dieting. Get lifelong results.
Noom Mood	Educational content, personalized courses and (optional) coaching. Activities include mindfulness and daily mood monitoring.	Noom Mood - Relieve Stress and Find Your Happiness (divinoom.wpenginepowered.com)

Self-compassion.org	Website focused on self-compassion by Dr Kristin Neff. Information, research and free activities/practices.	Self-Compassion
NHS	Information and tips for better sleep	https://www.nhs.uk/every-mind-matters/mental-health-issues/sleep/

APPLE, Asking People with Psoriasis about Lifestyle and Eating; PAPAA, The Psoriasis and Psoriatic Arthritis Alliance; FIRST, Foundation for Ichthyoses and Related Skin Types; IMPARTS, Integrating Mental & Physical healthcare: Research, Training & Services; HS, Hidradenitis Suppurativa; BAD, The British Association of Dermatologists; IAPT, Improving Access to Psychological Therapies; NHS, National Health Service; NICE, The National Institute for Health and Care Excellence.

*Development ongoing, not currently widely available.

Appendix 64: Push notification messages suggested by PPI contributors and Patient Organisation Leaders

Suggested by		Message
PPI Contributors	Male with X-Linked Ichthyosis	Taking time to love and care for your skin on a regular basis is important to help you and your skin feel better.
		When it comes to skin care, simplicity is key.
		Taking medication as prescribed by a doctor is more likely to help keep your symptoms under control.
		Eating healthy foods, such as green vegetables, lean proteins, oils and wholegrains, could help your skin.
	Female with rosacea	Your skin does not define you, in fact, it is the least interesting thing about you.
		Your skin is not your enemy.
		People love you for your heart and soul, your appearance does not change that.
		You are resilient and so is your skin.
		Your skin shouldn’t stop you from living in the moment.
		Living with a skin condition is a marathon, not a sprint – keep going, you can do this!
		You may not see big changes in your skin day to day, but small changes add up and can lead to a big change over time.
		The people you trust love you and want to support you.
		Knowing people who understand your condition can be comforting and validating.
		Millions of people worldwide have a skin condition. Although it can feel isolating and scary at times, you are not alone.

	Female with psoriasis	You are not alone. Support is available.
		There is so much more to your life than your skin.
		Covering your skin on the days you don’t want to show it can help you to get out there and enjoy yourself.
		You are an expert in your own skin condition. Your dermatologist can help you to find evidence-based treatments that work for you and your lifestyle.
		Learning to live with a skin condition takes time and, and patience is part of the process.
		You can adapt your wardrobe to suit your skin and the weather conditions, but it is important to wear what makes you feel good in yourself.
	Male with eczema	Learning to manage all aspects of your skin condition is a journey, and focusing on what is working well for you is most important.
		How do you feel about your skin today and why?
		I accept my skin, just as it is.
		You are unique, and so is your skin.
Patient organisations	The British Skin Foundation	You are not alone! 60% of people currently suffer, or have suffered, from a skin condition at some point in their lifetime.
		You don’t have to suffer in silence, healthcare professionals can provide physical and emotional support for your skin condition.
		Your skin condition is just a small part of who you are. It does not define you.

		If people can't see past your skin condition, are they worth your time?
		Educating people about your skin condition is your choice, not your responsibility.
		Everyone has skin, but no one has perfect skin.
		I can be kind and compassionate to myself.
	Eczema Outreach Support	Beauty is more than skin deep.
		Your skin tells a story about you.
		You shouldn't feel ashamed about your skin.
		Your skin tells a story about you and you should never feel afraid or ashamed to tell that story.
		Don't be afraid to challenge others if you don't feel seen or heard.
		Follow your dreams. Your skin will not stop you. You are stronger than that.
		Speaking up and asking for help is not a sign of weakness, everyone has limits and need support at times.
		Perfection is only a word. In real life it doesn't apply. We are all individuals.
	The Psoriasis Association	Health professionals are there to listen to your needs. A good health professional will work with you and support you to cope with and manage your skin condition.
		There are many treatments available and health professionals can help you to identify those that are most suitable for you and your life.

		Starting a new treatment plan? Having a follow up appointment scheduled with your doctor will ensure you have time to discuss how the treatment is working for you and to make any necessary changes
		There is no shame in admitting your skin condition is affecting your mental wellbeing. Health professionals can help you with this.
		Remember – it can sometimes take weeks before new treatments start to make a difference to your skin.
		There are many treatments available to help manage your symptoms. You might have to try a few before you find the one that works best for you.
		I choose to be kind to myself and my skin.
	Skin Care Cymru	I accept it might take time to find a treatment that works for me and my skin, and I will not give up.
		Keeping busy can help to avoid overthinking and scratching.
		Beauty comes from within.
		Stopping scratching the skin is hard, but there are strategies to help you.
		Your friends and family want to support you. It is important to make sure they support you in a way that you want and need.
		Speaking to other people living with your skin condition can help you to maintain positive outlook and feel part of a community.

		Eating healthily is good for your general health, but did you know it can benefit your skin and boost your mood too?
		It doesn’t matter what anyone else is thinking or doing, take care of your skin in a way that works for you and your life.
		There are other people out there living with the same skin condition who can support you.

Appendix 65: Reflections on the successes and challenges of PPI from the perspective of PPI contributors

Name	Feedback
Sue	I have found being part of the PPI group interesting. It has made me reflect on living with a skin condition and consider what it does mean for me. I feel that my contribution has been welcomed and valued and it is satisfying to think that my experience and knowledge may support other people living with skin conditions. It has not always been easy to find the time to take part alongside working full time but I was keen to continue as I recognise the benefits that the research and an app will bring for people living with skin conditions. Although I have made reference to the time factor conversely I feel that more frequent input would have maintained momentum. I am not clear about how the app will continue to be developed and maintained if funding is not made available to continue with the project. The PPI group often felt too small to really gather a varied and wide range of responses but I recognise that further work was being undertaken by the researchers to collect other responses from wider afield. The feedback received from the researchers has been detailed and welcome. The researchers have been sensitive but probing and appeared knowledgeable about the subject.
Daniel	I enjoyed working with the ppi group to create the app, there were challenges faced due to the changes on the person leading the project however in the end it found its comfort.

	I enjoyed being invited to zoom meetings to be shown the progress made and would love to be kept up to date on the success of the app. I was happy with the consistent emails allowing me opportunities to share my ideas. Though the project didn't always run smoothly, there were quiet spells where I didn't hear much from the group and didn't feel I could have helped as much as I wanted to. However in time these challenges were addressed. We were hoping to do a final review of the app on zoom but was unfortunately cancelled and we couldn't re arrange but I was glad throughout the project to help the way I did. On 2 occasions throughout the project I was contacted being told I would receive a financial gift for my help, however didn't receive anything. Overall I would say I enjoyed my work on the ppi group and would love to be involved with anything again. Despite the challenges faced we as a group were able to overcome them. And I enjoy sharing what I can in any way to help others who also suffer from skin conditions.

Appendix 66: Results on perceived trustworthiness of MiDerm from the acne interview study by Dale et al. (submitted)

Perceived trustworthiness of the MiDerm app

We recently completed eight online, individual interviews with participants who lived with acne and/or post-inflammatory hyperpigmentation and scarring (PIH&S). As a part of these interviews, we aimed to understand the perceived trustworthiness of an app developed for those living with skin conditions that is funded by an industry partner.

Six key concepts were identified from this data; (1) reputation of funding organization, (2) evidence basis of information, (3) patient involvement, (4) realistic expectation setting, (5) data protection concerns, and (6) look and feel of app.

1. **Reputation of funding organization**

Participants reported that the existing reputation of the organisation funding the research would influence how trustworthy they found the app. If they had an existing perception of the company as reputable, or if they had a positive experience with products developed by the company, this would improve trustworthiness. In addition to this, participants felt that an academic affiliation through university development would increase their likelihood to trust information given by the app.

> *"Well I know the company that you mentioned. I've used their products before and I think that their products are good. So definitely if I have a good experience with their product I'd be more likely to use it, or trust it." (Female, 30 years, Wales)*

However, some participants also had concerns. They explained that if the app was perceived to be encouraging use of, or selling, products produced by the funding organisation, this would reduce the perceived trustworthiness of information. They also mentioned that a perception of the funding organisation as costly would cause concern over the price of the app. One participant raised concerns over how far any industry partner could be trusted, and therefore felt it was impossible to entirely trust information developed by a partner organisation.

> *"I think that's the only thing like, if people are worried about, if, is there, I don't know if there's going to be a cost associated with the app or if it's, erm, going to be free to users, but that could be something that's a barrier for people, if it's associated with a brand." (Female, 29 years, Wales)*

2. Evidence basis of information

Participants emphasised that the evidence basis of information provided in the app was pivotal to its trustworthiness. They explained that those with skin conditions are often desperate for guidance and advice for self-management, and so it is important that information provided is research-informed. To improve trustworthiness, they suggested providing links to reputable guidance (such as NHS guidelines), referencing academic literature, and holding endorsements from dermatologists, health services.

> *"…you know, rather than just saying, 'Oh, some research has shown us that this works' but not saying what the research is. I'd probably want to look up what that research was, and where it was done, and you know, sort of what … you know, whether it's, you know going to be applicable to sort of my situation really. es, and patient organisations." (Female, 41 years, Wales)*

3. Patient involvement

Participants believed that involvement of people with skin conditions in the development and maintenance of the app to ensure the applicability of information would improve how trustworthy they perceived it to be. They reported that the inclusion of 'patient stories' within the app would evidence that those with skin conditions were considered in the app's development. In addition, participants suggested that the app should include reviews from those with skin conditions, and should be revised in accordance with feedback from users.

> *"… unless you've lived through that condition… I can tell you what it's like to live with cystic acne as someone who's got a background of potential polycystic ovary syndrome and who has had it since a teenager, you know… but I can't tell you what Rosacea's like… so yeah, I think gathering people's experiences and, and being able to help from that point of view and the good thing about the app is you're going to generally have people who, who are, erm in the situation using it." (Female, 29 years, Wales)*

4. Realistic expectation setting

Unrealistic claims made by the app would decrease it's trustworthiness, according to participants. They emphasised that the app should acknowledge individual different across conditions, users, and level of support needed, and not boast a one-size-fits-all approach. They reported that unrealistic claims led to reduced perceptions of trustworthiness, and would make them less inclined to use the app.

"Yeah, like, you know on toothpaste, when they're like, this clears ninety-nine, point nine-nine percent of your bacteria, it's like, as if! Just being realistic about things, I definitely think, as well." (Female, 20 years, Wales)

5. Data protection

Most participants reported that they would not be concerned about inputting their personal information into the app, so long as the information was strictly confidential and could be password protected. One participant had concerns over inputting personal data if GDPR data privacy principles were not adhered to. In addition to this, one participant explained the importance of allowing users to not include a photograph, or to include a photograph that did not include the hair.

"I've used an APP before. I'm not going to say the name of the company. But they always have you … want you to take a picture of yourself. But. I wear, I wear the hijab, for example, and if I have to do something like this I need to and grab a scarf, because I don't know who's going to see my picture. So if you could get, um, if you could change it a bit so that it's only your face, and not actually your hair, that would make it much better for me." (Female, 30 years, Wales)

6. Look and feel of the app

Participants said that a visually appealing design, with bright, calming colours, would encourage use of the app and improve trustworthiness. They explained that an app with a 'clinical' look and feel would be reminiscent of pharmaceutical companies, which would discourage trust and lead to the perception that the app was intended as a vehicle for selling products.

"Yeah, I mean I think, um, I think if it looks too clinical there's a danger of it being a bit like it is kind of, er, a sort of, you know, a pharmaceutical company and that it's, it's not, you know, sort of, not … but they're just trying to sell a product, erm. Whereas it's just … if it's more kind of, real people, you're a lot more … you're a lot more inclined to trust it and feel comfortable sort of, you know, joining any of the networks, or sort of reading the information that's there." (Female, 41 years, Wales)