- 1 A systematic review of the use of the Dermatology Life Quality Index (DLQI) in
- 2 routine clinical practice: evidence from 287 articles across 56 countries
- 3 Running head: Systematic review of use of the DLQI in routine clinical practice

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- 23 Engitix, Incyte, Indero, Insmed, Kymera Therapeutics, MoonLake, Novartis, Sanofi, UCB Pharma,
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- 1 Board for Amgen, has received payment or honoraria from L'Oreal and support from UCB
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- 3 pharmaceuticals, Lilly pharmaceuticals, L'Oreal, Novartis and UCB. Faraz Ali and Jeffrey Johns'
- 4 department receives income from royalties from the Dermatology Life Quality Index (DLQI) and
- 5 related instruments. Anjali Trivedi has no conflicts of interest to report.
- 6 Data availability: The data underlying this article will be shared on reasonable request to the
- 7 corresponding author.
- 8 **Ethics statement:** No IRB approval was required for this study.
- 9 Patient consent: Not applicable.

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12 What is already known about this topic?

• Although the DLQI is the most widely used measure for skin disease burden in clinical trials and research there is little evidence of its use in routine clinical use.

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What does this study add?

This study shows evidence of international use of the DLQI in routine settings, informing
clinical decisions and aiding in monitoring of treatment. The DLQI was embedded into
some clinics continuing routine practice. It gives some insights into healthcare workers
and patients experiences with the DLQI in routine settings and treatments for a large
number of countries and dermatological diseases.

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ABSTRACT

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- 2 **Background:** Although quality of life instruments are widely used in research it is challenging to
- 3 find evidence of their use in routine clinical use. The most widely used measure for skin disease
- 4 burden is the Dermatology Life Quality Index (DLQI), and its scores have validated clinical
- 5 meaning.
- 6 **Objective:** Although there is a substantial literature confirming the embedding of the DLQI in
- 7 clinical research and trials, this study aimed to identify evidence of the use of the DLQI in
- 8 routine clinical practice and explore the nature of its use.
- 9 Methods: The study followed PRISMA guidelines, and the protocol was registered with
- 10 PROSPERO. Medline (Ovid), Embase, Scopus and CINAHL (EBSCO) databases were
- systematically searched for articles describing studies using the DLQI in routine clinical practice.
- 12 Studies were excluded if participants were aged less than 16 years and if there were pre-
- determined treatment interventions as in a clinical trial. Information was extracted on
- publications' authors' opinions on the use of the DLQI in their routine practice.
- 15 **Results:** A total of 2,718 publications were screened and 287 articles met the inclusion criteria,
- reporting on 112 diseases and describing 66,434 patients from 56 countries, using the DLQI in
- at least 29 languages. 124 (42.2%) of the studies were reported as retrospective, 63 (22.0%)
- were observational, 52 (18.1%) stated DLQI data were retrieved from patient records, 29
- 19 (10.1%) as "real life", 39 (13.6%) reported "real world data", and 47 (16.4%) used consecutive
- 20 patient recruitment. 262 (92.0%) were conducted in a single country, 96 (33.4%) were
- 21 multicentred studies, 171 (59.6%) were conducted at a single site, 93 (32.4%) were conducted
- in hospitals, 66 (23.0%) specified outpatient clinics, 38 (13.2%) tertiary care, 4 (1.4%)
- community, 17 (5.9%) other settings and 35 (12.2%) unspecified. The most common diseases in
- 24 the study settings were psoriasis (106 studies, 36.9%), atopic dermatitis (32,11.1%), urticaria
- 25 (24,8.4%), hidradenitis suppurativa (22,7.7%), and vitiligo (17, 5.9%). Thirty studies (10.5%) used
- 26 DLQI score banding.
- 27 Conclusion: DLQI was widely used in routine care locations internationally, informing clinical
- decisions and monitoring of treatment. The DLQI was embedded into some clinics' continuing
- 29 routine practice.

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INTRODUCTION

The original article describing the DLQI stated "There is a need for a simple, compact uniform measure, applicable to patients with any skin disease, for use as an assessment tool in routine clinical practice"¹. There is a vast literature confirming the embedding of the DLQI in clinical research²⁻⁴, but this study's purpose was to collate the evidence of the use of the DLQI for that primary stated clinical purpose.

A systematic review of 22 randomised controlled trials (RCT)⁵ compared the additional use of patient reported outcome (PRO) measures to standard clinical care. Overall, studies reported a positive effect or gave justification for the use of a PRO measure. Many potential benefits of routine use of PROs in routine clinical dermatology practice have been described by an EADV Task Force on Quality of Life⁶ including improving patients' ability to discuss issues with the clinician⁷. Secrest et al.⁸ discussed incorporating PROs as a key indicator for clinical care, and emphasised the need to identify normal ranges for dermatology-specific PROs.

The DLQI¹ is the most widely used dermatology patient reported outcome (PRO) measure in routine practice and clinical trials9,10, because of the simplicity of reporting a single meaningful summary score, its ease of completion in two minutes, comparability between studies and over time as there is only a single version of the tool, and wide language accessibility¹¹¹. It is embedded in national guidelines and disease registries in >45 countries¹² and available in 138 translations¹³. However, users of the DLQI need structured access to evidence concerning its use. Our previous systematic reviews of 454 randomized controlled trials (RCTs) using the DLQI in 69 diseases and 43 countries³, as the primary outcome in RCTs⁴, as the benchmark comparator in the validation of 101 new quality of life (QoL) measures² and of DLQI validation data across 207 publications¹⁴ have highlighted the extensive use of the DLQI internationally and across many diseases and languages.

In a study of the practical reality of using the DLQI in a routine dermatology clinic ¹⁵ 417 patients attended and 268 questionnaires (64.3%) were completed. The DLQI information was used by clinicians in 64 consultations: in 37 (14% of 268), it influenced the clinicians' treatment decision-making. However, there has been no review published of DLQI use in routine practice. This aim of this systematic review was therefore to collate evidence of the use of the DLQI in routine clinical practice settings.

METHODS

For this study, "routine practice" describes the use of the DLQI within a routine patient-clinician interaction and included assignment of patients to a particular therapeutic strategy decided by the treating physician, not carried out as an interventional study and not decided in advance by

- 1 a trial protocol. The therapeutic decision fell within current practice and was clearly separated
- 2 from any decision to include the patient in a study. This specifically excludes randomised trials
- 3 where treatment intervention is determined by a study protocol, not by the care team. We also
- 4 Included therapeutic outcome monitoring studies.
- 5 Routine clinical practice occurs in a broad range of healthcare settings, including hospitals,
- 6 mental health facilities, rehabilitation centres, general practice centres, polyclinics and other
- 7 outpatient clinics. These settings may offer either physical or mental healthcare and may
- 8 provide care in both outpatient and inpatient environments.
- 9 Within the context of clinical practice, PROMs are used for individual patient management.
- 10 PROMs are systematically administered to patients to routinely monitor PROs in a standardized
- 11 manner. The PROM results may be used during patient-clinician interactions to inform
- 12 consultations/appointments, support patient-clinician communication, guide treatment
- 13 planning, and aid decision-making.

- 15 Additionally, we defined "retrospective" as a study based on existing data recorded for reasons
- 16 other than research or without an a priori research question. Even this definition is
- 17 problematic, because the data may be collected primarily for clinical decision making but with
- 18 some expectation of future analysis.

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Data sources

- 21 This study follows 2020 PRISMA guidelines for reporting systematic reviews and checklist 16. The
- 22 study protocol and detailed search strategy was published on PROSPERO Prospective Register
- of Systematic Reviews¹⁷ (CRD42022304734). Medline (Ovid), EMBASE, SCOPUS, and CINAHL
- 24 (EBSCO) online databases from 1st January 1994 (DLQI creation) to 2nd June 2023 were
- 25 searched and results corroborated independently by two authors (JJ, AT). Search terms
- 26 included 'DLQI' and 'dermatology life quality index'. Database specific "article type/study type"
- 27 keywords, language keywords (English) and age selection keywords were also used to search
- 28 the required types of study to be included e.g. MESH terms for RCT. Duplicates were excluded.

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Search strategy/Selection

- 31 Table 1 gives the eligibility criteria for included studies.
- 32 Search results were imported into EndNote20®, to keep track of references¹⁸. Two authors (JJ,
- 33 AT) independently compared study titles and abstracts retrieved by searches against the
- inclusion and exclusion criteria and examined full study texts potentially meeting the criteria

- 1 but whose abstracts lacked sufficient information. Rejected studies were recorded with
- 2 reasoning. A third author (FA) resolved and recorded any study selection disagreements. A
- 3 PRISMA flowchart gives search counts for inclusions and exclusions and reasons for study
- 4 exclusions¹⁶ (Figure 1).

Outcome measures extracted

- 6 Information was extracted on publications' authors opinions on the use of the DLQI in their
- 7 routine practice. Other detailed information recorded included the countries, number of study
- 8 sites and study settings, number of patients who completed the DLQI, mean/median age,
- 9 genders recruited, disease(s) studied, treatment(s), treatment duration, study design and study
- 10 period, if the study was retrospective, observational, real-world data or real life, used
- 11 consecutive recruitment and whether DLQI data were retrieved from patient records.
- 12 Additionally, data were recorded on the frequency and period of the DLQI data collection,
- mean/median DLQI scores, DLQI outcomes including any evidence of statistically significant
- 14 and/or clinically significant changes.

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Data extraction and synthesis

- 17 For data extraction, guidance of the Cochrane Handbook for Systematic Reviews of
- 18 Interventions was followed¹⁹. A REDCap database²⁰⁻²² (a secure web application for
- 19 building/managing online surveys and databases) was created based on the Cochrane
- 20 Handbook Version 6.2²³ and the updated guidance¹⁹ recommendations. The authors JJ and AT
- 21 independently extracted data from the included publications to parallel REDCap database
- 22 tables, and an adjudicator (JV) resolved any disagreements in data extraction. Missing data
- 23 were noted in the data templates, but none was sufficiently important to contact original
- 24 authors.
- 25 The DLQI was designed and validated for use in people aged 16 years and older ²⁴. But after
- searching the online databases, 79 were excluded because the participants were less than 16
- 27 years of age. Most of these studies utilized the Children's DLQI (CDLQI)²⁵: their inclusion from
- our initial search strategy did not include a method to sift these out.
- 29 A study's validity, reliability and relevancy can also be impacted by recruitment diversity bias ²⁶-
- 30 ²⁸. Due in part to genetic ancestry²⁹, minoritised populations can have different outcomes, and
- 31 thus recruiting for diversity is essential to elucidate any socio-demographic factors impacting
- 32 the study and results should be stratified by race/ethnicity if relevant to the study³⁰. This aspect
- is currently rarely addressed in systematic reviews. To raise awareness of this issue, appraisal of
- 34 representation of minorities ethnic participants in the studies was conducted using Naicker's
- 35 Critically Appraising for Antiracism Tool³¹.

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RESULTS

- 3 A total of 2,668 studies were provided by online database searching. There were 490 duplicates
- 4 and the remainder 2,178 were assessed from the articles' full text, of which 287 described
- 5 research on 66,434 patients meeting the inclusion eligibility criteria (Table 1). Publications
- 6 describing use of DLQI in routine practice have been increasing in number since 2010
- 7 (Supplementary Figure 1). The number of studies describing the DLQI used in routine clinical
- 8 practice published in peer-reviewed journals by year is shown is Supplementary Figure S1.

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Study sites and settings

- 11 Studies were conducted in 56 different countries and in at least 29 different languages. 262
- studies (92.0%) were conducted in a single country, and 96 (33.4%) were specified as
- multicentred studies, with 171 (59.6%) conducted at a single site, and 20 (7.0%) not specified.
- 14 93 (32.4%) were conducted in hospitals, 66 (23.0%) specified outpatient clinics, 38 (13.2%) 38
- 15 (13.2%) tertiary care, 4 (1.4%) community, 17 (5.9%) other settings and 35 (12.2%) unspecified.
- 16 124 (42.2%) of the studies were reported as retrospective; the rest were collecting DLQI data
- for a specific purpose within a routine clinical setting that was then reported within the
- 18 included study. Sixty-three (22.0%) studies were reported as observational, 52 (18.1%) stated
- 19 DLQI data were retrieved from patient records, 29 (10.1%) as "real life", 39 (13.6%) reported
- "real world data", and 47 (16.4%) used consecutive patient recruitment. 249 (86.8%) studies
- 21 used the DLQI for the reported study's purpose and 38 (13.2%) indicated they were using the
- 22 DLQI routinely without regard to the study. Patients from ethnic minorites were only reported
- 23 in the demographic data in 34 (11.8% of studies); in 251 (87.5%) of studies none were reported
- and two studies stated none were recuited. For all studies included, patient disease,
- demographics and study details based on keywords are given in Supplementary Table 1.

26 **Disease profile**

- 27 There were at least 112 different diseases or conditions reported. The most common diseases
- 28 in the study settings were psoriasis (106 studies, 36.9%), atopic dermatitis (32, 11.1%), urticaria
- 29 (24, 8.4%), hidradenitis suppurativa (22, 7.7%), and vitiligo (17, 5.9%) (Table 2).

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Treatments

- 32 The routine treatments used within the study setting were captured from the published data.
- These are shown in Supplementary Table 2, along with the diseases presented, treatment
- 34 duration, comments on the study design and the study period. We also captured the use of
- 35 biologics. These comprised dupilumab 21 studies, secukinumab 15, Ustekinumab 14,

- 1 adalimumab 13, guselkumab 9, omalizumab 9, etanercept 8, infliximab 6, ixekizumab 5,
- 2 brodalumab and tildrakizumab 4, golimumab 3, efalizumab and rituximab 2, risankizumab and
- 3 tralokinumab 1 study.

DLQI scores and other PRO/QoL measures

- 6 Data on DLQI scores reported are presented in Supplementary Table 3, including the frequency
- 7 DLQI was collected, the collection period, details of the DLQI, mean and medium DLQI scores
- 8 and DLQI outcomes. Any opinions about the use of the DLQI in their setting were also captured.
- 9 Very few studies reported the medium used for DLQI data collection e.g. paper, tablet, phone
- or computer in the setting, remote online or postal, so this data has not been presented. Thirty
- studies (10.5%) used DLQI score banding³²; 127 studies (44.3%) also used other PRO/QoL and
- severity scale measures in addition to the DLQI. Supplementary Table 4 presents these
- 13 PRO/QoL and severity scale measures collected by the studies, and the associated diseases.
- 14 Some author comments and opinions, and experiences of healthcare workers and patients with
- 15 the use of the DLQI in their routine practice setting, are given in Table 3.

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Retrospective studies

- 18 We determined 121 (42.2%) of the included studies reported themselves as retrospective
- 19 studies, based on this keyword. As a proportion almost twice as many retrospective studies,
- 20 49/121 (40.5%), stated DLQI data were retrieved from patient records, compared to non-
- 21 retrospective studies 52/287 (18.1%). 23/121 (19.0%) retrospective studies, compared to
- 22 29/287 (10.1%) non-retrospective, were reported as "real life" studies and 33/121 (27.3%)
- 23 compared to 39/287 (13.6%) were reported as "real world data". However, only 10/121 (8.3%)
- 24 retrospective studies compared to 47/287 (16.4%) non-retrospective studies used consecutive
- 25 patient recruitment, and 40/124 (32.3%) retrospective studies compared to 65/298 (21.8%)
- 26 non-retrospective reported themselves as "observational studies". Interestingly, only three
- 27 retrospective studies used score banding (2.5%) compared to 30 (10.5%) for all included
- 28 studies.

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Information provided

- The authors of the 287 included studies categorised them as addressing quality of life 141
- 31 (49.1%) studies, efficacy 84 (29.3%), safety 50 (17.4%), impact of disease 36 (12.5%), drug
- 32 survival 12 (4.2%), treatment outcomes 11 (3.8%), depression 9 (3.1%), tolerance 9 (3.1%),
- anxiety 6 (2.1%), disease burden 6 (2.1%), cost, financial burden or socioeconomic impact 5
- 34 (1.7%) and stigma and self-esteem 5 (1.7%). Other descriptors included sexual, dosage, sleep

and coping: some studies occur in multiple categories. Although every study used the DLQI, some did not explicitly mention they were studying QoL.

DISCUSSION

This review showedextensive DLQI use in clinical care routine settings. We excluded RCTs as they are not routine care, and we previously systematically reviewed DLQI use in that context³. Finding evidence of routine clinical use of a measure is challenging, as routine use is rarely reported. Our key approach has been to identify articles describing where DLQI information had been collected routinely and then retrospectively assessed.

DLQI data taken from patient records, consecutive recruitment (not necessarily all patients but maybe a subset e.g. one disease), or collection of DLQI data over a long time-period (unless the disease studied necessitated this) may be indicators of routine use. However, none provide definite evidence of routine use. We therefore considered "routine use" only where DLQI data had already been collected and was used retrospectively for the published study.

Of included studies, 121 (42.2%) stated they were retrospective i.e. they analysed data previously collected before the study. The rest (prospectively) collected DLQI data for a specific purpose within a routine setting. Almost twice as many retrospective studies than non-retrospective ones stated DLQI data were retrieved from patient records, were "real life" studies, or "real world" data, suggesting studies were of DLQI routine use in a routine clinical setting. However, a declaration of "consecutive patient recruitment" or studies reporting themselves as "observational studies" does not necessarily imply "routine use", particularly where consecutive may in some cases mean the next patient taken when convenient, rather than strictly consecutive arrivals.

Where a study aims to capture aspects of treatment (e.g. QoL, efficacy or tolerance) within a specific clinical setting, this is a local aim for which the outcome would not be relevant to a different setting. This is different from the goal of an RCT where broader representation of patients from different settings is desirable, where sufficient patient numbers to power the trial are needed, and the trial is designed to mitigate differences between study settings. However, only 59.6% of studies were conducted at a single site, with 33.4% multicentred studies (7.0% did not specify). These were often conducted across linked settings within a broader health care network.

The value of PRO measures in routine clinical practice has been discussed since 2004³³. Many studies have considered which characteristics of PROMs are important for use in clinical

practice³⁴ and investigated the impact of routine collection of PROMs on patients, providers and health organisations in different settings ³⁵, their impact on health outcomes³⁶, and implementation factors³⁷.

The importance of involving patients and the public in development and evaluation of health care service delivery is increasingly recognised³⁸. Patient Reported Outcomes (PROs) are instruments developed to ensure valid and reliable measurement of outcomes, such as QoL measures, or functional status associated with the health care received. PRO measures (PROMs) can provide a better understanding of the impact of an intervention and/or service on a patient³⁸.

 Studies were conducted in 56 different countries and the DLQI used in at least 29 different languages, indicating the impact of the DLQI internationally in routine practice. This may be due to its wide acceptance³, simplicity of reporting a single score that is meaningful³², ease of completion³⁹, knowledge of the minimum clinically important score difference^{40,41} to aid score interpretation, stability and familiarity over time due to there being only a single version of the tool, and being embedded in national guidelines and disease registries in >45 countries⁴² with availability in 138 translations¹³.

Results indicated inpatient therapy may improve QOL of patients with dermatological diseases and clinicians should consider assessment of DLQI to inform therapy decisions⁴³. If QoL measures are used routinely, high scores indicating severe disability provide an additional alert over the need for intervention⁴⁴.

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Several publications provide detailed analysis of DLQI use in routine clinical practice (see Table 2). Hahn et al.⁴⁵ investigated DLQI use in a midwestern US urban clinic and collected feedback from the healthcare team and patients. Harlow et al. ⁴⁶ examined use of the DLQI in primary care settings and recorded responses about ease of use and patient acceptability in general practice. Dilworth et al.⁴⁷ performed an audit of DLQI use in routine practice in consultant-led

and specialist nurse-led dermatology clinics clinics and reported some barriers and benefits.

A strength of this review is the large number of relevant articles identified. However, a limitation was to include only English language articles. Additionally, articles may not have been indexed in the databases we searched, as they only index specific non-English language journal articles if titles, keywords and abstracts are in English.

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Only 11.8% of studies reported ethnic participants, with the recruitment strategy unclear in 88.2%. Usually, it was unclear whether the recruitment ethnic mix was representative of the populations studied. Only 2.1% of study reports justified or appropriately explained results stratified by race/ethnicity. Differences in study outcomes for minority ethnic populations were

- 1 appropriately addressed and interpreted in only 5.2% of studies. It is important to publish data
- 2 on subjects' ethnicity as many dermatological conditions are affected by race and skin colour 48-
- 3 ⁵⁰.
- 4 Inevitably many health care settings using the DLQI routinely have not been identified as we
- 5 could only find those described in articles reporting specific studies. However, this review does
- 6 produce a snapshot of how and where the DLQI is being implemented, routinely in the case of
- 7 retrospective studies, or to achieve specific goals or data in a routine setting in others. It would
- 8 be of interest to carry out a broader systematic review, to assess from published reports how
- 9 many practitioners used any patient reported outcomes (including the DLQI) in their routine
- 10 clinical practice. The best direct way to measure how common DLQI use is in routine practice
- would be to identify a random sample of physicians' offices around the globe and ask for
- 12 completion of a questionnaire concerning the use of the DLQI. However, our study reports
- 13 published evidence of use, whereas a questionnaire survey would provide descriptive, rather
- 14 than evidence based, data.
- 15 The final paragraph of the original 1994 article describing the DLQI¹ stated "We hope that the
- use of the DLQI in the routine clinical assessment of patients with skin disease may make the
- patient-physician interaction more patient-centred by highlighting the psychosocial influences
- on the individual patient's well-being, as well as providing a useful practical measure for regular
- 19 use." This systematic review provides evidence that some of these hopes have been met.

CONCLUSION

REFERENCES

- 21 This study has revealed evidence of extensive use of the DLQI in routine settings from a series
- of studies including >66,000 patients from across 56 countries and in 112 different diseases.
- 23 Some articles describe the DLQI being embedded into continuous routine practice. This study
- 24 provides evidence of a successful translational journey of a QoL measure from research to
- 25 supporting clinical practice.

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Figure legend

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Figure 1. Identification, screening and inclusion of articles.

1 Table 1. Eligibility criteria for study selection.

Variable	Inclusion	Exclusion
Patients	- Adults ≥ 16 years, any gender, ethnicity, settings,	- Persons under the age of 16
	countries	
	- Any inflammatory and non-inflammatory	
	dermatological conditions	
Methods	- Full papers in peer-reviewed journals	- Not in English language
	- Published between January 1994 and June 2023	- 'Grey' literature including
	- Treatment given (described in the study) should	dissertations, conference abstracts,
	be the standard care provided to patients in that	reports, editorials, letters to editors,
	setting, that has been implemented into the routine	commentaries, protocols, reviews,
	practice of the setting, with its use being at the	conference proceedings, and
	discretion of the clinician. May include any drug,	dissertations
	therapeutic intervention, alternative or traditional	- Any study with an intervention
	medicines, educational or lifestyle interventions.	determined by a trial/study protocol
Setting	- DLQI used in routine practice	- No DLQI data given or setting is not
		routine care e.g. randomised controlled
		trial

Table 2. Diseases studied

	Number of studies	%
Psoriasis	106	36.9%
Atopic dermatitis	32	11.1%
Urticaria	24	8.4%
Hidradenitis suppurativa	22	7.7%
Vitiligo	17	5.9%
Eczema/Hand eczema	17	5.9%
Acne	15	5.2%
Alopecia	10	3.5%
"Any skin disease"	8	2.8%
Prurigo nodularis	8	2.8%
Pruritus	8	2.8%

Table 3. Selected comments and opinions of authors of articles

Reference	Authors comments and opinions
⁴³ Adisen 2015	Results indicated that "inpatient therapy may improve QoL of patients with dermatological diseases and that clinicians should consider assessment of DLQI to determine the therapy option for a patient".
⁴⁴ Ayyalaraju 2003	"If QoL measures were used routinely as one aspect of recording skin disease status, high scores indicating severe disability would provide an additional alert to a physician over the need for intervention".
⁵¹ Bardazzi 2020	Routinely recorded patient compliance to therapy and administered DLQI questions to their patients, "so we were able to verify their scores retrospectively from the hospital records. This score permit us to evaluate with a number the adherence to the therapy".
⁵² Berg 2011	"The choice of DLQI for evaluating QoL in these acne patients may be discussed. However, DLQI was chosen though there are more acne-specific instruments available. This choice is based on the fact that DLQI is easy to use, has previously been shown to measure impact of acne on QoL and the results can be used for comparison of other skin diseases". "in this study it was again demonstrated that DLQI can be used to evaluate treatment effects in acne".
⁵³ Cakmak 2023	"The DLQI is routinely administered to patients when they attend the allergy clinic for an omalizumab injection every 4 weeks".
⁵⁴ Chaptini 2016	This is a retrospective longitudinal study. "A strength of this study is that the DLQI was used to assess QoL for all patients, which, as described previously is a highly validated measure of QoL".
55Dalgard 2020	"The use of validated patient-reported outcome measures, such as the DLQI and the HADS, to guide clinical decisions, to assess improvement and to evaluate the effectiveness of the clinical service is appropriate, meaningful and feasible".
⁵⁶ Davies 2008	"Concerning patients views of the appropriateness of discussion of their HRQoL in their consultation, the mean ± SD score of patients who had QoL discussion was 4.9 ± 1.2, which was similar to that of patients who did not have HRQoL discussion (4.5 ± 1.5)".
⁵⁷ Dilnawaz 2013	"PASI and DLQI combined can thus be quite helpful and can have an impact on the overall care and the treatment plan". They noted that "There is a very high success rate of accurate completion of the DLQI. However, sometimes subjects do make mistakes".
⁴⁷ Dilworth 2015	"We recommend that PASI and DLQI should be recorded routinely in all new and return patients". "Performing PASI and DLQI assessments in clinic was beneficial. For new patients these were used as an aid to guide treatment. Patients with mild psoriasis were offered topical treatments and/or phototherapy while patients with severe disease were considered for systemic agents or admission. Patients in clinic are often seen by different doctors at their return appointments. Carrying out PASI and DLQI assessments offers a more standardised method of monitoring patients, reducing inter-observer variability. Enhanced nursing resources, both as specialist nurses to counsel patients as well as outpatient nursing staff to aid with performing the quantitative measurements, and to hand out questionnaires in advance of the consultation, would all aid in a more holistic consultation."
⁵⁸ Hagg 2015	"The strength of DLQI is the validity of the questions reflecting the reality of the patients' experience of living with the skin disease. However, DLQI is a self-reported measurement which may be affected by a number of unmeasured factors, and the comparability between individuals can be questioned. However, as both the patients' suffering and the societal costs are better expressed by the DLQI than by the PASI10, it is important to emphasize the importance of combining the DLQI with the PASI in the decision process when considering a biological therapy".
⁴⁵ Hahn 2001	"The DLQI is an easily administered instrument with a rapid method to measure QOL in various skin conditions. It is especially valuable because it can be readily used in a busy clinic. This index seems to capture data of greatest relevance to the dermatology population. The scoring system is straightforward. Our studies further show the reliability and validity of the index in a cross-cultural setting". "We find that the DLQI is a useful instrument for obtaining information about the impact of dermatologic disease on a person's QOL. The instrument is efficient to use and the form is easy to complete". "In general, patients seemed to be able to fill out the DLQI with minimal difficulty."
⁴⁶ Harlow 2000	"The DLQI was easy to use in general practice. It was acceptable to the patients, who found it quick and easy to complete: all but one of the patients completed the entire questionnaire correctly. Scoring was also quick and simple".
⁵⁹ Kinahan 2009	"The DLQI is an excellent clinical tool to measure how much the patient's treatment-induced skin problem has affected their skin in the past week. It measures broad categories that can affect the patient's QOL such as effects of actual dermatologic symptoms (itching, scratching) feelings related to the skin issues (embarrassment or self-

consciousness), effects on daily activities, leisure activities, work, school and gersignal relationships. In retrospect, it was not the ideal tool to measure these same effects in a long-terms univor population because many of the demandogic issues have reached." "The UsQ was a valid and reliable scale for assessing the influence of Skin problems on QoL". "The use of questionnaires such as DQI and PORM in Clinical practice," two snot feasible to measure indices such as body surface area (BSA), psoriasis area and seventy index (PASI), and dermatology life quality index (DQI) forceds hashert at every patient vistr". "Mazzotti 2003 "For this purpose, a short self-evaluation instrument such as 'the DQI's is an asset in every busy dermatological clinic". "This study suggests that the DQI performs well in Italian patients with psoriasis, in addition to those populations previously studied; the instrument is short and easy to administer to large numbers of patients even in busy demandological clinics. A valid and reliable quality-of-life, measure such as the DQI Quit as all to all both clinical and policy decisions in dermatology." "Meeuwis 2011 "deally, the physician takes the initiative to ask about QoI and sexuality. Optionally, a very short disease-specific questionnaire such as the DQI, which is practical and of clinical value when used in a busy clinical setting, may be used." "Nayak 2018 "As poriasis is a chronic disease with periodis of exacerbation and remission, DQI can and as a reference score, which can be useful in determining the change in QoI before churing, and after treatment due to significant postering may be used." "Sporial and the properties of the patient following remission or treatment." "In the present study, the most specific patient measure, the DQI, and solve the subject of the properties of the patient following remission or treatment." "Reinholz 2015" "Reinholz 2015" "As a relatively simple and quick questionnaire, it should also be suitable in the clinic setting as an adjunct		
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clinical value when used in a busy clinical setting may be used". "As psoriasis is a chronic disease with periods of exacerbation and remission, DLQI can act as a reference score, which can be useful in determining the change in QoL before, during, and after treatment due to significant, psychological and physical risk in psoriasis". "This study showed that psoriasis affects DLQI and that the impairment of QoL is directly proportional to the severity of psoriasis measured by PASI. The lowering in DLQI following decrease in PASI denotes the psychosocial wellbeing of the patient following remission or treatment". "In the present study, the most specific patient measure, the DLQI, was also the most responsive to change, as expected". "The DLQI has some drawbacks in its present form but probably represents a good compromise between the generic and specific. It can be used in any dermatological group and yet it can be responsive to change, as expected". "The DLQI has some drawbacks in its present form but probably represents a good compromise between the generic and specific. It can be used in any dermatological group and yet it can be responsive to change, as expected". "The DLQI has some drawbacks in its present form but probably represents a good compromise between the generic and specific. It can be used in any dermatological group and yet it can be responsive to change, as expected." "The DLQI has some drawbacks in its present form but probably represents a good compromise between the generic and specific. It can be used in any dermatological group and yet it can be responsive to change, as expected." "The DLQI has some drawbacks in its present form but probably represents a good compromise between the general as an adjunct to clinical observations. This would make it an important adjunctive assessment tool in chromation under the progress of scar treatments." "Thus, the DLQI allowed us to assess valuable information that we would have missed without its use and that would have been hard to come by using othe	⁶³ Mazzotti 2003	Italian patients with psoriasis, in addition to those populations previously studied; the instrument is short and easy to administer to large numbers of patients even in busy
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the follow-up of these patients". "The information was used more frequently if the patient was suffering from an inflammatory condition. The DLQI information was drawn on in 57 consultations (32.9%) with patients suffering from inflammatory conditions. In comparison, QoL information was used by the clinicians in only 7 consultations (8.1%) with patients suffering from non-inflammatory". "Specialist nurses used the DLQI more than any other group in their treatment decision-making. GPs with a special interest in dermatology used the DLQI information during 25 consultations (43.1%) and this influenced their treatment decision-taking in 21 (36.2%), more than the other groups (p < 0.01)". "Results showed that by using simple to administer questionnaires, could quickly and easily assess QoL of older people. The DLQI is a rapidly applied questionnaire that gives a good indication of dermatology QoL in older people". "We would recommend using the DLQI and HADS for a quick and easy assessment of patients within the setting of busy dermatology clinics". "Isojevic Timotijevic 2013 "analyzing not only the total scores of the questionnaires, but also the EQ-5D dimensions and DLQI and PDI subscales and their relationships with other variables (e.g. sociodemographic and clinical characteristics) allowed identification of psoriatic patients at risk of a higher QoL impairment and in particular specific problems that may affect their QoL "2Sondermann," "Using the DLQI alone, clinically important levels of depression, anxiety and addictive behaviour may be missed. Patients more severely affected by psoriasis and patients with	⁶⁸ Reinholz 2015	tool for monitoring the progress of scar treatments". "Thus, the DLQI allowed us to assess valuable information that we would have missed without its use and that would have been hard to come by using other methods. Not only does this demonstrate the DLQI's effectiveness as a diagnostic tool, it also shows how the use of a single questionnaire might lead to overlooking important information thus establishing the importance of a multi-level diagnostic approach". "Since a significant association between pathological scarring and varied intensities of influence on QoL could be established through this study, the general use of the DLQI or other QoL measures during scar
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		sociodemographic and clinical characteristics) allowed identification of psoriatic patients at risk of a higher QoL impairment and in particular specific problems that may affect
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⁷³ Szepietowski	"We demonstrated that DLQI can be successfully used for the assessment of QoL in large populational studies. This instrument is easy and quick to complete and can also be
2009	employed in QoL evaluation among older patients with skin diseases".
⁷⁴ Tang 2013	"Attending dermatologists or physicians should be encouraged to assess patients' QoL because management decisions are partly guided by the impact of psoriasis on this
	important parameter. The DLQI and SF-12v2 are two practical QoL assessment tools".

MEDLINE Ovid (n = 1022)
Embase Ovid (n = 317)
CINAHL EBSCO (n = 549)
SCOPUS (n = 780)
TOTAL (n = 2668)
Duplicates (n = 490)

Duplicate Records removed
before screening (n = 490)
Articles screened in EndNote for eligibility (n = 2178)

287 studies included in review including 121 retrospective studies

Inclusion criteria applied by search engines where applicable i.e. English language, journal articles, peer reviewed

Screening in EndNote records:

Not DLQI in routine practice (n = 1445)

Not peer reviewed (n = 42)

Not >=16 years old (n = 79)

Article not English language (n = 3)

Duplicate (n = 102)

Full text not available (n = 6)

Systematic review/meta-analysis (n=164)

Other (n = 50)

Total excluded (n = 1891)