Exploring the User Perceptions in the Development and Use of an MHealth App for Parkinson's Disease

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In Memory of my Mother (Fatema),

Who passed away without seeing me achieving my dreams. Mum made an untold number of sacrifices for me to pursue my schooling then left without having a chance to celebrate my achievements. Mum you are my great inspiration to complete this thesis, this work (thesis) is dedicated to you with my eternal love and appreciation.

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External outputs

The work from this thesis have been presented at various local and international conferences and abstracts of these presentations have been published in the following journals:

1. Chapter 4: Amani Khardali, Louise Hughes, Mark Wardle and Emma Lane. Use of iPad Based Pre-assessment Questionnaires in Parkinson's Clinics: A Qualitative Study of Patients' Perceptions. Parkinson's UK Research Conference 2018. (Poster presentation at the Research Conference Workshop 12th -13th November 2018 York, UK).

2. Chapter 5: A. Khardali, L. Hughes, E. Lane. Use of e-PROMs in Parkinson's disease clinics: A qualitative study of healthcare professionals' perceptions. Movement Disorder Journal 2019. 34 (supplement 2). (Poster presentation at the International Congress of Parkinson's Disease and Movement Disorders 22nd - 26th September 2019 Nice/France).

3. Chapter 6: A. Khardali, L. Hughes and E. Lane. An exploratory study of the perceptions of people with Parkinson's disease regarding the use of technology on medication reporting. International Journal of Pharmacy Practice 2020; Supplement 1: 44-87. (Poster presentation at the Health Services Research & Pharmacy Practice Conference, 16th –17th April 2020, Cardiff, UK).

Summary

Parkinson's disease (PD) is a chronic, progressive disease of the nervous system caused by the degeneration of the dopaminergic neurons in the mid brain, PD specific patient-reported outcome measures (PROMs) allow the comprehensive evaluation of the PD symptoms and its treatment from patients' perspective (e.g., UPDRs, NMSQuest, and PDQ39). While traditionally, paper versions of PROMs have been used to assess patients when they attend their regular clinic, this has not been regularly captured in a readily accessible format to show changes in symptoms over time. Technological advances offer alternative, simple ways to collect PROMs in a hospital setting in a timely manner. Electronic collection of PROMs (e-PROMS) has been variously introduced to improve the collection of patient's data within clinics. However, there has been no published evaluation on the usefulness of such digital technology in the routine collection of patient data. In 2016, a prototype iPad-based app was developed and piloted by a group of specialists in PD at Cardiff University (neurologists and pharmacists) as an assessment tool to gather the information of people with Parkinson's (PwPs) in a clinic setting. Despite positive feedback about using this iPad app, the need for further study was demonstrated to investigate the integration of this iPad app into regular clinical practice and evaluate how clinicians could utilize this information in their consultations.

The aims of this thesis are therefore to: (1) understand the needs and preferences of PwPs, their carers, and healthcare professionals regarding the use of a smart-device-app to enhance data collection in clinical-setting, and (2) understand the needs and preferences of PwPs regarding medication management and the potential for a smart device app to assist.

Multistage, mixed-methods studies were used involving PwPs, their carers, and healthcare professionals which identified the need for further patient-related information to be used during consultations in order to improve patients' understanding of their condition, enhance communication during consultations, and support patients' management.

Stage 1: Focus groups were conducted with participants recruited from Parkinson's UK support groups by using purposive non-random sampling. Each session was audio-recorded, transcribed verbatim, coded, and analysed using thematic analysis.

Stage 2: A mixed-methods study in two phases with PD healthcare professionals were conducted. In phase I, PD nurse specialists (PDNS) from the UK completed an 18-point survey and the data were analysed using descriptive statistics. The data was used to design and focus phase II in which semi-structured interviews were undertaken. Interviews were audio-recorded, transcribed verbatim, and analysed using the Consolidated Framework for Implementation Research.

Stage 3: A mixed-methods study in two phases with PwP was conducted. In phase I, PwP completed a questionnaire including closed and open-ended questions exploring views to using electronic self-reporting was distributed to PwP across the UK. The data was used to design and focus phase II in which semi-structured interviews were undertaken. Interviews were audio-recorded, transcribed verbatim, and analysed using the thematic analysis.

Findings from these studies reported that a mHealth app could be a useful intervention with the primary aim of focusing a consultation on the patients' needs and enable improved medication management. A range of potential advantages were reported and some of concerns to mHealth app use were highlighted. The participants were supportive of the development and use of a mHealth app and a series of recommendations were produced that could aid the design and integration of such an intervention in clinical setting. Overall, the use of an mHealth app appears to be a useful and acceptable to facilitate data collection in clinical-setting and support patients with management of their medications.

CONTENTS

List of Abbreviations

PD	Parkinson's Disease
PwP	People with Parkinson's
HCPs	Healthcare Professionals
PDNS	Parkinson's Disease Nurse Specialists
PROMs	Patient-Reported Outcome Measures
E-PROMS	Electronic-Patient-Reported Outcome Measures
EHR	Electronic Health Records
App	Application
mHealth	Mobile-Health
NMS	Non-Motor Symptoms
NMSQuest	Non-Motor Symptoms Questionnaire
NMSS	Non-Motor Symptoms Scale
MDS-UPDRS	Movement Disorder Society- Unified Parkinson's Disease Rating Scale
EQ-5D	European Quality of Life-Five Dimension Scale
SF-36	Short Form-36 Quality of Life Questionnaire
SCOPA-AUT	Scales for Outcomes in Parkinson's Disease-Autonomic Questionnaire
PDQ-39	Parkinson's Disease Questionnaire-39
HY	Hoehn and Yahr Scale
MCR	Medical Research Council
TAM	Technology Acceptance Modal
UTAUT	Unified Theory of Acceptance and Use of Technology
CFIR	Consolidated Framework for Implementation Research
SPSS	IBM SPSS statistics data editor® version 20
UK	United Kingdom
NHS	National Health Service
MDT	Multidisciplinary team
MMAS-4	Morisky Medication-Taking Adherence Scale-4 Items
NICE	The National Institute for Health and Care Excellence
MAO-B	Monoamine oxidase-B Inhibitors
COMT	Catechol-O-methyltransferase Inhibitors
PPI	Patient and Public Involvement
RCT	Randomized Controlled Trial

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Chapter 1: General Introduction

1.1 LITERATURE COLLECTION FOR THIS THESIS

According to Mertens (2015), there are several reasons for studying the current literature prior to starting research on a particular subject. Identifying what has been done before and what type of knowledge is available is the most apparent way to avoid repetition. To get a comprehensive insight into this subject, the researcher started by studying books related to methodology (qualitative, mixed-methods), scientific articles and grey literature (e.g., Google Scholar, Google Search, Ethos Library (theses), government websites (e.g., NHS Wales), the Parkinson's UK website, and the National Institute for Health and Care Excellence website (NICE) to get an idea of current research in the area of mHealth for Parkinson's disease. Relevant books were found in the Library of Cardiff University, and reviewed articles were found through database searches, such as Medline via Ovid, Scopus, IEEE Xplore Digital Library, and Google Scholar. Several keywords were used in the searching process, such as 'mHealth apps', 'Parkinson's disease', 'technology development', 'E-health', 'digital technology', 'nonmotor symptoms apps', 'PROMs', 'motor symptoms', 'e-PROMs', 'EHRs', 'intervention adoption' and 'implementation process', both separately and in combination with each other. This made it possible to understand the relevant literature, methods, and framework for this study.

Reading the literature is also essential, so a strong argument for the chosen research problem can be clarified (Mertens 2015). The literature search conducted broadly in Chapter 1 and in more depth in Chapter 3 supports the fact that more research is still needed regarding the innovation 'mHealth apps for PD' and how they can be developed, used, and adopted from a stakeholder's perspective, both people with Parkinson's (PwPs) and healthcare professionals (HCPs). This would help app developers and researchers to create relevant interventions in a wider context, both for science and practice.

1.2 INTRODUCTION

Today, technology offers easy and flexible tools for collecting patient information in a hospital setting (Cole et al. 2006; Richter 2006). These can allow HCPs to have a more interactive role with their patients in delivering clinical health services, including monitoring, tracking, and managing a patient's condition or treatment, and educating patients regarding their condition.

The digital transformation in healthcare, which aims to improve communication between HCPs and give patients easy access to their care, is one of the essential changes made across healthcare organisations in England (NHS England 2019a). In 2016, a published POSTnote was issued by the Parliamentary Office of Science and Technology that explained the plans and challenges in implementing and linking health information technology resources (e.g., Electronic Health Records (EHRs)) across the primary, secondary, and social care systems. If implemented, this will be intended to fundamentally transform the English National Health Service (NHS) to make patients' records closer to being paperless by 2020 (Bunn and Crane 2016). EHRs contain information related to medical history, treatment, health, and lifestyle, such as diet and exercise, and the intention is to make this type of information accessible to both patients and HCPs to improve the quality of care provided and engage patients in making decisions about their own health (Bunn and Crane 2016).

In addition to improving patient care, NHS England also aimed to implement EHRs to provide researchers with a more accurate tool for data collection and analysis (Bunn and Crane 2016). However, this has highlighted several challenges that need to be considered during the implementation and use of EHRs, including interoperability across different databases, staff training, and maintaining the privacy of patient data. Following this note, in 2019, NHS England published a long-term 10-year plan that aims to accelerate the redesign of patient care; specifically, Chapter 5 of this plan focused on upgrading digital technology to extend digital access to health services for patients and their carers, to better manage their health conditions and improve HCPs' access to patient records (NHS England 2019b).

Similarly, in Wales, the increased demand for technology use to improve healthcare services was identified in a 2015 report by the Welsh government titled 'A Digital Health and Social Care Strategy for Wales' (Welsh Government 2015). The report detailed the strategy and vision of using technology to improve the health and wellbeing of the people of Wales over the next five years (Welsh Government 2015). It supports the transition from paper-based to electronic records, making medical records accessible to all patients online and encouraging the use of smartphones and devices to manage patient health (Thomas 2015). NHS Wales is still working towards implementing EHRs across different health boards in order to achieve this vision (Wales Audit Office 2018; NHS Wales 2019).

The Welsh Minister for Health and Social Services published a set of principles aimed at providing better care and improved value for money for the NHS within Wales (Aylward et al. 2013). This set of principles, referred to simply as prudent healthcare, aims to place greater value on patient outcomes instead of the number of medical procedures provided. Prudent healthcare highlighted a set of six principles as follows:

- Prioritise the care by treating patients' greatest need first;

- Do no harm;

- Follow appropriate procedures to achieve the desired outcomes;

- Engage patients in their care;

- Apply evidence-based approaches within practice; and

- Establish health by engaging the public and patients in patient care.

Prudent healthcare also emphasised the need for co-production, a process by which HCPs, patients, and carers of patients all contribute to the improvement of patient health and wellbeing (Aylward et al. 2013). According to Batalden et al. (2016), co-production in healthcare is considered an interdependent work of both professionals and users in order to design, create, develop, deliver, assess, and enhance the relationships and measures that

influence health. In this case, the patients and HCPs have an equal role during a clinical encounter to ensure that the provided care is appropriate and meets the patient's needs.

The encounter between HCPs and patients in this care is recognised as a meeting of two experts. The HCPs have knowledge and experiences of diagnosis, aetiology, prognosis of condition, and treatment options, while patients have knowledge and experiences of living with disease, social circumstances, and attitudes to risks and personal preferences (Realpe and Wallace 2010). Hence, co-production depends on the sharing of information and decision making between patients and HCPs. In the literature, shared care, co-care, co-production, co-creation, and co-design are related concepts that in different ways emphasise the need to engage and encourage the interaction between patients and HCPs in the healthcare management process and are often used interchangeably (Schwarz et al. 2016).

Co-production can also support the movement towards patient-centred care, where patients and their carers regain their position at the centre of all decisions and plans about their own healthcare. According to the Institute of Medicine, patient-centred care is providing care that is respectful of and responsive to individual patients' preferences, needs, and values, and ensures that patients' values guide clinical decisions (Institute of Medicine (US) 2001). A previous study has shown that using a patient-centred care approach in clinical practice has the potential to decrease annual costs while enhancing the quality and safety of healthcare (Bertakis and Azari 2011). However, the findings of this study need to be interpreted with caution for several reasons. The study was based on residents' physicians rather than practicing physicians, and the study was conducted in a university hospital; therefore, the findings from those delivering and receiving care in other settings may be different. Also, this study was conducted in the US, where they have a different healthcare system from the UK. However, its findings may give insight into the positive impact of using a patient-centred care approach, with the potential to improve the patient's knowledge and the relationship between HCPs and patients, and reduce the need for additional speciality referrals, diagnostic testing, and hospital care (Bertakis and Azari 2011).

NHS Wales has encouraged the movement towards a patient-centred care approach within several health boards in Wales; for example, one of the Welsh health boards has started to pilot and implement a system called 'Patients Know Best', which is an application (app) that links with a patient's EHR and enables them to have more control over their medical information, such as accessing and viewing test results and medication, and contacting their HCPs to report any issues or to obtain advice (NHS Wales Governance 2016; Limb 2017). The findings of several case studies that have been done to evaluate this system have shown that it was successful in a range of different health departments, such as emergency care and chronic conditions, as well as reporting recommendations to adapt and implement this system in other departments within the health board (Patients Know Best 2019).

All the above-mentioned initiatives aim to encourage patients to participate in the design and delivery of healthcare services, as they may have an essential role to play in improving the quality of the healthcare they receive, improving patient outcomes and facilitating access to information. Furthermore, these initiatives for establishing EHR systems within hospital settings and moving towards patient-oriented care would support and facilitate the future development and integration of digital technology to assist data collection within clinical practice.

1.3 PARKINSON'S DISEASE (PD)

Parkinson's disease (PD) is the second most common movement disorder and mainly affects patients over the age of 60 (Tysnes and Storstein 2017; Abbas et al. 2018). According to a recent estimation, the prevalence for PD in the UK was estimated as 145,519 (7600 cases in Wales) in 2020, with an annual incidence of 22 - 32 per 100,000 (NICE 2018; Parkinson's UK 2018; Parkinson's UK 2020). Furthermore, the prevalence of PD is expected to have increased by 20 % in 2030 (Parkinson's UK 2020).The incidence of PD increases with age, with most people diagnosed with PD over the age of 60. However, 1 in 20 PwP first experiance PD symptoms when they are under the age of 40, with a higher prevalence and incidence of PD among males than females (Choices 2016; Ball et al. 2019).

PD is a heterogeneous, progressive neurodegenerative disorder that results from the loss of specific midbrain dopamine (DA) neurons in an area of the brain called the substantia nigra pars compacta. These neurons are responsible for producing dopamine (a chemical neurotransmitter that controls body movement and coordination) in the brain (Alexander 2004). The loss of these neurons reduces the amount of dopamine released, causing the development of characteristic PD symptoms such as tremors, rigidity, postural instability, and bradykinesia. These symptoms are known as classic motor symptoms of PD, and two of these three signs must be present for a patient to be diagnosed (Tysnes and Storstein 2017). A diagnosis of PD mostly depends on history taking and clinical examination. To date, no biomarkers exist to confirm the diagnosis, which can delay accurate diagnosis and the start of treatment (NICE 2017).

Besides these motor symptoms, PwPs may suffer from a wide range of nonmotor symptoms (NMS), as shown in Table 1.1. Recognition of these symptoms by HCPs can have a positive impact on a patient's quality of life (Martinez-Martin et al. 2011; Todorova et al. 2014; van Uem et al. 2016). Commonly, some symptoms occur and appear earlier than motor symptoms, such as excessive saliva, mild cognitive impairment, urinary urgency, and constipation (Khoo et al. 2013; Marinus et al. 2018). In studies conducted by Broeders et al. (2013) and Pedersen et al. (2017), the cognitive changes in newly diagnosed PwPs were assessed over five years (n = 59; n = 178 respectively). PwPs may present with mild cognitive deficits at diagnosis, and their cognitive abilities gradually deteriorate through the course of the disease and eventually progress to Parkinson's disease dementia (Broeders et al. 2013; Pedersen et al. 2017). However, the challenge is that most PwPs do not directly relate nonmotor symptoms to their PD, so the early detection of and education around these symptoms could improve the management of PD.

Table 1.1: Non-Motor Symptoms (adapted from Chaudhuri et al. 2006)

Nonmotor symptoms
• **Autonomic dysfunction**
• Drooling
• Erectile dysfunction
• Excessive sweating
• Gastrointestinal dysfunction (constipation)
• Orthostatic hypotension
• Urinary dysfunction
• **Disorders of sleep and wakefulness**
• Excessive daytime sleepiness
• Rapid eye movement sleep behaviour disorder
• Sleep fragmentation and insomnia
• **Neuropsychiatric symptoms**
• Anxiety and anxiety symptoms
• Apathy
• Cognitive impairment (other than dementia, mainly mild)
• Dementia
• Depression and depressive symptoms
• Impulse control and related disorders
• Psychosis
• **Other**
• Fatigue
• Olfactory dysfunction
• Ophthalmologic dysfunction
• Pain

In general, NMSs are poorly recognised and inadequately treated, particularly in the late stages of the disease, because of the difficulty in capturing and tracking all this information within the limited time of clinical consultations or the belief of patients and their carers that these symptoms are unrelated to PD (Chaudhuri 2010). In 2002, a study in the USA found that neurologists failed to identify the existence of depression, fatigue, and anxiety in more than 50% of consultations, and they failed to detect sleep disturbance in 40% of patients during routine consultations, as they relied only on their own judgement (Shulman et al. 2002). However, in this study, the identification of NMSs was improved by using the standardised questionnaires (depression was found in 44% of PwPs, anxiety in 39%, fatigue in 42%, and sleep disturbance in 43%). Additionally, these findings were encouraging to generate

approaches (tools) to support and improve the diagnostic accuracy of PD (see Section 1.5) (Shulman et al. 2002). Since then, awareness of NMSs has increased, and several tools have been developed to improve their identification (Bostantjopoulou et al. 2013; Del Rey et al. 2018). In 2006, Chaudhuri et al. developed a validated nonmotor symptoms questionnaire scale (NMSQuest) (Chaudhuri et al. 2006), and in 2007, they developed the nonmotor symptom scale (NMSS) (Chaudhuri et al. 2007).

By implementing these tools, clinicians have been able to recognise these symptoms to improve diagnosis and facilitate timely therapeutic management (Barone et al. 2009; Chaudhuri et al. 2010; Cosentino et al. 2013). An Italian multicentre survey study assessed the prevalence of NMSs using NMSQuest in 1072 PwPs and their impact on PwPs' quality of life, reporting that 98.6% of the PwPs experienced symptoms, including anxiety (56%), leg pain (38%), insomnia (37%), and dribbling of saliva (31%). They also found that NMSs, especially apathy, fatigue, and some of the psychiatric symptoms, had an adverse effect on quality of life (Barone et al. 2009).

In a UK study conducted by Chaudhuri et al. (2010) on 242 PwPs, the most commonly undeclared NMS during routine consultations were delusions (65.2%), daytime sleepiness (52.4%), intense and vivid dreams (52.4%), and dizziness (50%). The recognition of these symptoms was improved following the completion of NMSQuest, which allowed appropriate treatments to be started (Chaudhuri et al. 2010). In 2013, a study conducted by Cosentino et al. determined the prevalence of NMS in 300 PwPs who were seen at clinical practice and asked to complete NMSQuest. The findings of this study reported that at least one NMS was present in 99.3% of the evaluated PwPs, and the mean total NMSs was 12.41 (ranging from 0 to 27 of a maximum of 30).

Many studies have shown that the NMSs of PD can adversely affect quality of life for PwPs or their carers more than motor symptoms (Chaudhuri and Martinez-Martin 2008; Barone et al. 2009; Soh et al. 2011; Shearer et al. 2012). A review by Soh et al. (2011) identified three NMSs among the eight major determinants of quality of life in PD: depression, anxiety, and fatigue.

The early recognition of NMSs may allow for better optimisation of assessment and clinical decision-making processes, as early management of NMSs (e.g., pain, depression, and insomnia), alongside the management of motor symptoms, improved PwPs' quality of life (Shearer et al. 2012). However, the findings of a review conducted by Todorova et al. (2014) showed that the use of questionnaires and scales, such as NMSQuest, has predominantly been in research-based studies rather than clinical practice, where their use to improve the recognition of symptoms and influence treatment has lagged behind (Todorova et al. 2014).

Despite the use of existing scales and paper-based questionnaires, there is still a need to improve and standardise the assessment of NMSs within clinical practice and improve documentation of them (for example, pain, saliva, and risk of fracture) and the potential side effects of dopaminergic therapies in both neurology and gerontology clinics (Parkinson's UK 2019). In 2017, an international online survey (UK and USA) was conducted to assess the factors that impact the quality of life in PwPs. A total of 415 out of 492 PwPs mentioned that they did not discuss all of their symptoms of concern during consultations with their HCPs due to reasons such as short consultation time, forgetting, and lack of interest in the NMSs. Additionally, 87% (n = 467) of PwPs were interested in documenting their symptoms to facilitate the monitoring of their disease progression (Mathur et al. 2017). These findings provide insight into the importance of enhancing the utilisation of these scales. Using technology could facilitate the use of these scales (questionnaires) and enhance documentation of the NMSs and collection of data in PD clinical settings.

1.4 THERAPIES FOR PD

PD is non-curable, with treatment aimed at alleviating symptoms and improving patients' quality of life (Jankovic and Poewe 2012). The treatment of PD is multifaceted and requires the management of both motor and nonmotor symptoms in order to alleviate long-term complications and achieve good outcomes. The heterogeneity of symptoms makes the design of a therapeutic regimen for PD treatment very complicated (Jankovic and Poewe 2012; Ellis and Fell 2017).

The treatment of motor symptoms is based on dopamine replacement therapy, such as levodopa or dopamine agonists (Rascol et al. 2011; Nolden et al. 2014). Levodopa is the first line for symptomatic treatment of PD motor symptoms and is given in combination with peripheral decarboxylase inhibitors (either carbidopa or benserazide) to reduce peripheral side effects and improve efficacy. Other drugs that are used to treat PD include monoamine oxidase –B inhibitors (MAO-B inhibitors), selegiline and rasagiline, catechol-O-methyl transferase (COMT inhibitors), beta-blockers, amantadine, and anticholinergics (Rascol et al. 2011; Nolden et al. 2014; NICE 2017).

Besides pharmacological therapy, PwP also have access to other supportive therapies to enhance their quality of life, such as physiotherapy, occupational therapy, speech and language therapy, dietary therapy, and complementary therapies (Rascol et al. 2011; Nolden et al. 2014; NICE 2017). These therapies are effective in the symptomatic treatment of PD, but do not prevent progression of the PD. The different pharmacological treatments available for motor symptoms in PD are outlined in Table 1.2, adapted from the NICE guidance 2017 (NICE 2017). Some anti-Parkinsonian treatment is usually associated with motor and nonmotor symptom fluctuations and side effects. For example, dopamine agonists are associated with an increased risk of impulse control disorders and hallucinations, and L-DOPA is associated with motor fluctuations and dyskinesia with long-term use (Ellis and Fell 2017; NICE 2017).

Table 1.2: A summary of the different pharmacological treatment options available in PD based on NICE guidelines (2017)

Drug class	Example of drugs	Mechanism of action	Advantages	Disadvantages
Levodopa	Co-careldopa (sinemet) Co-beneldopa (Madopar)	Uptake by remaining dopaminergic neurons then converted to dopamine	Improved motor symptoms and improved activities of daily living	Motor complications, off-time phenomenon*, increased risk of dyskinesia Half-life ~60 mins
Dopamine agonists	Pramipexole (oral) Ropinerole (oral) Rotigotine (transdermal) Apomorphine	Direct stimulation of Dopamine receptors	Less improvement of motor symptoms and less improvement of activities of daily living, more reduction of OFF-time	Fewer motor complications, intermediate risk of adverse events (e.g., excessive sleepiness, hallucinations, and impulse control disorders)
Monoamine Oxidase B inhibitors (MAO-B)	Rasagiline Selegiline	Inhibits MAO-B and increases available dopamine in synaptic cleft	Less improvement of motor symptoms and less improvement of activities of daily living, OFF-time reduction, lower risk of hallucinations, and adverse event*	Fewer motor complications
COMT inhibitors	entacapone tolcapone opicapone	Inhibits COMT and increases half-life of levodopa	Improved motor symptoms and improved activities of daily living, OFF-time reduction, lower risk of hallucinations	More adverse events
Amantadine	amantadine	A glutamate receptor agonist that increases dopamine release and blocks reuptake	Reduced dyskinesia	Limited evidence of benefit to motor symptom or activities of daily living improvement

 *Off-time phenomenon refers to the shortened effectiveness of a single dose of levodopa, with motor symptoms (e.g., tremors) as well as NMS (e.g., anxiety and change of mood) re-emerging and worsening before the next dose of levodopa is due (Fackrell et al. 2018) *Adverse events refer to an increased risk of psychotic symptoms, impulse control disorder, and excessive sleepiness that associated with dopaminergic therapy (Voon et al. 2011).

Various therapies are used to treat the NMSs of PD, including antidepressants, anxiolytics, hypnotics, medication for autonomic dysfunction, analgesics, and antidementia medication

(Jankovic and Poewe 2012). Table 1.3 summarises the treatments for NMS in line with NICE recommendations and recommendations from the MDS Evidence-Based Medicine Committee (NICE 2017; Seppi et al. 2019). According to NICE guidelines (NICE 2017), when treating NMSs, it is essential to carry out a full medication review in order to establish whether any existing medications are contributing towards symptoms. If reducing an existing medication (dosage or frequency) helps to reduce the severity of symptoms and possible withdrawal effects, this choice must be considered. If there is a need to add a medication to an existing regime, the choice of treatment must be balanced, considering the increased risks and side effects of some of the medications. For example, cholinesterase inhibitors (e.g., rivastigmine) have a modest effect and are considered clinically useful in treating Parkinson's disease dementia. However, the reported tolerability issues of rivastigmine (e.g., nausea and worsening tremor) may limit its clinical use (Maidment et al. 2005; Seppi et al. 2019). Careful monitoring of side effects is required when administering rivastigmine (Meng et al. 2018).

Table 1.3: Treatment recommendations for NMS in PD, in line with NICE (2017) and MDS Task Force (2019)

Nonmotor symptoms	Recommended first line therapy	Recommended second line therapy	Efficacy
Depression	-Low intensity psychosocial interventions (physical activity programme, group-based peer support, or computerised CBT)	-Pramipexole (MoA: Dopamine Agonist). -Venlafaxine (MoA): Serotonin and norepinephrine Reuptake inhibitor - Individual or group CBT	-Pramipexole: Efficacious and clinically useful -Venlafaxine: Efficacious and clinically useful
Psychotic symptoms (Visual hallucinations and delusions)	-Reduce the dosage of any PD medications that may have triggered the symptoms	-Quetiapine (in PwP without cognitive impairment) -Clozapine if standard treatment is not effective MoA: Atypical antipsychotics (block dopamine and serotonin receptors)	-Quetiapine: Insufficient evidence and possibly useful* in clinical practice -Clozapine: Efficacious and clinically useful
Non-dementia	Cholinesterase inhibitor * (e.g., rivastigmine and donepezil)	Memantine.	Rivastigmine and donepezil:

Nonmotor symptoms	Recommended first line therapy	Recommended second line therapy	Efficacy
cognitive impairment	(MoA: Prevent the breakdown of the neurotransmitter acetylcholine or butyrylcholine and increase their amount in the synaptic cleft)	(MoA: N-Methyl-D-aspartate receptors antagonist)	Insufficient evidence and possibly useful in clinical
PD-Dementia	Cholinesterase inhibitor (e.g., rivastigmine and donepezil)	Memantine	Rivastigmine: moderate efficacy and clinically useful Donepezil: Insufficient evidence and possibly useful in clinical practice Memantine: insufficient evidence
REM sleep behaviour disorder (RBD)	Clonazepan (MoA: Benzodiazepine receptor agonists). Melatonin		
Excessive daytime sleepiness (EDS)	Adjust medications to reduce the occurrence of EDS	Modafinil (MoA: promotes wakefulness by unknown mechanism)	Modafinil: Insufficient evidence and possibly useful in clinical practice
Constipation	Lifestyle recommendations (such as increased fibre and fluid intake) Use of probiotics and prebiotic fibres	Laxatives	Probiotics and prebiotic fibre: Efficacious and clinically useful
Urinary urgency/frequency	Advise PwP to avoid excessive tea and coffee consumption Advise PwP to stay hydrated Bladder training exercises Anticholinergics		
Erectile dysfunction	Sildenafil (MoA: minimises breakdown of cyclic guanosine monophosphate (cGMP) by inhibiting cGMP specific phosphodiesterase type 5)		Sildenafil: Efficacious and clinically useful
Orthostatic Hypotension (OH)	Midodrine (MoA: α-receptor agonist)	Fludrocortisone (MoA: mineralocorticoid receptor and glucocorticoid receptor agonist)	Midodrine/Fludrocortisone: Insufficient evidence and possibly useful
Pain	Dopaminergic therapy Nonsteroidal anti-inflammatory drugs (NSAIDs) Physiotherapy and exercise programmes		

*Possibly useful due need for further adequate evidence based on high-quality RCT studies.

For PwPs experiencing severe motor complications that cannot be adequately managed with oral medication, advanced therapies can be used to reduce off-time and improve quality of life for both the PwP and their carer (Merola et al. 2016; Marsili et al. 2021). The advanced therapies in PD are device-aided therapies, such as continuous subcutaneous apomorphine infusion, duodopa (also known as L-dopa/carbidopa intestinal gel), and deep brain stimulation.

1.4.1 MEDICATION NONADHERENCE IN PD

Drug-related problems are those that exist when a patient experiences, or is likely to experience, a condition or a symptom that has an actual or suspected relationship with their drug therapy (Schröder et al. 2011). Drug-related problems may include issues relating to medicine effectiveness, side effects, and nonadherence to the treatment (Schröder et al. 2011; Covert et al. 2017). In PD, medication is often taken three to four times daily and in advanced disease, as frequently as six to ten doses per day, to maintain and prolong the effect of L-dopa. As a consequence, dose-related side effects are likely to increase (Freitas et al. 2017).

Many PwPs take more than one anti-Parkinsonian medication, in addition to multiple prescriptions for NMS and other chronic conditions. This polypharmacy may add further complexity to the management of PD and is a factor that might contribute to drug-related problems among older people (Fleisher and Stern 2013; Freyer et al. 2018). A complex medication regimen might directly affect nonadherence among PwPs, and they may experience symptoms such as worsening tremors, increased rigidity, forgetfulness, loss of balance, and agitation if they delay taking their medication or forget to take it on time (Hurtig 1997; Zahoor et al. 2018). In chronic diseases like PD, nonadherence to treatment is one of the most common drug-related problems among patients and can be costly due to the increase in hospitalisation, medical appointments, and healthcare services (Foppa et al. 2016).

According to the World Health Organisation (WHO), adherence is defined as 'the extent to which the person's behaviour (including medication-taking) corresponds with agreed instructions from a healthcare provider' (Sabaté 2015). This includes initiation of the treatment, implementation of the prescribed regimen and cessation of the treatment (Vrijens

et al. 2012). Primary nonadherence is related to refilling and initiation of the treatment, and secondary nonadherence is related to the medication not being taken as prescribed when prescriptions are filled (Fischer et al. 2010; Solomon and Majumdar 2010).

Several factors may affect poor adherence to treatment, which are generally classified into socioeconomic factors, therapy-related factors, patient-related factors, condition-related factors, and health system-related factors (Gellad et al. 2011; Sabaté 2015; Straka et al. 2018). Patient-related factors include patients' knowledge (whether the patient has sufficient information about the disease and the available medication) and sociodemographic factors, such as family support (Straka et al. 2018). Table 1.4 provides a summary of the main factors that might affect treatment adherence in general. Some of these factors, such as cost and income, may not affect medication adherence equally worldwide. Some countries provide coverage of prescription medications at little or no direct cost to patients (e.g., the UK) (Morgan and Lee 2017).

Table 1.4: Factors associated with nonadherence (adapted from Gellad et al. 2011; Daley et al. 2012; Malek and Grosset 2015)

Socioeconomic factors	Inability to take time off work Cost and income Social support and help from family
Therapy-related factors	Route of administration Treatment complexity Duration of the treatment period Medication side effects Degree of behavioural change required Taste of medication Requirements for drug storage
Patient-related factors	Demographic Factors (age, ethnicity, gender, education, and marriage status) Psychosocial factors (behaviours, motivation, and attitude) Patient–prescriber relationship Health literacy/Patient's knowledge about their disease and treatment Physical difficulties Risk behaviour (tobacco smoking or alcohol intake) Forgetfulness History of good adherence
Condition-related factors	Disease symptoms (e.g., impaired cognition, mood disorders, depression). Severity of the disease
Healthcare system-related factors	Lack of accessibility to healthcare Long waiting times for clinic visits Difficulty in getting prescriptions filled

It has been estimated that the reported rate of nonadherence in PwPs ranges from 0% to 60-70%. The wide range is likely to be due to the use of different evaluation methods, such as patient self-reporting, pharmacy refill data, and pill counts (Malek and Grosset 2015). A lower level of adherence was associated with complex therapeutic regimens, longer PD duration, NMSs (high depression and mood disturbances), and poor quality of life (Straka et al. 2019).

NMSs can be used to predict nonadherence among PwPs, as a recent cross-sectional surveillance study found a strong correlation between the frequency and severity of NMS and a poor level of medication adherence ($p=0.005$) (Straka et al. 2019). Even though this study included only those PwPs who were on three or more daily doses of PD medication, which may have limited its generalisability, its findings demonstrate that improving the recognition and management of NMS may have a direct impact on improving the level of adherence. Previous

studies have reported several strategies to improve adherence to PD medication, such as using adherence aids (e.g., medication calendar, diary, dispensing system, and dosette boxes); using devices like reminders or phone or watch alarms; educating patients and their carers about the importance of medication and engaging them in the therapeutic process; encouraging communication between patients and HCPs; and tying the medication-taking to other daily routines (Malek and Grosset 2015; Straka et al. 2018). A better understanding of the risk factors and strategies to improve medication adherence and documentation is important for both researchers and HCPs in developing a proper intervention with a good chance of being effective and successful (Lam and Fresco 2015).

The availability of mobile health (mHealth) technology (see Section 1.6 for further details about mHealth) might enable PwPs to be more active in the management of their medications and play an important role in medication adherences. The effectiveness of mHealth in supporting adherence among people with chronic conditions was assessed in a review by Hamine et al. (2015), especially the adherence-related behaviour (as forgetfulness). The review identified 27 randomised controlled trials (RCTs) that evaluated the impact of mHealth on adherence behaviours, and a significant improvement in adherence-related behaviour was reported ($P<.05$ to $P<.001$) in 15 of those studies (56%).

 A similar but more recent review by Armitage et al. (2020) assessed the efficacy of mHealth app interventions in supporting medication adherence in people with chronic diseases (cardiovascular disease, depression, PD, psoriasis, and multi-morbidity). The review identified nine RCT studies, and one of the identified studies focused on PD (Lakshminarayana et al. 2017). This review's findings showed that mHealth intervention users were significantly more likely to adhere to their medications than those who did not use the interventions (OR 2.120, 95% CI 1.635 to 2.747) (Armitage et al. 2020). However, the findings from all the included studies had a low certainty of evidence. Armitage concluded that the mHealth interventions were used for a short duration (ranging from 28 days to 16 weeks) and included a small sample size and a lack of sustainability assessment; therefore, further studies are still required to

investigate the impact of mHealth intervention use on medication adherence for a long duration, with the inclusion of a large sample size (Armitage et al. 2020).

A study by Lakshminarayana et al. (2017) reported a positive impact of the mHealth intervention on improving medication adherence among PwPs. However, it primarily focused on promoting self-management for PwPs in order to improve the quality of clinical consultation. Therefore, there is still a need to further investigate the role of mHealth interventions in PD medication adherence.

1.5 CHALLENGES TO THE APPROPRIATE METHOD OF REVIEW WITHIN PD SERVICES

PD care services national standards recommend that people with mild PD symptoms should be seen by a specialist (PD consultant or Parkinson's disease nurse specialists (PDNS)) every 6–12 months to review diagnosis and the need for treatment (NICE 2017). If PwPs have more complex problems, follow-up is recommended to be more frequent (2–3 months) in order to assess response to medication, titrate dosage, and revisit the diagnosis (National Collaborating Centre for Chronic Conditions (UK) 2006; NICE 2017). As mentioned previously, it has been reported that a short time for clinical consultations may impact the full clinical review of PD (Chaudhuri and Odin 2010). A report written by an 'E-patient' discusses the frustration related to the short available time for clinical reviews for long-term conditions (Riggare 2018):

> *I see my neurologist once or twice a year for about 30 minutes each time. So, he observes my symptoms and assesses the effect of the treatment he prescribes for one hour a year.*

The limitations of a 30-minute clinic review are described in this quote, where HCPs have only a snapshot of the patients' conditions to assess the impact of the treatment for either the rest of that year or until the next review. Performing a comprehensive assessment of patients' symptoms by HCPs within this limited time frame is difficult, so management plans are based on a limited amount of information and observations achievable within 30 minutes. In reality, many neurology follow-up appointments are less than 30 minutes, sometimes lasting just 15 to 20 minutes.

Alongside HCPs' observations, assessment is also based on information from patients (patient recall or diaries). This may impact the validity of such information due to poor patient awareness of the relevant symptoms of PD (especially NMSs) (Gallagher et al. 2010), which could lead to delays or inadequate interventions being started. In 2019, 358 PwPs completed a cross-sectional survey in the UK in order to identify the barriers to reporting NMSs to HCPs. The most reported barriers were acceptance of symptoms as part of life (n = 292), belief that no effective treatments was available (n = 222), lack of awareness that NMSs were associated with PD (n = 209), and the lack of priority of NMSs in the consultation (n = 108) (Hurt et al. 2019). Even though the original survey of this study was administered in 2015, the findings of this study may still reflect the current situation. There is still a need for interventions to enhance awareness and encourage PwPs to report their NMSs to HCPs.

There is no well-established bio-marker (a measurable indicator of a naturally occurring molecule or characteristic that can support the identification of PD progression) for PD (McGhee et al. 2013). Thus, clinical evaluation by HCPs is the primary focus of clinical assessment, and these assessment scales are often the primary/secondary endpoints in PD research (Espay et al. 2016). There are a number of assessment scales and screening tools developed for use in PD (see Section 1.6 for further details). These scales support the assessment of the severity of PD symptoms or alert HCPs that PwPs may be experiencing these symptoms (Todorova et al. 2014). However, sometimes it is challenging for HCPs to administer these assessment tools because of restrictions in consultation time. For example, the required time to complete the updated version of the Movement Disorders Unified Parkinson's Disease Rating Scale (MDS-UPDRS) is approximately 30 minutes, extending to approximately 45 minutes for the patient (to include the self-completed items) (Goetz et al. 2008). Additionally, the use of the paper-based form of this scale may limit its usefulness within clinical practice. As mentioned previously, the insufficient documentation of some of NMSs of PD was also reported within clinical practice, despite several paper-based forms of these scales being used (Parkinson's UK 2019). This indicated that the strategy for the use of these scales was not

adequately appropriate to document these symptoms, and different strategies to enhance the use and documentation are required. Some of these scales are easy to administer and take only a few minutes, such as NMSQuest (Chaudhuri et al. 2006). Interventions such as the mHealth app, which aims to enhance documentation of NMSs and use of these scales in clinical settings to support the clinic review, may be beneficial.

1.6 PATIENT REPORTED OUTCOME MEASURES (PROMS)

Patient-reported outcome measures (PROMs) are instruments that are used to evaluate a patient's health and wellbeing according to their own perspectives (Devlin et al. 2010). The US Food and Drug Administration presents a concise definition of PROMs: 'A measurement of any aspect of patient's health status that comes directly from the patient without the interpretation of the patient's responses by clinicians or anyone else' (US Food & Drug Administration 2009). The routine use of PROMs in clinical practice has the potential to improve communication between patients and HCPs during consultation, enhance the recognition of the patient's most concerning problems, support clinical decision making regarding treatment through enabling ongoing monitoring and tracking of symptoms, and empower patients to become more involved in their healthcare (Greenhalgh et al. 2005; Greenhalgh 2009).

In 2009, the national routine use of the PROMs programme was introduced into NHS England with the goal of improving patients' health and the quality and effectiveness of healthcare (Devlin et al. 2010). PROMs were to be used within the NHS across four key surgical interventions: hip surgery, knee surgery, hernia repair, and varicose vein surgeries (Devlin et al. 2010). In 2016, the benefits of this programme were highlighted by Kyte et al., and included encouraging the delivery of high-quality healthcare (i.e., improving the management and monitoring of patients in clinical settings and health board management decisions about resources and technical efficiency) and supporting audit research for further service improvement. However, as the PROMs questionnaires were predominately administered using paper-based methods, several drawbacks have been reported (Kyte et al. 2016). For example,

duplication of the data capture (which may cause additional burden on both patients and HCPs) and the PROMs data was not seen as useful due to inadequate provision of feedback to HCPs and patients (Kyte et al. 2016).

While the collection of PROMs can adversely affect the clinical workflow, contribute to the burden of HCPs and patients, and increase workload, there are still some methods in which these kinds of data can be used efficiently to support healthcare. Several considerations need to be addressed in order to use PROMs successfully and recognise the potential benefits: which PROMs data need to be collected, how the PROMs data are collected, how they are fed back to HCPs and patients, how they are actually used by HCPs in clinical encounters and monitoring, and whether they are following the guidelines for practice and clinical pathways (Devlin et al. 2010; Kyte et al. 2016). Digital technologies can support the electronic collection of PROMs data and facilitate real-time feedback to HCPs, which could minimise the burden on patients and HCPs during the data collection process. However, a need for further research into the use and value of PROMs, especially the electronic collection, was also highlighted in the NHS England report that evaluated the national PROMs programme (NHS England 2017).

The use of PROMs within clinical practice in NHS Wales can be supported by the aims of prudent healthcare (Aylward et al. 2013), which focus on the movement towards a more patient-centred care approach and deliver what matters most to patients. Indeed, patients' perceptions of their health (as measured by PROMs) are a valuable tool in patient-centred-care (Devlin et al. 2010). The increased use of EHRs within NHS Wales has also created an opportunity to enhance the use of PROMs. In 2016, a national programme to collect PROMs (in clinic/in home setting) was established across NHS Wales for a number of different health conditions, such as orthopaedic conditions (hips, knees, feet and ankles, shoulders, elbows, and hands), lung cancer, asthma, and cataracts (NHS Wales 2016a; NHS Wales 2016b). Currently, this programme is fully integrated with patients' records via the NHS Wales Informatics Service (NWIS), which makes the collected data available to all individual health

boards within Wales (Withers et al. 2020). This reduces the manual input of data and maximises its use by HCPs.

However, the current data collection in this programme is still not fully developed enough to support clinical practice and to be used in high level decision making. Further research is needed to evaluate the actual impact of the collected data on clinical practice (potential usefulness and risks). This programme is now considered part of the Value Based Healthcare Programme in Wales, which supports the delivery of prudent healthcare strategies. There is potential to adopt several e-PROM tools across different health conditions (Withers et al. 2020).

Even though there is increasing evidence that supports the use of PROMs in clinical settings, there is a poor evidence base regarding its actual impact after implementation, as the majority of published studies focus on assessing the facilitators and barriers of implementing PROMs in clinical settings and/or HCPs' and patients' perceptions regarding its use in such settings (Holmes et al. 2017; Foster et al. 2018; Kocks et al. 2018; Olde Rikkert et al. 2018; Aiyegbusi et al. 2019) rather than the direct impact on patient care. As such, more research is still needed to assess and evaluate the actual impact of using PROMs in clinical practice.

Alongside the condition's medical markers, the observational skills of HCPs, and patients' narratives, the use of PROMs scales can help and support HCPs in ongoing assessment as the condition progresses (Field et al. 2019). There are two types of PROMs: generic PROMs, such as the EQ-5D and SF-36, which have been used across several health conditions to assess patients' quality of life (Schrag et al. 2000; Lins and Carvalho 2016); and disease-specific PROMs (Devlin et al. 2010). Previous studies have reported that even though the routine use and collection of PROMs has become more widespread, HCPs have been using them on an ad hoc basis, often with little guidance, so there is a need for more support (Haywood et al. 2009; Bausewein et al. 2011; Snyder et al. 2012).

With restricted time for consultation in clinics, it is hard for HCPs in PD to comprehensively address and manage both motor and nonmotor symptoms, so NMSs are commonly overlooked (Shulman et al. 2002; Mathur et al. 2017). Several PD-specific PROMs are available that have the potential to allow for a comprehensive evaluation of symptoms from the patient's perspective (Martinez-Martin et al. 2017; Roos et al. 2017). A number of PROMs are currently available to collect the NMSs of PD-related data, such as the Scale for Outcomes of Parkinson's Disease (SCOPA-AUT), the NMSQuest, the NMSS, and the updated version of the Movement Disorder Society-Unified Parkinson's Disease Rating Scale Part 1 (MDS-UPDRS) (Visser et al. 2004; Chaudhuri et al. 2006; Chaudhuri et al. 2007; Goetz et al. 2008). Several PROMs are also available to evaluate motor symptoms, including MDS-UPDRS, Parkinson's Disease Questionnaire-39 (PDQ-39), the short version PDQ-8, and the Hoehn and Yahr scale (HY) (Jenkinson et al. 1997b; Goetz et al. 2004). A summary of these PROMs is given in Table 1.5. More detailed symptom-specific PROMs are available to use to assess symptoms related to depression, anxiety, sleep issues, and cognition (Leentjens et al. 2008; Kulisevsky and Pagonabarraga 2009; Högl et al. 2010; Williams et al. 2012).

The heterogeneity of data from PROMs, purpose of using PROMs, patient population, clinical settings, format of PROMs, available time to collect and use PROMs, recipients of PROMs data, and level of data aggregation are factors that make the use of PROMs within clinical practice more challenging (Greenhalgh 2009). The use of these PROMs within clinical practice is limited, and most HCPs rely on their patients' retrospective descriptions (patient's narrative) of their symptoms. Although used widely in clinical trials, there is increasing interest in extending the use of PROMs into clinical practice to enhance the clinical symptom management of PD and improve the quality of healthcare (NHS Wales 2016; Roos et al. 2017).

Table 1.5: Summary of available PROMs for Parkinson's disease

Category	PROMs	Description	Items	Domains of Questionnaire
	The SCOPA-AUT questionnaire (Visser et al. 2004)	Covered autonomic features of Parkinson's with frequent responses to each item: never, sometimes, regularly, and often	25 items	• 7 items to assess gastrointestinal symptoms • 6 items for urinary • 3 items for cardiovascular • 4 items for thermoregulatory • 1 item for pupilometer • Sexual (2 items for men and 2 items for women) dysfunction
Non-Motor Symptoms	**NMSQuest questionnaire** (Chaudhuri et al. 2006; Chaudhuri et al. 2007)	Covered all NMSs of Parkinson's with 'yes', 'no', and 'don't know' responses to each item that developed to identifies the occurrence of NMSs	30 items	• 8 items for gastrointestinal tract • 2 items for urinary tract • 2 items for sexual function • 2 items for cardiovascular • 1 item for apathy • 1 item for attention • 1 item for memory • 1 item for hallucinations • 1 item for delusions • 2 items for depression and anxiety • 5 items for sleep and fatigue • 1 item for pain • 3 items for miscellaneous symptoms (e.g., diplopia, weight loss)
	NMSS questionnaire (Chaudhuri et al. 2006; Chaudhuri et al. 2007)	Contains the same items and domains as the NMSQuest but was developed to assess the severity and frequency of nonmotor symptoms	30 items	• 2 items for cardiovascular including falls • 4 items for sleep/fatigue • 6 items for mood/cognition • 3 items for perceptual problems/hallucinations • 3 items for attention/memory • 3 items for gastrointestinal tract • 3 items for urinary tract • 2 items for sexual function • 4 items for miscellaneous

	MDS-UPRS (Goetz 2003; Goetz et al. 2008)	A comprehensive questionnaire for both motor and NMS of Parkinson's	65 items	• First part nonmotor experiences of daily living, includes 13 items • Second part motor experiences of daily living include 13 items • Third part motor examination include 33 items • Fourth part motor complications include 6 items
Motor Symptoms	**PDQ-39** (Jenkinson et al. 1997)	A questionnaire that had been developed to assess the health status of people with Parkinson's	39 items	• **10 items for mobility** • **6 items for activities of daily living (ADLs)** • **6 items for emotional wellbeing** • **4 items for stigma** • **3 items for social support** • **4 items for cognitions** • **3 items for communication** • 3 items for bodily discomfort
	PDQ-8 (Jenkinson et al. 1997)	Short version of PDQ-39 with only 8 items developed to facilitate the completion process of the questionnaire by the patients and make it more visible for use within busy clinics	8 items	• 1 item for mobility • 1 item for ADLs • 1 for emotional wellbeing • 1 item for stigma • 1 item for social support • 1 item for cognitions • 1 item for communication • 1 item for bodily discomfort
	HY scale (Goetz et al. 2004)	Clinical rating scale that includes 5 stages described the progression of PD and commonly used in early stages of disease to confirm the diagnosis of the patient	5 stages	• Stage 1: Only unilateral involvement, usually with minimal or no functional disability • Stage 2: Bilateral or midline involvement without impairment of balance • Stage 3: Bilateral disease: mild to moderate disability with impaired postural reflexes; physically independent • Stage 4: Severely disabling disease; still able to walk or stand unassisted • Stage 5: Confinement to bed or wheelchair unless aided

1.7 DIGITAL TECHNOLOGY IN HEALTHCARE

Nowadays, digital technology impacts every aspect of people's lives, and people are more dependent on technology than ever before (Bullhound 2015; Wardynski 2019). The innovations in the healthcare sector are usually provided as new services, new technologies, and/or new working methods (Salama et al. 2019). Digital smart technology (such as interventions that are delivered through smartphones, websites, tablets, and wearable technology) has provided a new platform to improve health and the delivery of healthcare (Hermes et al. 2020).

In evaluating the potential utility of technology in the literature, it is essential to consider the rapidly changing landscape in the development of technology and information sharing, which has opened up for new innovations (Espay et al. 2016). Innovations in technology make it possible to deliver safer, more effective, more cost effective, and more personalised healthcare (Murray et al. 2016), and digital innovations also have the potential to establish new types of relationships between HCPs and their patients (Torous and Hsin 2018). The WHO has identified digital healthcare solutions, known as electronic health (e-health), as one of the most important tools for the healthcare sector to meet future challenges (Bullhound 2015). They define e-health as the 'use of information and communication technology for health' (WHO 2006). In 2011, the WHO recommended that the healthcare sector utilise technology's advantages by creating mHealth apps to improve the quality of patient care and healthcare delivery (WHO 2011). MHealth is a subcategory of e-health and is defined by the WHO as 'medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices' (WHO 2011). However, the definition of mHealth in this thesis was restricted to the use of mobile devices (smartphones and tablets/iPads).

The health-related apps available on a mobile device are called mHealth apps, and they can be used by both patients and HCPs (Zapata et al. 2015). Yasini and Marchand (2015) classified mHealth apps into six categories based on their purposes and functionalities: consulting

medical information, communicating and sharing information, fulfilling a contextual need, obtaining/providing educational information, managing health-professional activities, and supporting health-related management of patients (Yasini and Marchand 2015). MHealth apps have been used with some success to promote healthy behaviours, enhance outcomes in patients with chronic conditions, report and manage side effects from treatment, collect patients' data, track and observe patients, and improve adherence to medications (Vandelanotte et al. 2007; Free et al. 2011; McLean et al. 2016; Wu et al. 2016; Morrissey et al. 2018; Warrington et al. 2019). This wide potential explains why mHealth apps are being introduced in the medical and public literature to improve patient care and healthcare delivery.

Many publicly available mHealth apps are available from the NHS App Library, and these provide information and support for different health conditions, such as cancer, memory and communication issues, sleep problems, diabetes, and others (NHS 2017). The ChatHealth app is an example of one of the apps available on the NHS App Library website that supports direct communication with HCPs. Another example is myGP, which facilitates booking appointments, ordering medication, and adhering to medication administration schedules via reminders.

The advanced capabilities of mobile devices (e.g., smartphones, tablets, and iPads) have dramatically increased the list of available mHealth apps that aim for better data collection within hospital and clinical settings. Several studies have demonstrated the advantages and challenges of electronic data collection by using different interventions via mHealth as an alternative to paper-based data collection (Hamou et al. 2010; Kaka et al. 2015; Stover et al. 2015). In Hamou et al.'s (2010) study, an iPhone app was developed for use with patients' databases in an atherosclerotic clinic to support the collection of patients' data imaging (such as ultrasound and CT-scan) and patients' feedback. This study concluded that the iPhone app had the potential to improve the accuracy of the collected data and clinic workflow (Hamou et al. 2010). However, there was no explanation of any specific measure to evaluate the app in real-world practice; therefore, it is difficult to isolate the specific impact this has on such outcomes.

These findings were supported by a 2015 study in which an iPad app was developed to enhance the collection of patients' data and replace the paper records in a rheumatology clinic (Kaka et al. 2015). The developed app was piloted by clinicians who evaluated the patients' data collected using either iPad or paper documents. They found that electronic data collection was a more efficient method than keeping paper records. Using the iPad app to enter patient information had a number of potential benefits, including reducing the number of missing fields and the time needed for transcription, which addressed the accuracy issue of paper records. However, while the iPad app allowed more accurate data to be collected, a key concern was that the time required for each consultation (patient–clinician encounter time) increased by 9.3 minutes (from 37.2 minutes to 46.5 minutes), which might impact clinic workflow. However, this was not viewed as problematic in this study. The time lag between the patient's clinic visits and entry of their data was eliminated, thus freeing up more time for the increased consultation length (Kaka et al. 2015). Overall, this app saved clinical staff time and resources and increased the quality of medical services.

Similarly, the electronic collection of PROMs via an mHealth device in an oncology clinic was found to be feasible and acceptable for both clinicians and patients. E-PROMs have the potential to offer substantial benefits in terms of facilitating data collection and interpretation by clinicians who can focus on the consultation and patients' needs (Stover et al. 2015). Schick-Makaroff and Molzahn (2015), using an example of two home dialysis clinics, explained some possible issues that might emerge from using an mHealth app (such as an iPad app) as a tool to collect patient information electronically. This included the additional load on the existing EHR system (e.g., capacity for data storage), security, privacy issues, and the extra costs associated with the required training to use the technology.

The focus of most of these studies is only on discussing the positive impact of mHealth apps in clinical practice, and further studies are needed to have a full understanding of the actual effect of the mHealth app to aid data collection in clinical practice. Nevertheless, these studies' findings provide insight into the possible impact of electronic data collection via mHealth apps,

which allow automated data collection for interpretation, save time for clinicians, and promote more efficient healthcare delivery.

With the increasing use of mHealth apps in healthcare and moving away from traditional paper-based documents, several studies have reported patients' preference for apps. One RCT study conducted by Yaffe et al. (2015) reported that an iPad-based app was found to be preferable to pen-and-paper documentation in a hand and upper extremity surgery clinical practice in collecting patents' data (P=0.001). However, this study included younger participants in the iPad arm (mean age 54) compared to the paper arm (mean age 57), which impacted this study's findings. A total of 40.3% of patients under the age of 50 reported their preference for iPad app use.

Similarly, another randomised study identified patients' preference for complete questionnaires about haematological or malignant solid tumours using an iPad app versus a traditional paper survey. The resulting patients' data were integrated into the EHRs for display immediately upon review by the HCPs (Martin et al. 2016). A total of 71% of cancer patients preferred the iPad-based survey to a paper-based study (17%), with no significant difference in the understanding level of the survey content between the two methods (Martin et al. 2016). However, this study had low certainty of evidence, as it included unbalanced sample groups, which impacted its findings: the number of participants in the iPad arm (n = 304) was higher than in the paper arm (n = 153). The aforementioned studies show the benefits of electronic data collection for patients with chronic conditions or older people, which might have implications for PwPs. This will be discussed in further detail in Section 1.8.

Along with improving data collection, a number of mHealth apps are available to support patients with chronic diseases (including diabetes, cardiovascular diseases, and chronic lung diseases) in managing their medications and improving their adherence (Gandapur et al. 2016; Badawy et al. 2017). Management of a chronic disease usually requires a long-term plan, and adherence is vital to improving health outcomes, quality of life, and cost-effective healthcare. MHealth apps have been shown to have a positive impact on improving management and medication adherence among patients with chronic diseases (Gandapur et al. 2016; Badawy

et al. 2017). MHealth features, such as text messages and alarm reminders (voice and vibration), were found to be useful in improving management of and actual adherence to medications (Goldstein et al. 2014; Park et al. 2014; Hamine et al. 2015). A text messaging service (that included health education and reminders to take prescribed medications) increased adherence to cardiovascular medications (based on electronic pill bottles), as demonstrated by the text message response rate (p=0.005) (Park et al. 2014). Similarly, an RCT by Goldstein et al. (2014) assessed the preference of older patients with heart failure and the impact of the use of an electronic pillbox system or mHealth app on medication adherence over 28 days. The findings showed that, even though no significant difference was reported between the two groups (p = 0.87), the participants reported their preference for the mHealth app (p < 0.001). However, this study had a low certainty of evidence, as it focused on assessing the feasibility and patient acceptance of using mHealth and was a small study with a short study duration. The mHealth app that aided adherence to medications was found to be a useful and acceptable tool among patients with chronic diseases in a systematic review that included 107 studies (27 of which were RCTs) (Hamine et al. 2015).

A recent systematic review by Armitage et al. (2020) evaluated the efficacy of mHealth apps in improving medication adherence in patients with chronic diseases (i.e., depression, cardiovascular disease, hypertension, and PD). The highest mean age of participants in the included studies was 70.9 years, and the majority of participants in these studies were aged 50 and over. The authors of this review concluded that mHealth apps improved patient adherence. Patients who participated in medication adherence mHealth apps were found to be more likely to adhere to their medications (OR 2.120, 95% CI 1.635 to 2.747) than those who did not use such interventions. This review included nine RCTs; however, all were considered to have low certainty of evidence due to the small sample size and lack of blinding, and these were small-scale studies with short study durations (Armitage et al. 2020). Even though the findings of this review provide useful and interesting information about the potential of the mHealth app in supporting adherence to prescribed medications among people with chronic disease, it needs to be interpreted with caution.

All studies discussed in this section concluded that using digital technology (mHealth app) within chronic condition clinical settings positively impacted the delivery of healthcare services and patients' outcomes. These findings could also be insightful for other chronic conditions, such as PD. It should also be noted that the ages of the participants in these studies ranged between 35 and 90 years old, which might well be applicable to the PD population. As previously mentioned, the average age of someone diagnosed with PD is 52.6 (45–90 years old) (Tysnes and Storstein 2017; Abbas et al. 2018; NICE 2018).

Despite the promising potential of the mHealth app in improving patients' care and healthcare delivery, it was reported that its introduction into the healthcare sector was a slow process, and these apps appear to be frequently underused after being downloaded (Goel et al. 2013; Becker et al. 2014). In a recent review of qualitative studies, Vo et al. (2017) explored patients' perceptions of mHealth apps to improve the usability of these apps. Trustworthiness (privacy and security), appropriateness, personalisation, and accessibility of these apps were the main identified issues that might impact usability in this review. However, it was obvious that the failure to understand these issues or users' perceptions of the apps in the early stages of development may limit their potential use. Most of these issues could be resolvable by reframing mHealth apps, tailoring design, and placing emphasis on patients' needs (Becker et al. 2014).

Given the wider spread of mHealth interventions, this provides a unique opportunity for the further development and utilisation of mHealth apps within healthcare. These apps may have the potential to facilitate the collection and sharing of data with HCPs, such as improving access to patients' EHRs, laboratory results, and medication information. It is imperative to understand and report users' perceptions, beliefs, and experiences of mHealth apps in order to facilitate the development of a successful mHealth app and improve its usability.

1.8 DIGITAL TECHNOLOGY IN PD

Following the early indicators of the usefulness of digital health technology interventions for other chronic conditions presented in Section 1.7, this section focuses on using such mHealth interventions to support PwPs.

In recent years, many digital health technologies have emerged that may deliver possible solutions to some of the challenges described previously, mainly for the objective assessment of PD symptoms. The possible uses of mHealth technology in PD include facilitating collaboration between health team members, improving data collection and documentation, improving time/distance-related limitations in clinical encounters, and tracking patient progression. Two emerging mHealth technologies have been developed for PD: wearable sensors and mobile apps (Espay et al. 2016). The use of sensors (e.g., accelerometers, gyroscopes, and microphones) incorporated within mHealth provides opportunities to quantify and capture PD symptoms and collect data about a PwP's daily life (Trister et al. 2016; Linares-del Rey et al. 2019; Majhi et al. 2019). Additionally, the ubiquitousness, portability, and convenience of smartphones and iPads have led to the development of a larger number of apps that can track PwPs' symptoms and collect their data (Linares-del Rey et al. 2019). The mHealth technologies (mobile apps and wearable sensors) enable the collection of objectives longitudinal data from PwPs and generate data for research purposes that might enhance knowledge about the disease, facilitate diagnosis, and support therapeutic strategies (Espay et al. 2016).

MHealth can be used by HCPs in clinical or research settings to objectively assess specific behaviours or symptoms, or self-administered by PwPs to identify, monitor, and track symptoms occurring in everyday life (Espay et al. 2016). The majority of mHealth interventions that have been developed for use in PD evaluate motor symptoms, while few mHealth interventions have been developed for the evaluation of NMSs (Espay et al. 2016).

A systematic review by Linares-del Rey et al. (2019) explored available mobile apps for PD in both the published literature and app stores (Apple, Android, and Windows). A total of 69 mHealth apps were found in this review that were specifically designed for PD (20 apps from the literature search and 49 apps from stores) (Linares-del Rey et al. 2019). These apps fall into two categories: assessment apps (52 apps), which target tremor, bradykinesia, upper limb dexterity, gait, physical activity, cognitive, and vocal aspects of PD, and treatment apps (13 apps), which target self-management and treatment adherence, support clinical decision making related to deep brain stimulation, and gait rehabilitation. A further four were both assessment and treatment apps. This review included 20 studies, all of which were considered to have a low certainty of evidence because of the small sample size included and poor methodological quality. However, this review provides valuable insights regarding the available mHealth apps for PD.

Two of those apps reported in the Linares-del Rey et al. (2019) review were focused on the collection of large-scale remote data with the aim of improving the level of understanding of the variety of PD symptoms (motor and nonmotor symptoms) and supporting the early detection and diagnosis of PD (Bot et al. 2016; Hadjidimitriou et al. 2017): mPower® and i-Prognosis®. The mPower® app was launched by Apple in 2015 (as part of their Research-Kit library) to promote the collection of frequent data regarding the severity of PD symptoms and response to medications (Bot et al. 2016). The mPower study recruited both PwPs and non-clinical subjects in the USA, and the majority of PwPs who used the app were over the age of 60 (Bot et al. 2016). However, no further information was available to understand the impact and usefulness of this app in the real world. The i-Prognosis® aims to collect data from a wide group of people, including healthy people and PwPs, by capturing their personal use and interaction with the smartphone during their daily activities (Hadjidimitriou et al. 2016; i-PROGNOSIS | AGE Platform. 2016). However, an international study is now being conducted to evaluate the impact of the usefulness of the i-Prognosis® app (i-PROGNOSIS 2020). In fact, these two apps demonstrate the current app development trend, which focuses on capturing

data about people's daily experiences and using these new tools to enhance the early detection and diagnosis of PD symptoms.

Several studies have evaluated the feasibility and effectiveness of the collection and analysis of multiple PD clinical features using mHealth apps (e.g., posture stability, tremors, medication adherence, voice and speech patterns, and bradykinesia) (Joundi et al. 2011; Lakshminarayana et al. 2014; Ozinga et al. 2015; Pan et al. 2015). These apps have shown promising results in relation to enhancing patient outcomes, engagement, and self-management. A few examples of these apps are ListenMee® app, StudyMyTremor® app, and uMotif® app. ListenMee® is an app designed to improve the gait of PwPs by synchronising walking to rhythmic auditory cues (Lopez et al. 2014). The app was found to significantly improve gait performance (p = 0.0117). This app was developed to aid patients' self-management; however, this study was conducted in a laboratory setting rather than in a real-world environment, which may impact the integrity of the findings. In addition, the small sample size (n = 10) may limit the generalisability of this study.

Araújo et al. (2016) evaluated the efficacy of the StudyMyTremor® app (already available in the app stores) versus electromyography (EMG) (a diagnostic tool that assessed motor function and health of muscles) in a clinical setting. The StudyMyTremor® app was developed to take advantage of the accelerometer within the iPhone to support the assessment of resting tremors in PwPs. A strong correlation was reported between EMG and the app (P=0.001), and the app was considered a reliable alternative to the EMG test for tremor frequency assessment in the clinic (Araújo et al. 2016). This study included a small sample size (n = 12; average age 67 years old) and more stable PwPs, which impacted the integrity of the study. The uMotif® app is a self-management app that can support the monitoring of symptoms in daily activities and enhance adherence to PD medications. This app is described in further detail in Chapters 3 and 6 (Lakshminarayana et al. 2017).

Several studies have investigated smartphone app use to objectively quantify a range of PD symptoms, such as bradykinesia, tremors, and postural stability (Joundi et al. 2011; Ozinga et al. 2015; Arora et al. 2015; Lee et al. 2016). For example, a PD smartphone-based software application comprising measures of finger tapping, voice, posture, gait, cognitive impairment, and reaction time has been developed and piloted as a new, remote, and non-invasive tool that aims to support the diagnosis of PD (Arora et al. 2015). This app was piloted over a short duration (average of 34.4 days) with 20 participants (including people with and without PD) with the ability to capture PD symptoms, differentiate between PwPs and healthy participants with high sensitivity (96.2%) and specificity (96.9%), and predict disease severity, as assessed by the MDS-UPDRS (Arora et al. 2015). However, this study's findings must be interpreted with caution, given the small sample size and short study duration, which might lead to low certainty of evidence. Likewise, an iPad with a built-in inertial sensor app used to assess postural stability in PwPs showed positive results that demonstrated the accuracy and validity of this app as a motion-capture system used within PD clinical settings (Ozinga et al. 2015). Similarly, a low sample size of 17 PwPs with mild to moderate PD might lead to low certainty evidence (Ozinga et al. 2015). When considering whether to conclude the usefulness or impact of an mHealth app for PD, these findings should be interpreted with caution owing to the small sample sizes taken from only PwPs with mild to moderate symptoms.

Further research should aim to establish the appropriate use of mHealth apps among a range of people with mild to advanced PD and fully explore the user experiences with digital interventions. While all of the aforementioned studies have demonstrated the potential of using mHealth apps to improve and support the diagnosis, detection, and management of PD, at present, it is not known if these apps are used in practice, and if so, whether they are used to inform immediate clinical decision making and how the HCPs have applied them. Users' experiences or perceptions (e.g., safety issues, privacy and security of the collected data, and users' digital literacy skills) of these mHealth apps have not been investigated in these studies. Only a few mHealth app studies for PD have discussed this briefly (Ferreira et al. 2015; Mitsi et al. 2017; Elm et al. 2019). See Chapter 3 for more details.

As mentioned previously, using PD-specific PROMs could support the current movement within NHS Wales towards patient-centred care, which focuses on providing healthcare services to improve patient satisfaction and outcomes. Previous studies have reported that delivering patient-centred care within PD clinical practice is a challenging process for several reasons, including the complex nature of PD, with a mixture of motor and nonmotor symptoms, and the limited available time for clinical visits (Van Der Eijk et al. 2013; Mathur et al. 2017). Using technology could be an effective solution to facilitate the use and collection of PD-specific PROMs within clinical practice. Morley et al. (2015) evaluated the acceptability and usability of e-PDQ-39. The author of this study conducted a mixed-method study (interview (n = 6 PwPs) and survey (n = 125)) and reported that the participants found the e-PDQ-39 an acceptable approach; however, no further information was available to fully understand and interpret these findings (Morley et al. 2014). In 2015, another study was conducted in the UK to evaluate the validity of e-PDQ-39. 118 PwPs were asked to complete both the electronic and paper versions of the questionnaire. The electronic version's validity was found to largely mirror that of the paper-based version (Cronbach's alpha was between 0.64 and 0.95) (Morley et al. 2015). However, the e-PDQ-39 was developed for use within clinical trials to facilitate data collection rather than clinical settings.

Nevertheless, previous studies that evaluated the use of the paper-based version of the PD-specific PROMs within PD clinical settings have found it to be an acceptable approach, and recommendations to use the electronic version of this scale to facilitate and improve its use have been reported (Neff et al. 2018; Damman et al. 2019). Further details about these studies are presented in Chapter 5.

After an extensive literature search, only one case study report was found that evaluated the implementation of PD-specific PROMs within PD clinical practice using a tablet computer in the clinic's waiting area (Arora et al. 2017). In this study, the implementation of ICHOM PD standard sets (including different types of scales related to motor symptoms, NMSs, hospital admission, falls, quality of life, cognition, and ability to work) was piloted in a PD clinic at Aneurin Bevan University Health Board in South Wales, UK. The implementation process was

found to be feasible, with 88% of Parkinson's PROMs questions completed across all fields. Several early benefits were identified, including enabling identification of the most concerning symptoms to the PwP, focusing consultations on the patients' needs, improving the clinic booking system and empowering PwPs by stimulating their thinking prior to their consultation and allowing them to speak during their consultation. The electronic collection of PROMs had a slight negative impact on clinic workflow (limited delays within the patient's clinical appointment time were reported) (Arora et al. 2017). Hence, this may call for further developments and improvements in the engagement of PD-specific PROMs apps for support from PD services within clinical settings. Further studies are still needed to validate the findings of this case study and to understand if they are transferrable to other settings.

1.9 LIMITATIONS OF THE EXISTING MHEALTH TECHNOLOGIES FOR PD

Although the literature has shown promising results evidencing the benefits of the integration and use of mHealth apps for PD, there is a low certainty of evidence and a lack of clarity related to the extent of the actual use of each app (Hansen et al. 2018; Espay et al. 2019). Reasons for this may include the complex manifestations of PD and because these apps may generate complex and large medical data, that is, 'big data', which might require a machine-learning approach to analyse extracted information (Hansen et al. 2018; Klucken et al. 2018). This may limit their widespread adoption in clinical practice.

The International Parkinson and Movement Disorders Society Task Force on Technology mentions several reasons that limit the usability of the currently available mHealth technologies for PD (Espay et al. 2016; Espay et al 2019). This includes the limited compatibility between developed mHealth apps and the currently used systems in clinical settings, the discrepancy between clinical needs and scientific research, the lack of biomarkers for monitoring NMSs, the relevance of data collected by mHealth apps, and the lack of efficient algorithms for analysing mHealth apps' data. There is still an unmet need for new developments that focus on the design of a more individualised tool that gives feedback to PwPs, HCPs, caregivers, and researchers, and that can be integrated with a patient database and display the information in a summarised and visually intuitive format (van Uem et al. 2016;

Espay et al. 2019). The lack of a large sample size for evaluating the currently available mHealth apps limits their credibility and generalisability. For mHealth apps to be accepted clinically, they should be evaluated with a large number of PwPs to ensure that they are not specific to a particular category of symptoms or personalised for a small set of PD populations.

Although several studies have evaluated the acceptance of mHealth apps for PD, there is still a need for further studies due to insufficient reported information in this regard. As described in Chapter 3, most of the existing studies that evaluate the acceptance and usability of mHealth apps for PD have used quantitative methods based on survey data, in which users rated their experiences after using mHealth apps. This method does not allow an in-depth understanding of the acceptance and usability of these mHealth apps, so there is still a need for further studies that evaluate users' perceptions of mHealth apps for PD.

The majority of the developed mHealth apps focus on motor symptoms (e.g., tremors, bradykinesia, gait abnormalities, and dyskinesia) rather than NMSs (e.g., depression, dementia, and cognitive impairment) (Espay et al. 2016; Zhang et al. 2021). This highlights the need to develop a new digital tool that can assess the diagnosis of NMSs and capture continuous, real-time (immediately available on EHR systems) data that could support the treatment and management of PD (Espay et al. 2019). A roadmap was provided by Espay et al. (2019), as shown in Table 1.6, that can facilitate and guide the development and implementation of patient-relevant mHealth technology within PD clinical practice.

Finally, the development of a standalone app will not achieve the potential to support the diagnosis and management of PD without integration across several HCPs who are working with PwPs because PwPs may need to be seen by several HCPs (MDT) across different healthcare sectors. Therefore, there is increasing recognition that the healthcare services for PwPs need to be more comprehensive, integrated, coordinated, and patient-focused to ensure the continuity of care, and with the technologies nowadays, this seems to be achievable. This is demonstrated by the aims of the International Parkinson and Movement Disorders Society Task on Technology, which is convened by people interested in PD research to work together

to improve and customise treatment and to increase adaptation to available technologies (Espay et al. 2016).

Table 1.6: Levels and phases of development of patient-relevant mHealth technologies (source: Espay et al. 2019)

What to measure?	Prerequisites	Testing	Output
Domains relevant for assessment	Active involvement of large patient organisations, MJFF (Fox Insight questionnaire)	Mixed-methods (quantitative/qualitative) evaluation	Definition of a targetable set of PD-relevant symptoms and resources
How to measure?			
Selection of software and hardware	Agreement on sensor and hardware selection, app interface	Implementation and measurement of adherence and data reliability	Validation of a set of sensors and software capturing patient-relevant data, best balance of compatible hardware/software
What to display?			
Open-source Platform and interface integration	Agreement on protocol, platform design, and algorithm development	Run-in phase, test rules, website development for data compatibility and synchronisation	High-quality interfaces for sensor data integration and visualisation
How to disseminate?			
Regulatory pathway and commercialisation	Assessing costs of development, implementation, and maintenance	Incentives for financial reimbursement stakeholder's adoption	Application ready for patients, clinicians, regulators, and healthcare systems

VISION

VISON IMPLEMENTATION

PROCESS

1.10 PROTOTYPE IPAD-BASED APPLICATION

A prototype iPad-based app was designed and developed by a group of PD specialists at Cardiff University (neurologists and pharmacists) as an assessment tool to gather PwP information in a clinical setting (Mohamed et al. 2016). It was also intended to capture details that might facilitate the identification of troublesome NMSs and other complications earlier. This approach could support a more informed clinical management of treatment and provide a longitudinal record of symptom progression. Initially, the developers thought that electronic data collection (e-PROMs) through an iPad could be a viable alternative to paper versions at PD clinics, especially given the short clinical consultation time (Mohamed et al. 2016).

This app was developed to be completed by PwPs or their carers at every clinic appointment. The PwP is asked to use the app and complete tasks in the waiting area before a routine check-up at a PD clinic. Then, the data are transferred and stored in the patient's database (electronic health records) and provided to the treating HCPs to support the clinical encounter. As such, the app includes the NMSQuest, the quality-of-life questionnaire EQ-5D, and the two-finger tapping function, as shown in Figure 1.1. As stated above, the NMSQuest is a validated questionnaire covering most of the NMS of PD (Chaudhuri et al. 2006). The EQ-5D is a quality-of-life assessment scale that comprises five questions and a scale to rate general patient health (Schrag et al. 2000). The two-finger tapping feature in the app is considered a physical motor test in which the participant is asked to alternately tap two circles on the iPad screen with their index finger. The intention was that the iPad app would be linked directly to the existing EHR in the clinic where the patient's information is usually stored. Thus, the entered information would be immediately available on the neurologist's computer.

The feasibility of using this iPad app has been investigated previously in a clinical environment, and the preliminary results of this investigation were positive and encouraging (Mohamed et al. 2016). Most participants preferred that in the future, an iPad app be used to collect their information instead of the paper version of PROMs, and 90% of the participants found that using an iPad to enter their data made the process easier. Clinical staff were concerned most

about their workload if the patients needed assistance to complete this app or if using this app would add further stress to the current resources; however, they still felt that the iPad app would improve the quality of patient care regardless of their own concerns (Mohamed et al. 2016). While this feasibility study showed positive feedback about using this iPad app, further research is needed to investigate the integration of this app into regular clinical practice and to evaluate how clinicians will use this information in their consultations.
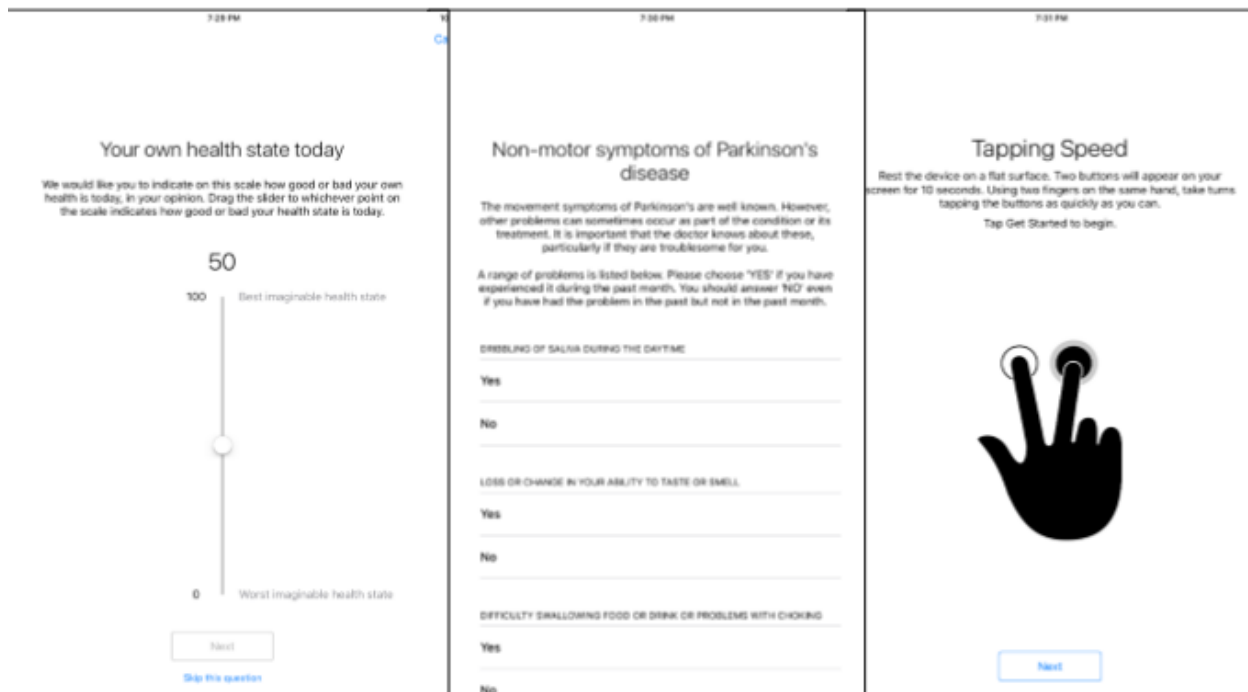
Figure 1.1: Screenshots showing parts of each section of the prototype iPad-based app

1.11 INVOLVING HCPS AND PATIENTS IN THE DEVELOPMENT OF SMART-DEVICE APP INTERVENTIONS

Although the development of information and communication technologies within health services has increased rapidly in recent years, they do not seem to be established or commonplace in clinical settings (May et al. 2003; Hansen et al. 2018). Among the main barriers to the successful implementation of mHealth app interventions in PD clinical settings appears to be the lack of involvement of patients, HCPs, or medical charities and organisations in the development and testing stages (Espay et al 2019). Studies that have involved the end users of apps, including patients and HCPs, have reported that it might be difficult to

incorporate such technology into existing clinical practices, while other barriers include issues with the content and design of apps, the need for training and support, cost, and privacy and security (Maguire et al. 2008; Gibson et al. 2009; Vo et al. 2019). The perceptions of end users of apps, including patients and HCPs, are important to ensure the successful implementation of any new technological interventions, such as an app that will be used by them in clinical practice.

In addition, as patients trust the opinions of their HCPs (Häyry 1991; Taylor 2009), it is essential to involve HCPs in order to develop and evaluate an intervention to be used by patients, who are subsequently likely to trust their recommendation of interventions, as well as to ensure that an intervention would be suitable from both a patient and HCP perspective. Therefore, this PhD thesis will involve both PwPs and HCPs in order to understand and explore the required features, acceptability, and feasibility that can help in the future development and implementation of a digital tool such as an iPad app within PD clinical practice.

1.12 AIMS OF THIS THESIS

The main aim of this thesis was to systematically examine and explore users' views and opinions regarding the features, content, capability, and acceptability of a mHealth app (iPad-based app) to aid data collection (PD-specific PROMs) in PD clinical settings and to help PwPs better manage their Parkinson's medications. This thesis can help explain the how and why of the users' acceptability of technology, as well as utilise the findings to guide the development of a future mHealth app for PwPs.

Specific Objectives of this PhD

(1) Explore the factors that might impact users' acceptance and usability of an mHealth app for PD (mobile phone/ tablet iPad) to be used within the PD clinic settings, based on the users' perceptions: A rapid review (Chapter 3).

(2) Explore the views and preferences of older people without Parkinson's, PwPs, and carers regarding the potential use of an mHealth app (tablet-based app) to gather PD-specific PROMs in PD clinic settings (Chapter 4).

(3) Explore the feasibility and acceptance of using an mHealth app (tablet-based app/e-PROMs tool) within PD clinical settings from the perspective of HCPs by determining their views and opinions on the value of e-PROMS for PwPs and preferences for specific features (Chapter 5).

(4) Explore whether an mHealth app might serve to improve the PwPs' relationship with, or understanding of, their PD medication, and explore medication management and adherence in PwPs. This study was conducted to provide a comprehensive suggestion to develop an mHealth app for PD that supported both data collection and improved medication management (Chapter 6).

1.13 FRAMEWORKS TO GUIDE THE WORK OF THIS PHD THESIS 'DEVELOPMENT OF ELECTRONIC RESOURCES IN PD CLINICS'

Because of the limited literature in this area, there is a need for frameworks to guide the development of a mHealth app that can be used in PD clinical settings, so the Medical Research Council (MRC) framework will be used for that purpose. The MRC offers guidance for the development, evaluation, and implementation of complex interventions to improve health services (Craig 2008). It is a systematic, multistaged approach to developing and evaluating interventions that will help researchers and intervention designers understand the process that can affect the successful implementation of that intervention. The MRC provides four stages for the development, evaluation, and implementation of a complex intervention; these stages may not follow a linear or a cyclical sequence (Figure 1.2).
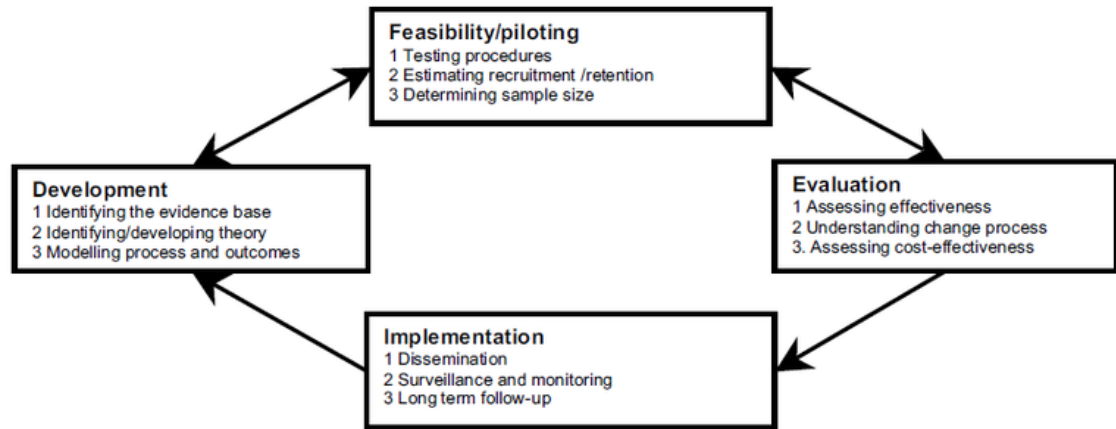
Figure 1.2: Key elements of the MRC framework for the development, evaluation, and implementation of complex interventions (source: Craig 2008)

The first stage outlined by the MRC is the development phase, in which researchers need to be clear regarding the rationale of the intervention by identifying the evidence base, relevant theories, and outcomes of such an intervention. If there is a gap in the literature, the researchers will need to conduct further work on the development phase before beginning the evaluation phase. Therefore, a rapid review of the factors that might affect the acceptance and usability of mHealth apps for PD was conducted and is presented in Chapter 3. This review could potentially help to understand information needs and users' preferences regarding an mHealth app for PD. In addition, the development phase of a mHealth app intervention (to enhance the collection of PD-specific PROMs and the management of PD medications) for this thesis will be reported in Chapters 4, 5, and 6 using qualitative and quantitative data. It is intended that these three chapters will contribute to the evidence base about which mHealth app tools (designs and components) are effective and acceptable for both PwPs and their HCPs, and in which settings, in order to enhance the clinical management of PD.

The second phase of the MRC focuses on piloting the intervention and assessing its feasibility and acceptability, while the third phase focuses on evaluating the effectiveness of the interventions, including the cost and understanding any necessary changes required within the health board or clinical settings to implement the intervention. Once the researchers have provided evidence on the acceptability and effectiveness of the intervention, during the final

phase of the MRC, 'implementation' is required from the researchers by utilising the intervention in clinical practice and conducting long-term follow-up surveillance and monitoring studies of the intervention, though these phases are beyond the remit of this thesis.

The MRC framework for the development and evaluation of complex interventions for healthcare highlights the importance of identifying relevant theories and modalities to gain a deeper understanding of the behaviour to be targeted by the intervention and the changes that may be expected to occur (Craig et al. 2008). The focus of this thesis was exemplified by the first phase of the MRC framework, which provides insight into the processes that are likely to realise the targeted behaviour prior to the development of the intervention and then allows the intervention to be specifically designed to address these processes (Craig et al. 2008).

Previous early phase studies of the development of mHealth apps for chronic conditions (e.g., diabetes mellitus and mental health conditions) have shown that many studies have used a user-centred, phased approach or philosophy similar to the MRC framework, which includes the iterative involvement of patients in the development phase, as well as HCPs using qualitative research methods, such as semi-structured interviews and focus groups (Cafazzo et al. 2012; Whittaker et al. 2012; Scheibe et al. 2015). In addition, several studies on digital health intervention tools and a specific model and framework to guide the development and evaluation of mHealth interventions have been used in this thesis, aiming to increase the rigour of such studies and facilitate the translation of the literature into replicable and evidence-based mHealth app interventions. These can be systematically evaluated, used, and integrated into healthcare settings. It is essential to use these models and frameworks to guide the development of interventions, as the interventions may contribute to the evidence base regarding which interventions are effective, for which population groups and in which settings to achieve the best outcomes. Thus, the MRC framework offers a proper overarching framework for the early phase development of a mHealth app intervention for this thesis.

In addition, two other models for the development and use of mHealth app interventions were also taken into consideration in this thesis, namely the 'person-based' approach for digital

health-related behaviour change: the Technology Acceptance Model (TAM) and the Unified Theory of Acceptance and Use of Technology (UTAUT) (Davis 1989; Davis 1993; Venkatesh et al. 2003; Holden and Karsh 2010; Yardley et al. 2015).

The TAM was developed by Davis (1989) to understand users' acceptance of information systems or technologies and focus on external factors, such as benefit perceptions and the perception of usage amenity as the main influence for technology acceptance. The major limitation of this model is that it does not consider social influences or efforts for using technology or provide subjective information about factors that relate to the behaviour intention to use technology (Malatji 2020). UTAUT was developed on the foundation of TAM: in UTAUT, other factors, such as gender, age, experience, characteristics of information technology (IT) application, and voluntariness of use (e.g., optional or compulsory), serve as a moderating effect on the usage intention and behaviour towards technology (Venkatesh et al. 2003). Generally, the UTAUT includes four determining factors: performance expectancy, social influence, effort expectancy, and facilitating conditions (Venkatesh et al. 2003). These factors allow for further identification of the main influences on technology acceptance in any given context (Venkatesh et al. 2003).

According to TAM and UTAUT, four factors predict the acceptance of technology: perceived usefulness, defined as the degree to which using technology can improve health outcomes; ease of use, defined as the effort required to use the technology; social norms, defined as the individual's beliefs or behaviours that might affect their willingness to use technology; and facilitating conditions that might be related to infrastructure, resource constraints, and literacy skills (Davis 1989; Davis 1993; Venkatesh et al. 2003; Holden and Karsh 2010). In the area of user behaviour, the TAM and UTAUT are two of the best-known models that can be used to measure user acceptance of an electronic system or mHealth app.

Prior to the development of an intervention, it is essential to explore the views and opinions of the end users regarding the intervention to develop an understanding of their needs and requirements and the type of intervention they expect to be most useful (Yardley et al. 2015). Greater attention should be paid to the views of key stakeholders, such as patients and HCPs,

in the early phases of the development of digital interventions (Yardley et al. 2015). Therefore, the person-based approach (Yardley et al. 2015) was also chosen to accompany the MRC framework, TAM, and UTAUT to guide the work in this thesis, as this approach highlights the importance of understanding the perspective of the people involved in using the intervention (i.e., PwPs and HCPs). The person-based approach goes beyond evaluating the acceptability and usability of technology; it allows for a deep understanding of the psychological context of the views and behaviours of key stakeholders. Perceptions from this approach can be used to anticipate and interpret the usage and outcomes of an intervention and amend the intervention to make it more convincing, feasible, and relevant for users (Yardley et al. 2015).

These frameworks for the development of complex digital interventions in healthcare were considered suitable for use as an overarching framework to guide the early phase (exploratory work) conducted for this thesis, as they offer a systematic, phased approach that enables app designers to develop the evidence base for a future digital intervention to be used within and support PD clinical practice. The benefit of using these approaches is that the development of a future intervention will be guided by the evidence and tailored according to the findings, which will enable the design of an intervention that is useful, acceptable, feasible, and fit for purpose. Figure 1.3 presents an overview of the major elements of this thesis.

MRC, TAM, UTAUT, and person-based frameworks identify the evidence-based and relevant regulations.

Aim of thesis: Understand the needs and preferences of PwPs and HCPs regarding the development of a smart-device app (format and content) and its feasibility within PD clinical settings.

Chapter 3: Rapid review

Exploring factors impacting the acceptance and usability of mHealth app for PD.

Stage I Chapter 4: Qualitative study (focus groups) with PwPs and their carers regarding e-PROMs app.

Stage II Chapter 5: Mixed methods (questionnaire/ semi-structured interviews) with HCPs of PwPs regarding e-PROMs app.

Stage III Chapter 5: Mixed methods (questionnaire/ semi-structured interviews) with PwPs regarding an app to aid management of PD medications.

2020   2017   2018   2019

Figure 1.3: An overview of the work presented in this thesis

Chapter 2: Research Methodology

2.1 INTRODUCTION

The TAM, UTAUT, and person-based approaches have influenced and guided the knowledge claims of the research in this thesis and its conduct. In this chapter, the philosophical background, the researcher's epistemological and ontological position, and the paradigm through which the research was conducted are outlined.

Several scientific research approaches are available to investigate social views and problems, and each approach has its own strengths and weaknesses (May 1993). The epistemological and ontological assumptions also include different methods and their suitability for evaluating social views and problems depending on the research questions. This thesis was not designed using a specific scientific orientation or its associated methods. Instead, an open approach to the research questions at each stage was used, which supported the choice and adoption of the appropriate methodology. This resulted in a range of appropriate approaches to investigate perceptions regarding the use of technology pre-and post- PD clinics. For this reason, both qualitative and mixed-methods approaches were implemented sequentially.

2.2 PHILOSOPHICAL ASSUMPTIONS

All social scientific research is supported by certain philosophical assumptions about worldviews. According to Kuhn (1962) and Creswell (2003), the conduct and outcomes of research are determined by worldviews or paradigms. A paradigm is 'the net that contains the researchers' epistemological, ontological, and methodological premises'; it is also defined as 'the beliefs that guide the action' (Guba 1990, 17). The paradigm includes three different aspects: ontology, which focuses on addressing the nature of reality; epistemology, which focuses on addressing the identity of who knows and what can be known; and methodology, which is based on addressing the method of finding out what can be known (Guba 1990; Guba and Lincoln 1994). The findings of these types of research characterise the philosophical assumptions of different paradigms, such as positivism, constructivism, and pragmatism, as shown in Table 2.1.

Table 2.1: Overviews of different types of research paradigms

Issue Paradigm	Positivism	Constructivism	Pragmatism
Ontology	One existing reality or truth	Multiple existing realities or truths	The truth or reality is an element of negotiation, debate, or interpretation.
Epistemology	Truth or knowledge can be measured.	Truth or knowledge needs to be interpreted to investigate its underlying meaning.	Truth or knowledge can be examined using whatever methods are best suited to answer the research question.
Research type	Quantitative	Qualitative	Both quantitative and qualitative
Research nature	Explanatory/prediction	Exploratory/discovery	Both explanatory and exploratory
Research objective	Measuring factors, testing theories	Seeking understanding of people's beliefs and experiences/ generating theories	
Data collection method	Experiments/ questionnaire	Interview/focus group/ observation	Combine both quantitative and qualitative or use one of them
Data analysis	Statistical analysis	Qualitative analysis	Statistical and qualitative analysis
Researcher position	Standing out of the research context, biased	Standing in the research context observing, interacting, or interpreting	Standing out and in the research context

The research for this thesis was conducted using a pragmatic approach. As mentioned in Chapter 1, the focus of this thesis was to explore end users' views regarding the potential use of an mHealth app in PD clinical settings, as well as their views on any factors pertaining to the implementation of such usage in clinical settings. In each stage, different methodological approaches were used, as each stage focused on a different aspect of using technology. Therefore, for this thesis, a multistage evaluation mixed-methods design was selected to address a set of incremental research questions that all advance one programmatic study (Creswell 2015).

The main debate among researchers regarding qualitative and quantitative approaches is related to epistemological and ontological assumptions. The role of researchers in quantitative research is to see truth or reality as an objective that can be assessed without the observer (positivism) (Sale et al. 2002). On the other hand, the role of the researcher in qualitative research (constructivism) is much more subjective as it involves exploring how people's experiences might affect reality. Constructivism is a generic term that covers several subtypes, such as radical, moderate, and social constructivism (Young and Collin 2004). In radical constructivism, the individual mind constructs reality and depends only on the individual cognitive process, whereas in moderate constructivism, the systematic relationship of the individual to the external world constructs reality. In social constructivism, individuals' social relationships construct reality and knowledge (Young and Collin 2004). Combining these paradigms (pragmatism) has the potential to bring the strengths of both and overcome their individual weaknesses (Johnson and Onwuegbuzie 2004).

Pragmatism offers an attractive philosophical partner for the mixed-methods approach, where the researcher tends to use more flexible, with practical approaches to address the research questions (Burke Johnson and Onwuegbuzie 2004). Pragmatism is defined as follows:

> A deconstructive paradigm debunks concepts such as truth and reality and focuses instead on what works as the truth regarding the research questions under investigation. Pragmatism rejects either choice associated with the paradigm advocates, wars for the use of mixed-methods in research, and acknowledges that the values of the researcher play a large role in the interpretation of results. (Tashakkori and Teddlie 2010, p.713)

According to Creswell (2009) and Tashakkori and Teddlie (1998, 2003), pragmatism can be described as follows:

- Pragmatic researchers put aside the debate about paradigms and focused on the best strategies to answer the research questions.
- Depending on the research questions, the researchers can choose the appropriate methods (qualitative or quantitative) and mix them when needed rather than being restricted to one paradigm.

- Pragmatic researchers are free to use the best methodological strategy to meet the research's values and purposes.

- Pragmatic researchers believe that both subjective and objective realities are measurable, and that reality is what provides the best understanding of the research questions.

As stated above, the main concept of pragmatism is doing what is best for the research. The philosophy of pragmatism brings together two different but complementary and powerful philosophical paradigms. Pragmatism refutes the incompatibility of data types and analysis approaches and shows the possibility of combining different approaches into one piece of research (Teddlie and Tashakkori 2009). Indeed, the diversity of philosophical assumptions and research methods used to collect and analyse data strengthens the research. In keeping with the assumptions of pragmatism, the aims and objectives of the second and third stages of this thesis were placed centre stage, and each ontological and epistemological principle regarding the status of knowledge and reality was placed to one side.

Finally, given the empirical nature of this thesis, a general consensus was formed early that it would be necessary to assess the first stage of this study by using the qualitative method and the second and third stages using mixed-methods (qualitative and quantitative). The intention was to gain both a subjective individual experience and a broad understanding of the experiences.

2.3 THE RESEARCH DESIGN PROCESS

Creswell (2015) described three basic types of mixed-methods design and three advanced designs. The three-basic mixed-method designs include a) convergent parallel design, b) explanatory sequential design, and c) exploratory sequential design. Further information regarding these types is presented in Chapter 5. The three advanced mixed-methods designs included a) the intervention-embedded design, which researchers use when they need to include qualitative data to answer a secondary research question within the predominantly quantitative study; b) the transformative design, which is used when the researcher seeks to address issues of social justice and calls for change; and c) the multistage evaluation design,

which is used when the researcher seeks to conduct a study with a central aim and sustained line of several research questions. Within this, the researcher can use multiple mixed-methods approaches, as well as single quantitative or qualitative approaches.

In essence, this thesis is mixed-methods in nature (multistage evaluation design) to facilitate the evaluation of an intervention's development and its future implementation in a clinical setting (Creswell 2015). The purpose of this mixed-methods study was to employ a separate research design that allowed for the selection of several complementary methods driven by the nature of each stage's research questions. The multistage mixed-methods design allows for the investigation of a broad research question from different angles. Hence, a qualitative method was employed to address the questions of the first stage of this thesis; then, a mixed-methods approach was used to address the second and third stages (see Chapter 1, Section 1.13). An overview of the study design is summarised in Figure 2.1. The study design of each stage is elaborated through a discussion of the design process, data collection and analysis, recruitment of participants, and outlining of the ethical considerations of each stage in Chapters 4, 5, and 6.
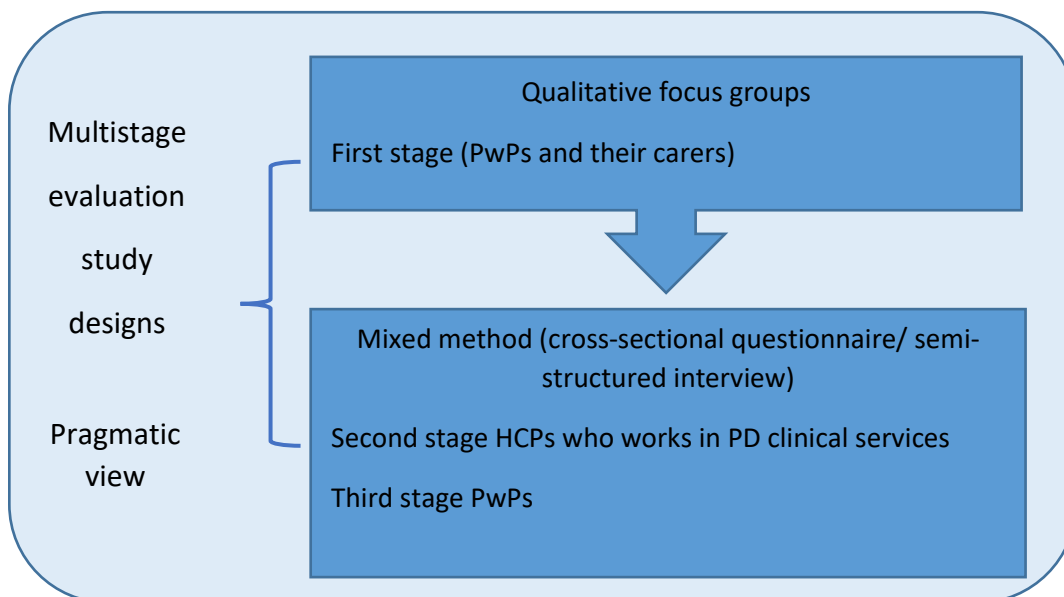
Figure 2.1: Research design overview

There are many approaches that can be used to analyse qualitative and quantitative data. In this thesis, the most applicable methods were considered and used at each stage. For the quantitative questionnaire data in Chapters 5 and 6, this was the calculation of descriptive statistics; for the qualitative data, thematic analysis, content analysis, and framework analysis were chosen as appropriate and conducted iteratively throughout (Braun and Clarke 2006; Schilling 2006; Srivastava and Thomson 2009; Erlingsson and Brysiewicz 2017). Further details regarding the choice and application of the relevant analysis methods are discussed in the relevant empirical chapter (Chapters 4, 5, and 6).

Finally, the approach of quantifying data in qualitative research studies has been reported to be controversial since the 'paradigm wars' of the 1970s and 1980s (Maxwell 2010). Several qualitative researchers have opposed and critiqued the use of quantitative inferences of qualitative data. The reasons for these critiques are mostly centred on a philosophical stance; they believed that these quantitative inferences were incompatible with the constructivist stance of qualitative research and suggested the existence of a single 'objective' reality, which can be assessed and analysed statistically in order to reach generalisable conclusions (Chi 1997; Maxwell 2010; Scherp 2013). On the other hand, other qualitative researchers have favoured the inclusion of quantitative inferences, such as 'some', 'the majority', 'few', 'most', and simple counts of data, in order to aid in the contextualisation and interpretation of qualitative data (Chi 1997; Maxwell 2010; Scherp 2013; Monrouxe and Rees 2020). Using a content analysis approach enables the researcher to quantify and examine the presence and meanings of words (i.e., data) and concepts and then make inferences about the findings within the data (Schilling 2006; Erlingsson and Brysiewicz 2017).

Maxwell (2010) and Monrouxe and Rees (2020) mentioned several potential advantages of integrating quantitative inferences into qualitative research studies. This includes:

1. Quantifying qualitative data helps facilitate pattern recognition and extract meaning from qualitative data and allows a researcher to distinguish and understand regularities or peculiarities in qualitative data.

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2. Quantifying qualitative data enables a researcher to identify and correctly characterise the diversity of findings, perceptions, or beliefs in the setting or group studied. It also enables precision statements in terms of the importance, frequency, or strength of findings.

3. Quantifying qualitative data can help a researcher identify patterns that are not apparent simply from the unquantified qualitative data and can provide a more transparent and in-depth understanding of what is going on in a particular setting or for individuals who belong to a specific category.

Although Maxwell (2010) also notes that there needs to be some caution, this quantification does not suggest generalisability.

> Quantifying qualitative data can lead to the inference (by either the researcher or the audience) of generalisable conclusions than is justified by overestimating a specific context within which this conclusion is drawn. However, a specific setting or population sample may be unrepresentative, and providing quantitative inferences may lead a reader to ignore this limitation.

Despite the ongoing controversy over quantifying qualitative data, the researcher agrees on the legitimate and valuable uses of quantitative inferences in qualitative research. This is to identify the most concerning issues and to make an indication of the common needs and suggestions of target users, which could help mHealth app developers make informed decisions about the necessary features to redesign the prototype iPad-based app, as well as to understand the potential facilitators of, and barriers to, mHealth adoption and usage for PD. In particular, content analysis was used to quantify the occurrence of certain codes, themes, or concepts in the qualitative data set appropriate to the research objectives (Vaismoradi et al. 2013). This is covered in more detail in the relevant empirical chapter (4).

2.4 REFLEXIVITY AND THE RESEARCHER'S REFLECTIONS

Reflexivity enables the researcher to acknowledge their role in the research, which leads to improving the quality of the research and increasing its transparency to the reader (Finlay and Gough 2003). In qualitative research, it is important for the researcher to reflect upon their values and beliefs about the researched topic and the interaction between the researcher and

the participant (Schram 2006). Also, it is important for researchers to reflect on how their social background, assumptions, positioning, and behaviour affect the research during its conduct and analysis (Finlay and Gough 2003). The researcher should be aware of these factors and of how they could influence participants' responses when collecting and interpreting the data to minimise any bias in arriving at conclusions from the evidence presented in the study.

Initially, as my background was based in pharmacy and dealing with medications, I was aware that I did not have experience dealing with PwPs or older people in general. I may not fully understand their experiences with PD or their psychosocial impact on the technology use context. In addition, I rely on technology in every aspect of life. I feel very confident with it, as I have many interactions with a range of devices, software programmes, and tools in my daily activities. Even though I was supporting the move towards technology use within the healthcare sector due to the potential benefits that digital technology holds, including improved accessibility to patients' data, facilitation of data collection, and enhanced tracking of patients' health status, I was aware that my own personal bias towards technology use might have an impact on the participants as well as on the way the data were collected, analysed, and interpreted. In addition, I was aware of the vulnerability of technology and how any electronic system can be vulnerable to a wide variety of concerns and threats, including security and privacy concerns, physical concerns, and technical concerns.

During my work in this thesis, I made efforts to maintain a neutral stance and provided participants with an open interview setting, giving them the opportunity to express their feelings and beliefs and trying to avoid expressing my own feelings, regardless of whether I agreed or disagreed with them. In addition, I was careful not to suggest my own views or express the assumption that technology would be a positive approach. I was open to both positive and negative perceptions and attitudes towards technology use.

Because I had no previous experience conducting qualitative research, I started to learn about this research methodology before commencing this thesis. I took several research courses inside and outside Cardiff University to understand the different qualitative research designs and gain the necessary skills to perform this kind of research. Additionally, before starting the

first stage of this thesis, I conducted two focus group discussions with participants of a similar age range to this thesis's target population (PwPs). These two focus groups included 10 participants (older people with an age range between 66–77 years old), and I used the same topic guide that I intended to use in the main study with PwPs (Stage 1, Chapter 4). A slight modification to the topic guide questions was made (e.g., generalising the questions related to PD to other chronic health conditions) to facilitate general discussion about technology use within an older population. This valuable opportunity enabled me to develop and improve my interviewing skills to perform this kind of research to the necessary level. In addition, practicing the topic guide with a similar target population demographic to this thesis gave me the insight to understand the potential future dynamics of how the conversation could flow with the PwPs and helped me to practise obtaining the necessary information by further probing in important areas to address the aims of that study (see Chapter 4).

While conducting the first stage of this thesis, I was aware of the need to build rapport and trust with the participants and of how that may influence their responses during the focus group discussions. At the beginning of each focus group, I reassured participants that the discussions were confidential, that their responses would not be discussed with anyone outside the research team and that any published data would be anonymised. Also, through the focus group sessions, the collaboration and discussions among the participants before and during the sessions enabled me to elicit their reflections on the use of technology versus the paper-based approach to collecting data from the PROMs. Enabling the participants to see the difference between the two approaches and to reflect on what they saw provided me with an opportunity to see how they changed or retained their views and beliefs.

Employing reflexivity provided me with a clear outlook of what occurred in the setting and a greater awareness of my own role. This allowed me to determine the results and conclusions based on what I saw in the focus group discussions and what I heard from the participants. The extent to which the participants provided a positive or negative view during the discussions depended on how I kept my position as a pragmatist, how I asked the questions and how I created a suitable environment that could provide and enable a broad discussion and

negotiation between the focus group participants and me. Throughout the focus group discussions, I was aware of how the participants might have perceived me. For example, some participants may have perceived me to be more supportive of the opinions that value the use of technology due to the age difference between us. I was conscious of how this might affect participants' confidence and openness during the conduct and analysis of focus groups, so I made every effort to build a relationship prior to the discussion to make the participants feel comfortable. I assured the participants that their views and beliefs would be respected whether they supported the value of technology or not, regardless of my personal views. I tried to avoid expressing my personal views during the focus group discussions since this could reduce the validity of the data.

As I am an international researcher who obtained her PharmD degree and work experience in Saudi Arabia, where they have a different healthcare system from the UK, I started the second stage of this thesis by exploring the perceptions of healthcare providers in NHS Wales with no previous background or experience of the healthcare system in the UK. At this stage, I was very much a learner and gradually built up my knowledge. I was excited to explore the reality of this new system and how the future use of technology and e-PROMs could improve the health services provided to patients. The use of a mixed-methods approach at this stage provided me with a general level of knowledge, as the results from the first phase of the questionnaire gave me a baseline level of understanding. Then I found myself asking basic questions at the beginning of each interview in phase II, such as 'How do the HCPs provide their services to the PwPs?' 'What kind of data do they collect before they see the patients and how they do use it during the clinical visit?' and 'How might using technology or e-PROMs affect the current provided services?'. This provided me with a steep learning curve. As I initially found myself looking to understand and explore the services provided to PwPs from a broader perspective, I then began to explore the role of each HCP and to investigate how using e-PROMs could affect that role to draw the final conclusion of this stage based on the perceptions of the participants. My position at this stage of this thesis was as a researcher seeking understanding of what is

best for both HCPs and PwPs to improve provided care without any preference, and I made this clear at the beginning of each interview.

During the last stage of this thesis, which was regarding the use of technology to support medication use, I followed the same procedures as those in the first stage (focus group), including introducing myself, explaining the purpose of the interview, and providing reassurance regarding the anonymity and confidentiality of the processes that would be used. When interviewing the participants, I was aware that how they perceived me (pharmacist/in favour of using technology) might influence their answers, which could bias the findings. To handle this issue, I reassured the participants about the purpose of the interview and made it clear that I did not have any contact with their HCPs, that their views would be used only to understand the issues they might have regarding their medications, and that I was trying to explore a possible solution to tackle these issues and to understand the possible role of technology in medication management.

I opted for an open interview setting, giving the participants the chance to say what they knew regarding PD, PD medications, and technology use. In addition, as my background is in pharmacy, I expected that some of the participants (PwPs) might ask me about their medications or for any advice in that regard. I made it clear to them at the beginning of each interview that I was interviewing them regarding their perceptions of technology use, that I could not provide any medical information, and that they would have to contact their HCPs if they had any concerns regarding their medications.

Chapter 3: Factors Affecting User Acceptance of MHealth Interventions in Parkinson's Disease: A Rapid Review

3.1 INTRODUCTION

Detection, diagnosis, monitoring, and management of PD is very important, yet can be challenging (Espay et al. 2016). This has encouraged technology developers to explore digital solutions, such as sensors, and mHealth with cloud computing to facilitate data storage and improve the healthcare provided to PwPs (Espay et al. 2016; Espay et al 2019). As mentioned in Chapter 1, with the advancement of technology, several mHealth app interventions have been developed for the detection and management of PD (Linares-del Rey et al. 2019; Majhi et al. 2019). These interventions have the potential to improve care, monitor and track PD symptoms, transmit data to HCPs, and promote self-management of the disease. However, these interventions are often developed for use in clinical trials or in non-clinical settings, including the at-home environment and in communities. Given that these interventions could be powerful tools to assist HCPs and PwPs during clinical encounters, the mass development of mHealth interventions raises the question of their potential effectiveness and usefulness in clinical practice.

Several studies have rigorously evaluated the feasibility, effectiveness, and usability of mHealth interventions in PD (Lorenzi et al. 2016; Silva de Lima et al. 2016; Fung et al. 2018; Sekimoto et al. 2019; Tang et al. 2019). Most of these studies have placed emphasis on quantitative measures to evaluate the utility of these interventions, such as rates of adoption and enrolment, and feasibility and clinical outcomes, largely excluding the users' perspectives (PwPs and/or HCPs). The adoption and acceptance of mHealth in PD is still in an early stage, which, given that mHealth interventions for PD will not be of any value or benefit unless accepted and adopted by their target users, means further investigation into this is needed (Espay et al. 2019; Li and Chang 2020). Most mHealth research has failed to capture the complexity of PD to satisfy the diagnostic needs of HCPs as well as the therapeutic needs of PwPs (Espay et al. 2016). Reasons for this failure include mHealth research failing to capture the demographic and socioeconomic data of target users (e.g., age and digital literacy skills),

mHealth tools not being utilised as anticipated in clinical settings (have limited clinical application), and insufficient engagement and acceptance of stakeholders (PwPs, carers of PwPs, HCPs, and healthcare regulators) (Espay et al. 2016; Espay et al. 2019; Li and Chang 2020). This final component is key, and the early recognition of the user's perceptions, attitude, and experience of mHealth app interventions is essential to understand the factors that might impact its future acceptability and usability.

After an extensive search, only two studies were found that addressed the factors that might impact whether PwPs accepted mHealth (Li and Chang 2020; Grosjean et al. 2020). A quantitative study by Li and Chang (2020) mentioned that having a confirmed diagnosis of PD was the catalyst to use the mPower app and that disease progression, especially impaired motor or cognitive abilities, was a hindrance to its effective use. This was not a surprising finding. As mentioned in Chapter 1 (see Section 1.8), the mPower smartphone app was designed to collect data from people to identify early markers to aid in PD diagnosis (Bot et al. 2016). It was expected that the majority of app users would be people who had a confirmed diagnosis of PD. In addition, the author of this study focused on analysing the collected data from the app intervention in order to identify the possible factors that might impact the acceptance and usability of the app, rather than evaluating users' perceptions.

Grosjean et al. (2020) conducted a qualitative systematic review in order to identify the factors that might impact the usability of mHealth (wearable sensors and mobile phones) for disease self-management and found that technological, social, and financial factors were essential to enhance the acceptability and usability of mHealth intervention by PwP. However, this review only included papers published until 2018, with a focus on acceptability in non-clinical settings. Therefore, given the fast development of mHealth apps and the scarcity of information available from the users' perspective, there is still a need to further explore the factors that might impact users' acceptability of mHealth apps in PD.

3.2 AIMS OF THE PRESENT REVIEW STUDY

The purpose of this chapter is to perform a rapid review of the existing literature that addresses the perceptions of users and factors that impact the acceptability of mHealth

interventions (smartphone/tablet iPad) for PwPs. The analysed interventions aim to support PwPs during clinical encounters in relation to disease and medicine management. The findings of this review could contribute to the development and design of a more acceptable mHealth intervention for PwPs.

3.3 RAPID SYSTEMATIC REVIEW METHODS

Rapid reviews are an emerging form of knowledge synthesis that utilise processes similar to a full systematic review (Khangura et al. 2012). However, some of the elements of systematic reviews are simplified or omitted in rapid reviews to generate information in a timely manner (Watt et al. 2008; Ganann et al. 2010). This rapid review streamlines systematic review processes by limiting the scope of the literature search and inclusion criteria (see Section 3.3.3), while still aiming to generate valid conclusions. One person (the researcher) was responsible for conducting the review. Later, the researchers' lead supervisors validated the conclusions by reviewing the findings. The important evidence-based synthesis was maintained, despite it being a rapid review, in order to reduce potential bias as much as possible.

3.3.1 METHOD

The study was performed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Liberati et al. 2009). At all stages of this review, including the search, data extraction, data syntheses, and quality appraisal, 10% of studies were double-checked for consistency by the researchers' lead supervisors. All inconsistencies were resolved through discussion.

3.3.2 SEARCH STRATEGIES

The search shown in Figure 3.1 was developed according to the participants, intervention, and context (PICo) framework (Butler et al. 2016). This framework is specific to the research question relating to qualitative research or specific qualitative designs, and it is a modified version of the clinical and quantitative review questions PICO (Population, Intervention, Comparison, Outcome) framework (Butler et al. 2016). The PICO framework is a widely known method used in evidence-based practice to frame, refine, answer clinical or healthcare-related

questions, and develop literature search strategies, for example, in systematic reviews (Butler et al. 2016). Using the PICo framework to develop the review research question facilitates the search strategy by identifying the main concepts of the research question that need to be answered (Aslam and Emmanuel 2010). As the aim of this review focused on exploring the acceptance factors of mHealth interventions for PD, the search was limited to Parkinson's disease on the kinds of conditions qualified for inclusion, and there were no restrictions on the study design. Both qualitative and quantitative studies were included to enable the researcher to identify all studies that involved users' perceptions in their outcomes (ensuring inclusivity).

The following search strategy was used:

1. Population (P): included studies focusing on PwPs and/or HCPs (as these are the target users of the mHealth intervention).
2. Intervention (I): included studies involving mHealth use (smartphone/tablet/iPad).
3. Context (Co): included studies addressing the users' perceptions that might impact mHealth technology acceptance or use.

A systematic search of titles and abstracts was conducted in Ovid MEDLINE (1946–2020), Ovid EMBASE (1947–2020), Scopus (2004–2020), and other sources, such as Google Scholar, in November 2020. Google Scholar offers both academic and grey literature (documents not formally published by academic publishers, such as academic theses, organisation and government reports, etc.) (Haddaway et al. 2015). Advice was sought from a pharmacy subject librarian on developing a suitable search strategy. The search strategy was tailored to the above databases because they provide access to comprehensive and up-to-date research in the fields of science, technology, and social sciences. Additionally, the grey literature (Google Scholar, especially the academic articles and conference abstract) was included in this review, as its quality can be assessed. Conference abstracts can contain adequate information. According to Scherer and Saldanha (2019), minor differences were found when comparing conference abstracts with fully published articles from the same study, and that is usually the conference abstracts reporting preliminary findings. However, other forms of grey literature,

such as blogs, were excluded, as these resources are not peer-reviewed and are unlikely to contain empirical data.

Search terms focused on the three concepts of the review question: ('mHealth', 'smart devices (smartphone/tablet)'), 'Parkinson's disease', and 'acceptability' (See Appendix 3.1). Alternate terms relating to the same concepts were combined using the Boolean operator 'OR', and different concepts were combined using 'AND'. Searching strategies in Google Scholar were conducted using the same concepts, but the search technique was different, as follows: quotation marks were placed around keywords: 'Smart device', 'mHealth', 'tablet', 'iPad', 'Parkinson's disease', 'Parkinson's', 'PD'. Google Scholar automatically places 'AND' between key words. The alternate terms of the same concept were combined using 'OR', with the terms enclosed in parentheses: ('Parkinson's disease') ('smart device' OR 'mHealth') ('acceptability' OR 'satisfaction').

Duplicates were electronically removed in the reference manager software prior to the review of abstracts. A preliminary screening of titles and abstracts of citations was conducted for appropriate studies to include in this review based on relevance to the search terms. When there were doubts regarding relevance, full-text articles were obtained and reviewed to ensure the appropriateness of the inclusion/exclusion criteria. Additionally, references of the included studies were searched manually for further studies; however, no additional studies were identified.

3.3.3 ELIGIBILITY CRITERIA

The study screening was conducted by the researcher following a four-stage process of identification, screening, eligibility, and inclusion (Liberati et al. 2009) (See Figure 3.1). In order to be as inclusive as possible, the review included studies published in English between 2010 and 2020. The first reference related to the development of a mHealth app intervention for PD was published in 2011, so 2010 was selected as the earliest limit of searching.

The included studies were required to meet the following criteria:

Inclusion Criteria

1. Studies in which the primary participants were PwPs (any disease stage) and/or HCPs for PwPs.

2. Studies in which the intervention was a mHealth app intervention (smartphone/ tablet) by itself or as part of a system.

3. Intervention outcomes that included the user's perspective (i.e., users' satisfaction, users' feedback, acceptability, or usability) included:

> 3.1 PD medication adherence or management, disease management, and promotion of self-management.

> 3.2 Type of data collected via intervention: Objective or Subjective.

> 3.3 Intervention with clinical value in PD clinical practice that may support patients during clinical consultation.

4. Study design: qualitative, quantitative, or mixed-methods.

Exclusion Criteria

Studies were excluded from the review based on the following criteria:

1. Studies that included only non-PD participants (participants had neurodegenerative diseases other than PD).

2. Studies not written in English.

3. Studies that did not provide sufficient information on the mHealth intervention/data type/users' perspective to be adequately reviewed.

4. Studies that looked at mHealth interventions outside clinical practice (e.g., in home settings) only.

5. Studies that only evaluated the efficacy of the mHealth intervention without mentioning users' perceptions.

6. Studies in which interventions were a method of data collection only and were not interactive (e.g., they did not support patients' clinical consultations).

The studies excluded from this review were left off for multiple reasons; however, only one main reason is reported in Figure 3.1.

Data Extraction and Synthesis

Data were collected and extracted from each study onto a template under the following headings: research identification (authors, year of publication, country of study sample, study

focus, study population), intervention (intervention type, mHealth type, feature of the intervention), research methods (study design, method, outcome measures, length of intervention use), and main findings. The data extraction template was first used by the researcher and then reviewed and refined by the researcher's lead supervisors.

Because of the nature of the aggregated data, a statistical meta-analysis was not appropriate. Therefore, a qualitative approach (content analysis) (Krippendorff 1980) was performed to synthesise the results in relation to the motivators for and concerns about mHealth intervention use from the perspectives of PwPs and/or their HCPs. The content analysis was used to provide a direct and detailed analysis of the factors, concepts, and themes underpinning the acceptance and usability of mHealth for PD contained in the literature. Content analysis allowed the researcher to gain conceptual insights in detail by moving across the papers, which facilitated an objective, subjective, and text-driven review of the literature. The synthesis also considered the identification of factors that might impact users' acceptability.

Quality Appraisal

The methodological quality of the included studies was assessed using two tools. The Effective Public Health Practice Project (EPHPP) checklist was used for the quantitative research studies. This tool provides an overall quality rating based on eight individual quality sections, including selection bias, study design, confounders, blinding, data collection methods, withdrawals and dropouts, intervention integrity, and analysis. Additionally, this tool is recommended for quality assessment in reviews that are inclusive of a wide range of study designs (i.e., RCTs and uncontrolled studies) (Jackson and Waters 2005). The Critical Appraisal Skills Programme (CASP) checklist was used for the qualitative research study. The CASP tool contains 10 questions that help make sense of qualitative research, and it is one of the most commonly used tools for quality assessment in qualitative research (CASP 2020; Long et al. 2020) (Appendices 3.2 and 3.3). There is no consensus regarding the most appropriate or gold standard critical appraisal tool to be used; however, the tools were applied based on the study design for which they were intended (Katrak et al. 2004).

The quality of each study was rated as good, moderate, or poor based on the researchers' judgement of each section included in both checklists. The rating of the 10 sections of the CASP tool was considered as follows: 'good' (if all questions were answered Yes), 'moderate' (if questions between 1–5 were answered No) and 'poor' (if there is > 5 questions were answered No). The researcher followed the EPHPP dictionary to rate the quantitative studies, which is as follows: 'good' (if all sections were rated strong), 'moderate' (if one section was rated weak), and 'poor' (if two or more sections were rated weak); however, the final rating of the study was based on the researchers' judgement (EPHPP 2021). This review focused on the findings of studies that were appraised as 'good' or 'moderate' quality (Armijo-Olivo et al. 2012). However, studies that were appraised as 'poor' quality were also included and referenced where appropriate because of the limited available information on users' perceptions of mHealth interventions in PD.
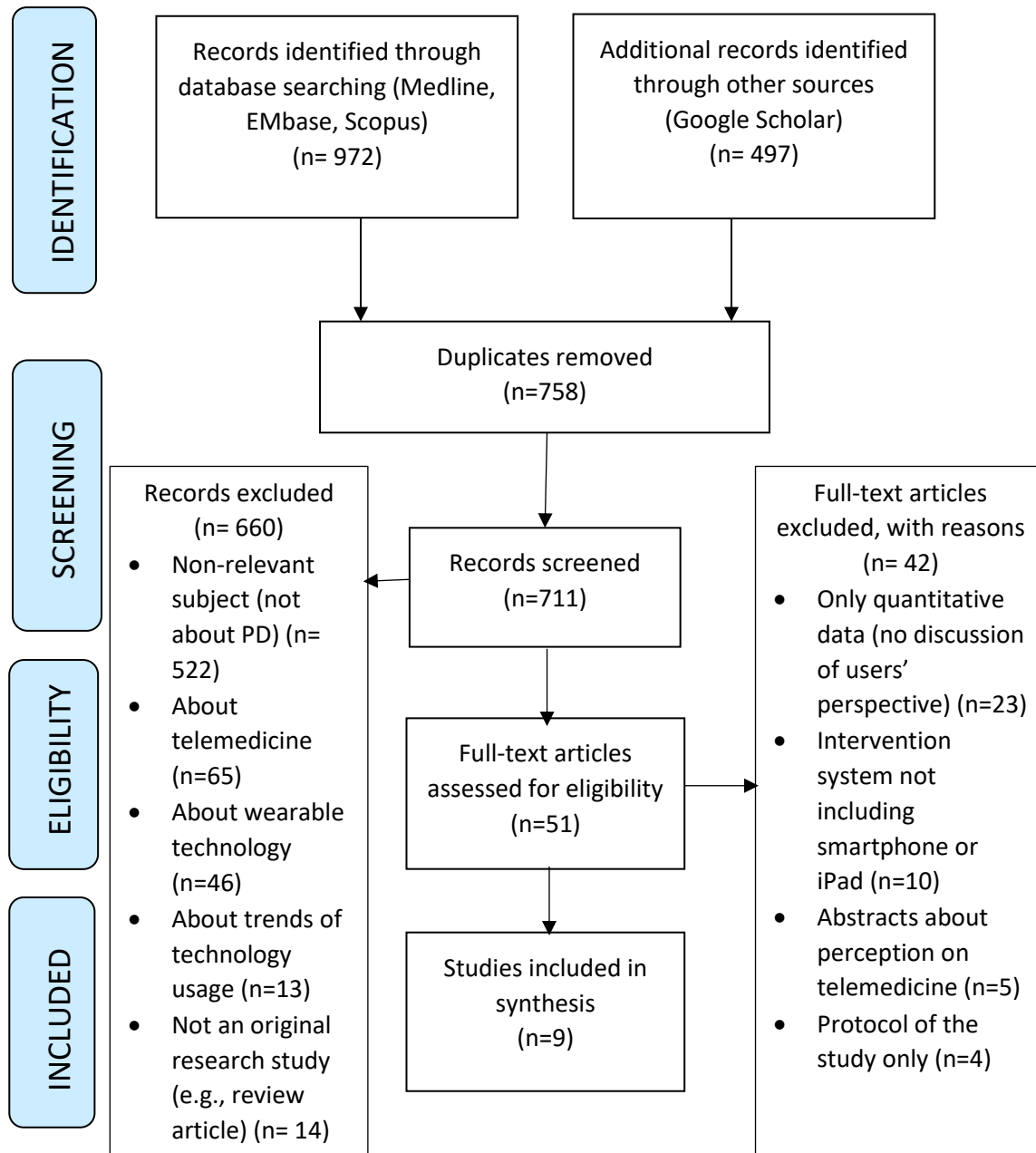
Figure 3.1: Flowchart of the study selection process based on the PRISMA-P protocol

3.4 RESULTS

The literature searches during the identification stage generated 1,469 articles, which resulted

in 711 articles after the removal of duplicates. Those articles were screened, and a total of 51

articles were considered appropriate for eligibility screening. Of those, 9 articles were selected

after screening using the inclusion and exclusion criteria. One study was categorised as good quality, six were of moderate quality, and two were of poor quality. Further details on the selection process and reasons for the exclusion of articles are reported in Figure 3.1. Additionally, Table 3.1 describes the relevant characteristics of the articles included in this rapid review.

3.4.1 POOLED STUDY CHARACTERISTICS

There were considerable differences in the methodology and sample size of the included studies. The number of participants (PwPs) ranged from n = 7 (Wannheden and Revenäs 2020) to n = 204 (Hu et al. 2020). All studies included PwPs who were in their early stages and excluded advanced stages (H&Y 4 and 5), PwPs with dementia, and those with severe physical inability. The average age of the PwP participants ranged from 53.5 years old to 68.75 years old. Additionally, two of these studies included HCPs (Elm et al. 2019; Wannheden and Revenäs 2020). Three of these studies were from the USA (Mitsi et al. 2017; Elm et al. 2019; Wannheden and Revenäs 2020), two from Europe: Spain, Italy, Ireland, Sweden, and Israel (Bayés et al. 2018), Portugal, Germany, and Norway (Ferreira et al. 2015), and one each from Australia (Lee et al. 2016), Japan (Sekimoto et al. 2019), China (Hu et al. 2020), and the UK (Lakshminarayana et al. 2017).

Three of the studies were feasibility studies, one was an RCT, one was a randomised crossover study, one was a prospective pilot study, one was a validation observational study, one was a surveillance study, and one was a qualitative study (focus group discussion then questionnaire) (see Table 3.1). Four studies specified the length of time that participants were required to use the mHealth app interventions. From these, an average of 75 days (range 3–180 days) was obtained. The mode was 3 days, and the median was 57.5 days.

Two studies reported users' opinions and attitudes as their primary aim (Hu et al. 2020; Wannheden and Revenäs 2020). The secondary aim of seven of the nine included studies was to report users' opinions and levels of satisfaction with the acceptance and usability of the applied mHealth interventions. Seven studies collected the perceptions of the user (PwP), one collected data only from neurologists (Elm et al. 2019), and one from both PwPs and HCPs,

which included neurologists, PDNS, and physiotherapists (Wannheden and Revenäs 2020). Methods of data collection included users' satisfaction and/or intervention's ease of use questionnaire (7 studies) and focus groups (2 studies). Eight of the nine studies evaluated the users' perceptions after the development of the interventions, while one evaluated the users' perceptions during the development stage of the intervention, which resulted in intervention updates and improvement in the acceptance and usability of the intervention (Elm et al. 2019).

Three app interventions were run on a smartphone device (Lee et al. 2016; Lakshminarayana et al. 2017; Hu et al. 2020), two interventions were run on a tablet iPad device (Mitsi et al. 2017; Sekimoto et al. 2019), and one intervention was run on both smartphone and tablet iPad devices (Wannheden and Revenäs 2020). A further three smartphone app interventions were part of a system that included wearable sensors (Ferreira et al. 2015; Bayés et al. 2018; Elm et al. 2019). Almost all interventions had features to assess and track the motor symptoms of PD (e.g., tremors, hand dexterity, gait, and bradykinesia), and three of those also had features to assess the NMSs of PD (e.g., constipation, cognition, mood, and sleep) (Ferreira et al. 2015; Lakshminarayana et al. 2017; Elm et al. 2019). A further four of these app interventions also had a feature to monitor medication intake and adherence (Lakshminarayana et al. 2017; Bayés et al. 2018; Elm et al. 2019; Sekimoto et al. 2019). Two of the nine studies were designed for their interventions to be used in clinical settings (Mitsi et al. 2017; Wannheden and Revenäs 2020), while six designed their interventions to be used in home-based settings and remotely collected users' data (Ferreira et al. 2015; Lee et al. 2016; Lakshminarayana et al. 2017; Bayés et al. 2018; Elm et al. 2019; Sekimoto et al. 2019). However, these home-based interventions had features that enabled users to either generate reports of their performance or send the collected data through cloud services to HCPs in order to inform clinical encounters (decision-making process). Additionally, seven studies reported promising findings from their interventions in supporting clinical encounters and decision-making processes. The participants of two studies reported interest in a smart device intervention that supported the decision-making process and improved communication with HCPs (Hu et al. 2020; Wannheden

and Revenäs 2020). All of these interventions were still in the early phase of evaluation and assessment and will need further studies to validate their findings.

Almost all of the included studies in this review evaluated the users' perceptions of their intervention as a secondary outcome through a follow-up questionnaire that was conducted at the end of the study (e.g., system usability scale (Brooke 1996) and IBM post-study usability scale (Lewis 1995)). In general, the assessment strategies used in the included studies were not described in detail to allow full understanding and interpretation of the findings. Little evidence was identified that directly addressed the factors that might influence users' acceptance and usability of the mHealth app for PD. However, the available evidence does not suggest that the use of the mHealth app for PD was acceptable to cut corners, as the findings were limited.

 Of note was the insufficient reporting of the findings from the users' perception questionnaire in eight of the included studies (Ferreira et al. 2015; Lee et al. 2016; Lakshminarayana et al. 2017; Mitsi et al. 2017; Bayés et al. 2018; Elm et al. 2019; Sekimoto et al. 2019; Hu et al. 2020). The reason for this could be that the primary focus of these studies was to evaluate the efficacy of the interventions rather than the users' perception. Also, as shown in Table 3.1, it was noticed that most of the included studies had a small simple size and/or included people only with mild to moderate PD who were not suffering from severe complications. This would impact the generalisability of the findings of these studies, which need to be interpreted with caution.

Table 3.1: Detailed summary of included studies

Author (year) and country	Study focus	Study population	Intervention	Methods	Outcome measure	Main findings	Quality* note
Ferreira et al. (2015), Europe (Portugal, Germany, and Norway)	To explore feasibility and usability of SENSE-PARK system that aimed to collect PD symptoms including gait, hypokinesia, dyskinesia, tremors, sleep, and cognitive symptoms	PwPs (n = 11) **Inclusion criteria** 40–85-year-old PwPs Stage 1 to 2 on H&Y scale Experience or interest in using digital devices **Exclusion criteria** Illiteracy Inability to handle the device for any reason	SENSE-PARK system 3 Wearable sensors, Wii Balance Board, software, and smartphone app **Intervention focus** Motor symptoms (gait, hypokinesia, dyskinesia, tremors) NMSs (sleep and cognition)	Multicentre, feasibility and usability study, open-label study, two period study (first period with no feedback to the participants then second period participants provided with the feedback about their performance), Qualitative (interview) Descriptive analysis **Study Period** 12 weeks	Frequency of dropouts, willingness to use system, users' satisfaction Surveys on usability	Participants reported good acceptance levels and were willing to use the system even after the study ended. All participants completed the study. Providing feedback to the participants motivated them to continue using it. Additionally, participants found the system useful and simple to use, especially the users' interface of the system and the instructions provided to complete the task. Participant liked that the system helped to monitor changes in their condition.	Moderate
Lee et al. (2016), Australia	To validate a smartphone app against the gold standard tool in the clinical practice (MD-UPDRS-III),	PwP (n = 103) **Inclusion criteria** Patient diagnosed with PD **Exclusion criteria** Stage 4 and 5 HY PwPs	Smartphone app included four tests: Timed tapping test, rapid alternating movements, tremor tracker, and cognitive interference test.	Quantitative, validation and observational study, descriptive statistics, Pearson's or	MD-UPDRS-III, two target tapping test, Montreal cognitive assessment, Victoria stroop test	A strong correlation was reported between data obtained from the app and MD-UPDRS (P<0.001). The majority of participants had positive experiences of study participation (96%), 4 dropped out because of the	Good

Author (year) and country	Study focus	Study population	Intervention	Methods	Outcome measure	Main findings	Quality* note
	and to assess the practicality, compliance, and user satisfaction of the app	Patients with physical or cognitive impairments	**Intervention focus** Motor symptoms (hand dexterity)	Spearman's correlation **Study period** 18 months	Surveys on compliance and user satisfaction	difficulties using smartphones in general, and 40% (n = 36) of participants experienced difficulties with apps. Most participants (83%) felt comfortable using the app and mobile technology. 8% of participants perceived cost of mobile apps a limitation for future use.	
Lalshminarayana et al. (2017) UK	To assess the impact of a smartphone app to improve medication adherence, promote patient self-management, and quality of clinical consultation	PwP (n = 158) **Inclusion criteria** Idiopathic PD patient older than 21 years Prescribed one or more Parkinson's medications and had a stable medication regime Access to a smartphone and/or tablet or internet at home **Exclusion criteria** People diagnosed with dementia, cognitive impairment, or psychiatric illness	Parkinson's Tracker App included: A sliding petal interface to track 10 self-monitoring measures (e.g., sleep, exercise, and mood). A reminder system with alerts to track medications Option to generate reports of data entered to aid clinical consultation Games to assess physical activities (finger tapping test) Information about PD **Intervention focus** Motor symptoms (bradykinesia, tremors)	Quantitative, Multicentre, RCTs, 7 centres across UK (England and Scotland). **Study period** 16 weeks	MMAS-8, PDQ-39, patient-centred questionnaire for PD, NMSQ, hospital anxiety and depression scale Questionnaire and interviews to assess acceptability and ease of use of the app	The use of the app significantly improved medication adherence (p = 0.0304), improved patient's perceptions about the quality of clinical consultation (p = 0.011). Participants recognised the benefits of the app, such as sharing valuable information with HCPs and participating in decision making during consultation. Additionally, the simple design of the app's user interface and user experience with technology use improved the acceptability and usability of the app.	Moderate

Author (year) and country	Study focus	Study population	Intervention	Methods	Outcome measure	Main findings	Quality* note
			NMSs (cognition, mood, and sleep) Medication management				
Mitsi et al. (2017), USA	To evaluate the feasibility, potential benefit, and user satisfaction of using a tablet-based app to assess motor function	PwPs (n = 19) Healthy volunteers (n = 17) **Inclusion criteria** Healthy people or PwPs 17–75 years old H&Y stages I–IV **Exclusion criteria** Atypical Parkinsonism Other CNS disorders for PwPs People physically unable to perform tasks on intervention	iMotor app (tablet-based app) including 3 different tapping tests and a report generator section (summarising tests results) **Intervention focus** Motor symptoms (hand movement)	Single centre, Cross-sectional, feasibility and exploratory study **Study Period** NA	Tapping variables (total number of taps, velocity, interval, duration, and accuracy of tap), and Questionnaire on users' satisfaction	Significant difference in almost all tapping variables were reported on PwPs compared to healthy volunteers, except tapping accuracy (p > 0.167). A high rate of users' satisfaction was reported by participants; 79% of participants found the app very easy to use, 63% were very willing to continue using the app, and all participants reported that they would use the app if their HCPs recommended it.	Poor
Bayés et al. (2018), Europe (Spain, Italy, and Ireland) and Israel	To assess the accuracy of the REMPARK system in recognising the motor fluctuations	PwP (n = 33) **Inclusion Criteria** 50–80-year-old PD patients with severe motor conditions (freezing of gait and/or dyskinesia)	REMPARK system included: Wearable sensors (to monitor motor fluctuations) Smartphone app (offer range of options such as	Multicentre, A prospective, pilot study in home of PwPs (Spain, Italy, Israel, and Ireland). **Study period**	Recording motor status in diary while using the system, UPDRS-III	The system is able to detect the motor fluctuations, demonstrated 97% (sensitivity) in detecting OFF state and 88% specificity in detecting ON state. Participants found the system acceptable and were satisfied.	Moderate

Author (year) and country	Study focus	Study population	Intervention	Methods	Outcome measure	Main findings	Quality* note
	during ON and OFF states	**Exclusion criteria** PwPs with dementia	medication management, visualisation of the detected symptoms, and filling in specific questionnaire and scale and sending the collected data via specific server to the HCPs) **Intervention focus** Motor symptoms (on-off fluctuation)	5 days	Surveys on usability and user satisfaction	User-friendly systems with high security levels were considered by participants.	
Sekimoto et al. (2019), Japan	To assess the feasibility and safety of using a tablet device video-based telemedicine systems as part of patient care in PD To assess user satisfaction with the use of telemedicine system	PwP (n = 10) **Inclusion criteria** 20–75 years old PD patients Access to Wi-Fi at home **Exclusion criteria** Not mentioned	Video-based telemedicine call by using the FaceTime app in a tablet device The use of telemedicine was a supplement to the patients' clinical visits. **Intervention focus:** Motor examination Medication review	Randomised, crossover, pilot study Comparing the patient's regular visit every 2 months with an intermediate video call to a control period regular visit only **Study period** 12 months	PDQ-39, HY staging scale, UPDRS, Beck depression inventory Surveys on user satisfaction	No significant difference was reported in outcomes measures between two periods (P>0.05). Participants found the tablet-based telemedicine system easy to use, useful to reduce anxiety level regarding medication and disease progression. Participants also agreed that the system made it easier to communicate with their HCPs.	Moderate
Elm et al. (2019), USA	To evaluate feasibility and usability of mHealth app-	PwPs (n = 51) HCPs (n = 14 neurologists) **Inclusion criteria**	Smartwatch + Fox Wearable companion mobile app	Feasibility and observational, exploratory	Retention of PwPs, number of hours of data	39/51 participants completed the study. The reasons for drop-out were fatigue, and system specific and technical	Moderate

Author (year) and country	Study focus	Study population	Intervention	Methods	Outcome measure	Main findings	Quality* note
	derived data to inform clinical decision making	18 years and older PwPs Stage 1 to 3 on H&Y scale. Access to WiFi at home **Exclusion criteria** PwPs with cognitive impairment	(To collect e-PROMs and medication reminders) **Intervention focus** Motor symptoms (tremor, rigidity, dyskinesia, gait problem, bradykinesia) NMSs (constipation, voice problems) Medication management	study focus group **Study Period** 6 months	streamed, and HCPs' feedback	issues. HCPs perceived that the medication compliance and severity of e-PROMs were the most beneficial components of the system that support clinical care.	
Wannheden and Revenäs., (2020), Sweden	To explore the expectation and desired of PwPs and HCPs' about features of e-Health to support co-care in PD practice	**Stage I**: PwP (n = 7), HCPs (n = 9 (4 neurologists, 3 PDNS, 2 physiotherapists)) **Stage II**: PwPs (n = 31), Carers for PwPs (n = 6)	**The co-care prototype app (smartphone or tablet) included:** Pre-visit form Patient self-tracking Graphical overview Clinical decision support Self-care recommendations, and Asynchronous communication **Intervention focus** Not mentioned	Qualitative, workshop, focus group discussion, thematic analysis, Descriptive analysis **Study period** 4 half-day workshops	**Stage I:** important features of the app porotype and its impact on care **Stage II:** Survey on usability and acceptance of the prototype	Participants perceived that the co-care design prototype app had potential to improve quality of care in terms of effectiveness, timeliness, and patient-centredness. Patients' digital literacy, patients' acceptance, and extra workload on HCPs were the main constraints to using the e-Health system. 31 (84%) of participants' benefits of the app and all features of the prototype app were rated as important or very important, especially features related to communication, graphical	Moderate

Author (year) and country	Study focus	Study population	Intervention	Methods	Outcome measure	Main findings	Quality* note
						overview, or summary of the inputted data.	
Hu et al. (2020) China	To explore acceptability and practicality of a smartphone app for PD self-management among PwPs	PwP (n = 204) **Inclusion criteria** Diagnosed with PD Physically and cognitively able to complete the questionnaire **Exclusion criteria** Not mentioned	PD self-management smartphone app **Intervention focus** Not mentioned	Quantitative, surveillance study Descriptive statistics, Chi-squared test	Attitude toward mHealth use and PD self-management app	Participants had positive attitudes toward the intervention, 82.84% reported willingness to use self-management app. Participants said a cost-free app, easy to use with a medication reminder system and help to manage their PD condition is preferable. PD education section, ability to communicate with HCPs, and ability to record symptoms were the most interesting features reported by participants (80.88%, 77.46%, and 65.69% respectively).	Poor

*See Appendices 3.2 and 3.3 for more details of the quality note

3.4.2 THEMES

Findings from the qualitative content analysis were categorised into two main themes: (1) motivators to accept and use a smart device intervention, which included the subthemes of perceived usefulness, perceived ease of use, interactivity, design, and users' engagement, and (2) concerns about the acceptance and use of a smart device intervention, which included the subthemes of trust, long-term use, PD-related status, financial factors, and workload.

3.4.2.1 THEME 1: MOTIVATORS

1. Perceived usefulness

Five of the nine studies included in the review (Lee et al. 2016; Lakshminarayana et al. 2017; Sekimoto et al. 2019; Hu et al. 2020; Wannheden and Revenäs 2020) described the usefulness and benefits of the smart device app intervention for PD. In the Lee et al. (2016) study, 93% of PwPs reported usefulness of the smartphone app, which could support the patients' physical examination during clinical encounters with their HCPs (by giving indications of motor symptoms progress). Also, 16 out of 42 participants who reported not owning a smartphone device at the beginning of this study showed an interest in purchasing one after their experience (Lee et al. 2016). However, these findings should be carefully interpreted, as the majority of the PwPs in this study seemed to be in favour of technology use (60 out of 91 of participants reported using the internet on a daily basis) and 81% and 54% of participants owned a computer and mobile device, respectively.

Lakshminarayana et al. (2017) reported the usefulness of the PD Tracker app indirectly by using a patient-centred questionnaire for PD. This questionnaire included subscales that evaluated patients' perceptions of the quality of the care provided (e.g., information, accessibility, collaboration, and patient involvement) (van der Eijk et al. 2012). The PD Tracker app was found to have a significant impact on improving collaboration and patient involvement in the decision-making process during clinical encounters (p=0.011) (Lakshminarayana et al. 2017). However, the users' perception of the usability of PD Tracker app in general is not reported, and further evaluation is still required.

In Sekimoto et al.'s (2019) study, nine participants out of 10 reported that the mHealth intervention (iPad app) had the potential to improve communication between PwPs and their HCPs. Additionally, several perceived benefits were reported in a surveillance study conducted by Hu et al. (2020), which generally assessed the use of Parkinson's disease management apps rather than the actual use of these apps. For example, the 204 PwPs reported their willingness to use such apps if the apps for PD were found to have the potential to improve the management of PD (69%, 141/204) and communication with HCPs (74 %, 151/204), facilitate the findings of PD-related information (61%, 124/204), reduce the psychological burden of PD (78 %, 160/204), and help HCPs to track the impact of PD medications and make changes based on that (71%, 145/204). Similar findings were also reported in a qualitative study conducted by Wannheden and Revenäs (2020) that evaluated the use of mHealth apps for PD in general rather than a specific app. The participants reported that the mHealth app could improve access to care and communication with HCPs, enable tracking of the impact of PD medication and improve medication adherence.

2. Perceived usability (ease of use)

Six studies (Ferreira et al. 2015; Lee et al. 2016; Mitsi et al. 2017 Bayés et al. 2018; Sekimoto et al. 2019; Hu et al. 2020) discussed the concepts of usability for smart device app intervention. Two different usability requirement concepts were discussed in these studies: ease of use (Mitsi et al. 2017; Sekimoto et al. 2019; Hu et al. 2020) and user-friendliness (Ferreira et al. 2015; Bayés et al. 2018). Both concepts serve a practical purpose, which is simplicity and lack of effort required for the intervention system. Although different questionnaires were used to evaluate the users' perceptions in Ferreira et al.'s (2015) study (PSSUQ (Lewis 1995)) and Bayés et al (2018) study (SUS (Brooke 1996) and QUEST-questionnaire (Demers et al. 2002)) (each scale has questions related to ease of use), insufficient data (details) were reported in this regard to allow further understanding and interpretation of the findings. However, it was reported that the participants liked the intervention and found it to be user-friendly (Ferreira et al. 2015; Bayés et al. 2018). In Mitsi et al.'s (2017) study, 79% of PwPs found the iMotor app very easy to use. Sekimoto and

colleagues (2019) reported that 9 out of 10 PwPs found the mHealth intervention (iPad app) easy to use. In Hu et al. (2020), 169 of 204 PwPs who completed the study questionnaire emphasised the need for an easy-to-use intervention system in order for them to consider using it. In contrast, 40% (36 out of 91) of PwPs in the Lee et al. (2016) study reported experiencing difficulty in using the mHealth intervention system, and 4 PwPs dropped out at the beginning of the study due to difficulties in using smart device (smartphone). However, the reasons for the reported difficulties were attributed to NMSs of PD, such as poor hand dexterity (n = 18/36), fear of new technology use (n = 12/36), poor vision (n = 4/36) and reduced clarity of thoughts (n = 11/36).

3. Training/technical support

Five out of nine of the included studies provided users with technical support in order to facilitate the use of interventions (Ferreira et al. 2015; Lee et al. 2016; Mitsi et al. 2017; Bayés et al. 2018; Elm et al. 2019). The technical support was provided through personalised contact, as some of the studies had dedicated a member of the research team to dealing with technical issues (Bayés et al. 2018; Elm et al. 2019). Three studies also provided users with training in how to use the intervention to improve their performance and deal with troubleshooting themselves (Ferreira et al. 2015; Lee et al. 2016; Mitsi et al. 2017). In Lee et al.'s (2016) study, when training was provided, 11 out of 13 of the participants who were uncomfortable with technology use at the beginning of the study reported that they felt comfortable using the smart device intervention by the end.

4. Interactivity

The mHealth intervention, which enabled users to generate feedback summaries of their performance and progress reports and provide access to the collected data, was valued by users. Three studies (Lakshminarayana et al. 2017; Elm et al. 2019; Wannheden and Revenäs 2020) had features that enabled users to generate a feedback summary of their performance. However, no further data were provided in these studies to fully understand either the impact

of the generated summary on the clinical encounter or why the users valued having it. Therefore, further studies are needed to investigate this.

Three studies showed the importance of integrating the mHealth intervention with the patient database (EHRs) (Bayés et al. 2018; Elm et al. 2019; Wannheden and Revenäs 2020). In the Bayés et al.'s (2018) study, PwPs were requested to send their collected data from the intervention system to a specific server in order to allow HCPs to act on it. Similarly, in Elm et al.'s (2019) study, the mHealth intervention (which included four sections as follows: medication intake, patients' diaries (e-PROMS), and two sections that were related to hourly symptoms and daily displays) was integrated with the patients' database in order to support the clinical practice. The information related to NMSs (constipation), the medication intake section, and the e-PROMs diary section were the most valued and beneficial sections in supporting and informing clinical practice according to HCPs (neurologists) (88%, 85%, and 85% respectively). In the qualitative focus group discussion, the HCPs emphasised the need to integrate the mHealth intervention with the patients' database to facilitate and improve the delivery of care for PwPs (Wannheden and Revenäs 2020).

5. **Design**

Two studies discussed the design of an acceptable smart device intervention, such as the interface and content (Hu et al. 2020; Wannheden and Revenäs 2020). In the surveillance study conducted by Hu et al. (2020), PwPs rated the most important features and contents for a smart device app for PD as follows: PD education section (81%), features that enable communication with HCPs (78%), recording of PD symptoms (66%), provision of PD-related information (60%), and medication recommendations (55%). However, the perception of PwPs who did not own a smart device or who were in advanced PD stages may differ regarding the desired features and content for a smart device intervention, as most participants in this study owned a mobile device (196/204) or a smartphone (133/204) and were in their early stages of PD (115/204 were on stages I–II and 89/204 were on stage III, based on the H&Y scale).

Similarly, the most suggested features for a smart device app for PD were also reported by Wannheden and Revenäs (2020). This included graphical display of the collected data, general information about PD (symptoms, treatment, and possible ongoing research), and a feature for users to flag essential data. The app should enable HCPs to flag symptoms to support a clinical encounter, and PwPs to flag and send requests for recommendations regarding medications and activities (Wannheden and Revenäs 2020). Additionally, almost all studies emphasised the need to develop a user-friendly device intervention for PwPs.

6. User engagement

Two studies (Elm et al. 2019; Wannheden and Revenäs 2020) showed the impact of engaging end users of a smart device intervention in the early stages of development to improve acceptance and usability of the intervention. Wannheden and Revenäs (2020) involved both HCPs and PwPs in guiding the design and development of their prototype app (Mini Fair app) to support the concept of co-care in PD. This led to designing the app based on the desired functionality demonstrated by both HCPs and PwPs (pre-visit form for PwPs, graphical overview of the data, option to flag or request advice, and option for direct communication). Subsequently, 84% of PwPs liked the app and perceived the value of the prototype app; they also rated the functionality of the app as either important or very important (86% vs 97%) (Wannheden and Revenäs 2020). However, this study is considered to have low certainty of evidence, as it had a biased sample size (the included PwPs were highly educated and experienced with technology), which would limit the generalisability of its findings. The authors of Elm et al.'s (2019) study reported that involving HCPs (14 neurologists) resulted in improvement of their intervention (e.g., addition of separate display for each section within the intervention and addition of markers for medication intake across e-PROMs section). Subsequently, this improved the usability of the intervention system to support clinical practice (Elm et al. 2019).

3.4.2.2 THEME 2: CONCERNS

1. **Trust**

Two studies (Bayés et al. 2018; Hu et al. 2020) discussed trust factors, such as perceived privacy and security of the mHealth intervention and their impact on the users' intention to accept and use it. In Bayés et al. (2018), security was reported with the highest score on the QUEST-questionnaire (Demers et al. 2002), which is used to assess satisfaction with wearing the sensors and the potential concerns about adverse events. However, no further information was reported in this regard to allow full understanding and interpretation. No adverse events related to wearing the sensor device were reported in this study, which could be the reason for the highest scores reported in the questionnaire.

In the Hu et al. (2020) study, 139/204 of PwPs reported their willingness to use a smart device intervention if they felt that their privacy was protected. However, no additional details were provided regarding the rest of the participants in this study, who did not express any concerns with regard to data confidentiality and privacy within the mHealth app. The findings were not enough to draw a conclusion about whether they had any concerns but did not want to express their thoughts in this regard. Therefore, a further study to investigate this issue is still needed.

2. **Long-term use of the intervention.**

Two studies (Lakshminarayana et al. 2017; Elm et al. 2019) highlighted issues with the long-term use of mHealth interventions without providing further explanation for the high reported attrition rate in their studies. In Elm et al.'s (2019) study, it was noted that the usability of the intervention by PwPs dramatically decreased over the study duration. The PwPs were asked to stream data from the watch (sensor part of the system) and report symptoms and medication intake using the app more than once per day. However, the data streaming and collection via the intervention dropped from 145% in the first month to 66% by the end of the study (Elm et al. 2019). No specific measure was used in this study to determine the reasons behind the discontinuation of the intervention use.

In Lakshminarayana et al.'s (2017) study, the attrition rate was high, especially in the intervention arm, as only 68 PwPs completed the study out of 104 at the beginning. The reasons for this could be that participants were requested to perform many tasks (e.g., recording sleep, exercise, mood, and energy; input medication intake; and perform tapping and cognition tests) on the tracker app, which could increase the cognitive load of the users, and tasks may not have met the participants' needs at that time. However, Lakshminarayana et al. (2017) reported that 29% (n = 14/49) of 72% that retained the use of app throughout the study period (n = 49/68) had continued to use the mHealth app intervention after the study terminated for over 6 months. No further data were provided to clarify the factors that motivated them to continue using the app. Further study is needed with this subgroup in order to explore this.

3. PD-related health status

Two studies (Lee et al. 2016; Wannheden and Revenäs 2020) highlighted users' concerns about the impact of PD symptoms, such as physical and cognitive ability, in using an mHealth intervention. In Lee et al.'s (2016) study, 40% (36/91) of PwPs reported difficulty using the smartphone app due to poor hand dexterity (18/36), poor vision (4/36), and decreased clarity of thoughts (11/36), which is considered a nonmotor symptom related to PD. Similarly, in a qualitative study conducted by Wannheden and Revenäs (2020), which included both PwPs and HCPs, concerns were raised regarding the impact of PD symptoms on PwPs' ability to use mHealth interventions. The PwPs noted that fatigue, which is considered a nonmotor symptom, would impact their ability to use the intervention. The HCPs also noted that PwP patients with advanced symptoms, such as hallucination and impulse control issues, would not be able to use the intervention. This emphasised the importance of offering support services for PwPs who may experience difficulty in using an mHealth intervention.

4. Financial factors

The cost of the mHealth app intervention was reported in two studies (Lee et al. 2016; Hu et al. 2020) as a potential concern for the acceptance and use of the intervention. In a surveillance

study conducted by Hu et al. (2020), 136/204 of the PwPs showed interest in using an mHealth app intervention if no financial outlay was required. Similarly, 7 out of 36 PwP who expressed concerns regarding the use of the mHealth app in the Lee et al. (2016) study reported that the cost of the mHealth app intervention would impact their future intention to use it. However, in this study, 16 of 42 PwPs who did not own a smartphone reported their willingness to purchase a mobile device in order to use an mHealth app in the future.

5. **Workload**

In one study (Wannheden and Revenäs 2020), concerns regarding the additional workload for HCPs when using a smart device app intervention were reported. For example, both HCPs and PwPs expressed their concerns about the use of smart device intervention, which could increase the administrative workload for HCPs and double their documentation burden. HCPs were also worried that PwPs may overuse the intervention to report multiple issues, which could increase their workload. However, these findings were based on the HCPs' expectations of the possible impact of mHealth use in PD clinical practice rather than on the impact of the actual use of intervention; therefore, further investigation is still required to evaluate that.

3.5 DISCUSSION

Given the significant focus on digital technology use within the PD field (Espay et al. 2016; Espay et al. 2019), exploring the factors that might impact end-user acceptance is crucial. This rapid review provides a comprehensive picture of the information available to date on the factors that might impact the acceptance and usability of mHealth app interventions for PD. In reality, the studies identified had very limited data on users' perceptions, as their focus was mostly on quantitative measures, such as feasibility and usability.

More studies would likely have been available if the definition of mHealth was broadened to include wearable technology (sensors) (See Chapter 1, Section 1.7). The definition of mHealth was restricted to mobile devices, smartphones, and tablets/iPads, as the focus of this thesis was to explore perceptions towards the use of an iPad-based app. In addition, going into details

of including other types of mHealth technology, such as sensors and personal digital assistants, is beyond the remit of this thesis.

The qualitative findings provided insight into what users perceived as motivators of and concerns about mHealth-based PD acceptance and usability. It is worth noting that these motivators and concerns provide a better understanding of the factors that might influence a user's decision to use or not use an mHealth app for PD. In this section, the findings (motivators and concerns) were analysed and categorised into two main factors: (1) technological and organisational factors and (2) social factors.

Technological and organisational factors

1. Learnability

Learnability was impacted by the availability of technical support, which could impact users' intentions to accept and use mHealth app interventions. From the findings of the current review, providing technical support and training could improve users' confidence and compliance in their use (Lee et al. 2016; Elm et al. 2019). This findings is in line with a previous review that concluded that providing adequate support and proper training could play an important role in increasing users' intention to use and accept an mHealth intervention (Jacob et al. 2020). In addition, the more frequently end users utilised the mHealth app, the more understandable and operable it became, and the more likely they were to continue using the app in the long term (Lee et al. 2016; Lakshminarayana et al. 2017). This finding is in line with that of Grosjean et al. (2020) and Jeon and Park (2015) for mHealth acceptance factors in PD and the management of obesity, which highlighted that technical support and training had great value in improving usability (Jeon and Park 2015; Grosjean et al. 2020).

2. Interactivity/data access management

Interactivity is linked to the clinical value that an mHealth intervention would have to support both PwPs and their HCPs during clinical encounters. The mHealth intervention that enables users to generate a feedback summary of their performance and provide access to the collected data for both PwPs and HCPs was perceived to be more acceptable (Ferreira et al.

2015; Lakshminarayana et al. 2017; Bayés et al. 2018; Elm et al. 2019; Wannheden and Revenäs 2020). The generated feedback summary can provide insight into disease progression and support individual symptom management. Similarly, an mHealth intervention that integrated well with clinical databases was highly appreciated (Elm et al. 2019; Wannheden and Revenäs 2020), as it would ensure that the collected data was available for HCPs to act on and would alleviate the workload of HCPs.

Integration of the mHealth intervention with the patient database within a clinical setting could increase the collection of data needed to enhance the quality of patient care, improve disease control, and personalise treatment plans (Bayés et al. 2018; Elm et al. 2019; Wannheden and Revenäs 2020). Furthermore, the interventions that supported medication adherence (alert users about medication use) and flagging symptoms for both PwPs and HCPs were highly valued (Ferreira et al. 2015; Lakshminarayana et al. 2017; Wannheden and Revenäs 2020). This is an important finding and is supported by the International Parkinson and Movement Disorders Society Task Force on Technology, which emphasised the need to develop an intervention that can be easily integrated into PD clinical practice to facilitate its adoption and better inform clinical practice (Espay et al. 2016).

This finding is in line with findings by Jacob et al. in their systematic review (2020), in which the proper planning and integration of mHealth with clinical practice was deemed essential for successful adoption of the intervention by HCPs. Some of the studies included in Jacob et al.'s (2020) review reported that HCPs had positive perceptions regarding an mHealth intervention that integrated well with clinical practice (Putzer and Park 2010; Putzer and Park 2012).

3. Design

The design of mHealth is an essential factor to consider, as it has the potential to influence users' intentions to use such an intervention. Interface, content, and user-friendly design have been identified as important influencing factors in several studies (Ferreira et al. 2015; Lee et al. 2016; Lakshminarayana et al. 2017; Elm et al. 2019; Hu et al. 2020; Wannheden and Revenäs 2020). The choice of design should be well informed by users' needs and capabilities.

Many of the PwPs and HCPs whose views were included in this review emphasised that the interface of the intervention should be simple and clear in order to reduce the cognitive load for PwPs and facilitate its use (Ferreira et al. 2015; Lakshminarayana et al. 2017; Elm et al. 2019). In addition, other features, such as clear guidance and instructions to facilitate the navigation of the intervention, an education section about PD, the capability to record and flag the most concerning symptoms to HCPs, and features to aid medication intake and adherence, also need to be considered when designing an mHealth intervention for PD (Ferreira et al. 2015; Lakshminarayana et al. 2017; Elm et al. 2019; Hu et al. 2020; Wannheden and Revenäs 2020). These features might make an mHealth app more appealing to target users and influence their acceptance and uptake of the app. Furthermore, mHealth interventions need to provide actionable data (features that visually and graphically display the data in the patient's database) in order to aid the clinical encounter and keep the users (HCPs) motivated to use and engage with the intervention (Elm et al. 2019; Hu et al. 2020; Wannheden and Revenäs 2020). A user-friendly design was also one of the important reported features identified in included studies. This finding is supported by several previous studies that highlighted the significant impact of user-friendly design on stimulating users' acceptance and usability of interventions (Alsswey and Al-Samarraie 2020; Grosjean et al. 2020; Jacob et al. 2020).

4. Perceived privacy and security risk

Privacy and security of user data are of high importance for the acceptance and use of mHealth interventions. Previous studies that explored the factors influencing the effective use of mHealth reported that privacy and security played an essential role (Peek et al. 2014; Azhar and Dhillon 2016; Spann and Stewart 2018; Kaium et al. 2019). However, in the current review, only two of nine studies highlighted the importance of and relationship between privacy and security variables and willingness to use mHealth interventions (Bayés et al. 2018; Hu et al.2020).

Actually, not many studies have considered evaluating such factors of their interventions. Indeed, users may be more reluctant to use an mHealth intervention if they perceive that it

invades their privacy (Frik et al. 2019). For example, the review by Spann and Stewart (2018) reported that there was a thin line between mHealth apps collecting enough data to serve their purpose and becoming intrusive (e.g., feeling being watched or collecting non-medical data), which is one reason people reject the use of the mHealth intervention. The review by Peek et al. (2014) found that privacy concerns were not a significant issue, as many participants from different studies included in the review reported their willingness to give up some of their privacy if the use of the mHealth app would be beneficial to them. Therefore, future researchers and developers should examine and evaluate users' trust (privacy and security of the data), address their needs against the cons of mHealth interventions, and capitalise on the influence of potential facilitators, such as perceived usefulness, to promote mHealth acceptance and use.

5. Workload-related factors

Additional workloads on HCPs can also cause challenges that impact their intentions to use mHealth interventions. Double documentation of data caused by lack of integration and overuse of the intervention by PwPs reporting health issues raised concern for HCPs. HCPs may refrain from accepting and using the intervention altogether if they believe that it will increase their workload (Wannheden and Revenäs 2020). Therefore, adequate integration of mHealth interventions within routine care is essential to improve acceptance and usability. It would be essential to explain the purpose behind the use of intervention and clarify the roles of each member of the clinical staff in order for them to make essential adjustments to their new responsibilities and ways of working. This result is in line with the study by Jacob et al. (2020), in which workload factors were among the organisational factors that most impacted HCPs' willingness to accept and use mHealth.

Social factors

1. Attitude and social influences

User perceptions and attitudes towards mHealth interventions may impact their decision to accept and use the intervention (Davis 1985). As mentioned in Chapter 1 (Section 1.11),

according to TAM, attitude is impacted by two main factors: perceived usefulness and perceived ease of use (Davis 1985). The participants from different studies included in this review were receptive to the idea of using the mHealth app for PD. These studies assessed user attitudes by measuring elements such as user satisfaction, preference, and level of comfort (Ferreira et al. 2015; Lee et al. 2016; Mitsi et al. 2017; Bayés et al. 2018; Sekimoto et al. 2019; Hu et al. 2020).

In addition, perceived, or experienced usefulness may have a direct influence on users' acceptance and intention to use an intervention (Kaium et al. 2019; Yee et al. 2019). Users are more likely to use an intervention when they understand and recognise its benefits. The participants from different studies included in this review believed that the mHealth app for PD would have the potential to improve communication with HCPs, reduce physiological burden, improve management of PD and support decision-making processes, allow individual adjustment of treatment, and empower PwPs (Lee et al. 2016; Lakshminarayana et al. 2017; Bayés et al. 2018; Sekimoto et al. 2019; Hu et al. 2020; Wannheden and Revenäs 2020). This finding mirrors the findings of previous studies that explored the factors influencing adoption of mHealth among people with chronic disease and states that the perceptions of the usefulness of mHealth will play a significant role in whether people intend to adopt and use the technology (Cajita et al. 2018; Spann and Stewart 2018).

For the mHealth app to be truly useful, it has to be user friendly and intuitive so that users can use it easily, including those unfamiliar with technology. The perceived ease of use could also impact users' intentions to use and accept an mHealth intervention (Davis 1985; Kaium et al. 2019; Yee et al. 2019). The importance of ease of use was also emphasised in previous reviews by Spann and Stewart (2018) and Kaium et al. (2019). These reviews found that ease of use was one of the essential factors affecting users' acceptance and use of mHealth. Several studies included in the review reported that users found their mHealth interventions easy to use (Ferreira et al. 2015; Lee et al. 2016; Bayés et al. 2018; Sekimoto et al. 2019).

Although it is to be expected that the perceptions of the usefulness and ease of use of the mHealth intervention play an important role in whether people intend to accept such

interventions, it is worth noting the important effect of social influence. The PwP may also be motivated by key figures within their social environment when deciding whether to use mHealth interventions for PD, for example, their HCPs. Therefore, social influence and endorsement are considered factors that might influence PwPs' decisions to accept and use an mHealth intervention (Yee et al. 2019). Recommendations by reliable people, such as HCPs, may foster acceptance and usability of the intervention (Mitsi et al. 2017), which could be a reflection of the trust that PwPs tend to put on their HCPs. Therefore, active promotion of an intervention and its impact on users' outcomes may encourage their use.

2. PD health status and long-term use

Some symptoms of PD, such as cognitive impartment and physical inability, may have an impact on the ability of the user and consequently affect their intention to accept and use an mHealth app intervention (Lee et al. 2016; Wannheden and Revenäs 2020). It is important to note that more evidence is needed to confirm these findings, as these studies excluded PwPs with physical and cognitive impairment. However, the findings from Li and Chang (2020), showed a significant impact of PD symptoms such as cognitive impairment and motor inability on the usability of some tasks within the mPower smartphone app intervention. PwPs who suffered from cognitive and severe motor impairment tended to use the mPower app (tapping and cognition tests) less frequently ($p = 0.007$ and $p = 0.006$) (Li and Chang 2020).

Besides technical issues, PD symptoms such as fatigue and cognitive impairment may be the reasons for the high attrition rate in the Elm et al. (2016) and Lakshminarayana et al (2017) studies. In the Lakshminarayana et al. (2017) study, the participants were required to perform multiple tasks in the app, which could increase cognitive load and therefore impact their intention to use and continue using the intervention. Similarly, PwPs in Elm et al.'s (2016) study were required to wear the smartwatch and fill out the PROMs questionnaire on the smartphone intervention concurrently. This could have led to increased feelings of tiredness and fatigue and affected the willingness to use and continue using the mHealth intervention. Therefore, PD-related symptoms are another important factor to consider when designing an mHealth intervention. The design should be based on the PwPs' needs and accommodate PD-

related symptoms, such as motor and cognitive problems, to encourage the acceptance and efficient use of such technologies.

3. Users' engagement at the early development stage

Involving end users during the early development stages may support the acceptance and usability of an mHealth intervention (Yardley et al. 2015). Factors such as user feedback, collaborative involvement and co-design have been shown to encourage acceptance and usability of the intervention (Elm et al. 2019; Wannheden and Revenäs 2020). For example, 10 modifications were made in the intervention developed by Lee et al. (2016) based on HCP feedback, such as simplifying the interface and adding medication intake markers across the PROMs data. These modifications improved the usability of the intervention.

Similarly, involving both PwPs and HCPs at the early development stage in the Wannheden and Revenäs (2020) study facilitated the development of the intervention (mini fair prototype app) to support the co-care approach in PD clinical practice. Therefore, future research should consider engaging target users when designing the mHealth intervention for PD to ensure that the intervention addresses the target users' needs, capabilities, operability, and preferences, which may contribute to the acceptance and use of the mHealth app for PD.

4. Financial factors

The final factor that might have an ambivalent role in whether older people used or intended to use the mHealth app was the cost of the device and the app. Cost-saving is one of the self-service technology aspects that has a positive impact on users' satisfaction (Meuter et al. 2000). Cost was identified as an important determining factor in accepting and using mHealth interventions in two studies (Lee et al. 2016; Hu et al. 2020).

However, this does not mean that users are unwilling to pay for an mHealth app intervention. In the Lee et al. (2016) study of mHealth apps for hand dexterity, they found that participants reported their willingness to purchase a mobile device to be able to use such an app after trying it out. This may indicate that the financial cost associated with purchasing mobile devices or mHealth apps is not a big concern for PwPs if the mHealth app proved to be

beneficial for them. This finding echoes previous research on the factors that influence the adoption of mHealth among people with heart failure (Cajita et al. 2017). This study found that perceived financial cost was not significantly associated with the intention to adopt and use mHealth (p = 0.345). Further study is needed to investigate whether mHealth apps for PD are cost effective, and if so, recommendations to subsidise the cost of these interventions by researchers should be considered to facilitate mHealth acceptance and use.

3.6 QUALITY OF STUDIES

Almost all of the studies in this review used an uncontrolled design (assessed the effect of an intervention in a single group of patients with no control group), and most of them are still in their early development and evaluation phases with limited available qualitative data. Therefore, the current evidence for the acceptance and usability of smart device interventions to support the clinical encounter for PD is still limited. Although these studies provide insight into some of the potential factors that might impact users' intention to accept and use an intervention, further studies that focus on the users' perspective (PwPs and HCPs) are needed.

Most of the included studies were critically appraised as being of moderate or poor quality, which limits the conclusions that can be drawn. Limitations of some studies included in this review were small sample sizes (n = 2), short study periods (n = 3), and underreporting of reasons for participant drop-out (n = 2). In addition, the sample size of the included studies was limited to PwPs with no severe physical or cognitive abnormality or diagnosis of dementia or advanced PD stages (H&Y 4-5) (n = 5). It might be very challenging to consider including these subgroups of PwPs in the use of an mHealth intervention without seeking support from the patients' carers, so carer input is another area that needs to be considered when designing an mHealth app for PD. Further research is needed to investigate this consideration and mHealth app-related characteristics to provide a more granular view of the factors that might influence the acceptance and use of mHealth for PD.

Investigating the reasons for the study drop-out may give insight into the further clues for the potential concerns and barriers to the usability and acceptance of mHealth interventions for PD. It was noted that not all studies had reported a response rate or completion rate of the

users' perception questionnaire, and therefore, it is hard to confirm whether participants avoided giving feedback due to poor levels of satisfaction or negative experiences with the intervention. Additional limitations included that some studies only included participants who had access to their own device, who had WiFi access at home or who already had experience with technology use. However, these criteria may have biased findings, as those who participated in these studies may have expressed more favourable perceptions towards mHealth intervention use than those who were unable to participate.

Nevertheless, the findings, especially the user perspectives, were generally comparable across studies of good, moderate, and poor quality, so the conclusions of this rapid review were drawn from all included studies. Finally, many of the included studies in this review relied on self-completed questionnaires (to assess users' satisfaction or attitudes) or self-reported data collection. Findings may have been affected by recall bias or the Hawthorne effect (Merrett 2006), where participants may have changed their attitudes and perceptions due to knowingly being observed or awareness of being part of the experiment.

3.7 STRENGTHS AND LIMITATIONS OF THIS REVIEW

This review's strengths lie in the inclusion of all kinds of available evidence, regardless of the type of research method (qualitative, quantitative, or mixed-methods). Several databases and references of the included studies were searched, and study characteristics were reported. In addition, the researcher critically appraised the studies on their quality, which was considered when drawing conclusions.

While this review contributes to the understanding of the factors that might impact acceptance and usability of mHealth intervention from the users' perspective, the findings of this rapid review should be interpreted with caution. This review has several limitations. First, the limits of rapid reviews should be acknowledged, as only one researcher (the PhD student) was responsible for initially conducting the screening process of the titles and abstracts of the retrieved studies, and the selection and synthesis process. However, all of these processes were reviewed and revised by the researchers' lead supervisors as appropriate. Additionally, this rapid review is limited by the lack of inclusion of all the studies that employed other means

of mHealth (e.g., wearable sensors), as they are different kinds of technology, and including them is beyond the scope of this review. This review focuses only on the smartphone and iPad, either by itself or as part of a system. However, involving studies that employed wearable sensors only in their interventions could have been useful for further understanding the current technological development and the factors that might impact acceptance and usability.

Prior to the search, it was decided to include only academic published literature and conference abstracts (as types of grey literature). Other types of grey literature were excluded from the search, as they were not peer-reviewed and unlikely to contain empirical data, and for several other reasons, such as time restrictions. Including grey literature would require time and require more than one researcher to identify information related to the research questions and evaluate the quality of this information (Adams et al. 2016). However, including other types of grey literature, such as blogs, may result in identifying further factors that may not be raised within peer-reviewed studies and provide a more granular view of factors that might influence acceptance of mHealth interventions. Therefore, future reviews should consider including all types of grey literature in order to have a comprehensive understanding of the factors that might influence the acceptance of mHealth for PD.

Most of the included studies focused on a quantitative analysis of their interventions. Nevertheless, the primary focus of this review was to explore user perspectives, which required a qualitative approach to provide rich information. Other factors for the acceptance of mHealth interventions might have been missed, and further qualitative studies are still needed to comprehensively capture users' perceptions of mHealth intervention use for PD.

3.8 IMPLICATIONS

The findings of this review identified that at the technological, social (individual), and organisational levels, several factors are associated with mHealth intervention acceptance and usability. This may offer benefits within the PD field as it provides insight for future research directions. For example, this review may provide a landscape for researchers and developers of digital interventions in the PD field to identify new research areas of innovative mHealth

intervention and their users' perceptions and the context of their use. Additionally, the findings suggest that new research into mHealth for PD should focus on target users' perceptions in order to develop an intervention that meets their needs and requirements. Therefore, this thesis aims to explore the a priori perceptions of PwPs and their HCPs in order to better understand their needs and attitudes, which could inform and enhance the future development of an iPad-based app prototype (Chapter 1, Section 1.10).

This review provides further understanding of the factors previously identified by Grosjean et al. (2020), who focused on designing a socially acceptable mHealth app for PD self-management. Although the research in this domain is not a completely new field, the findings of this review reinforce the need for substantial exploration of user perspectives towards usability, acceptance, and adoption of mHealth intervention in PD clinical settings.

Second, this type of intervention appeared to be acceptable to both PwPs and HCPs, as they recognised the potential benefits of this type of interventions in improving healthcare services. Specifically, findings of this review suggested that real-time data collection, medication adherence, and symptom-monitoring interventions have the potential to improve PwPs' self-management of their condition and provide HCPs with a better understanding of patients' symptom experiences, while improving the communication and relationship between PwPs and HCPs. This may lead to improved management of PD in a timely fashion, supporting decision-making processes and reducing costs for the healthcare system. This type of intervention also has the potential to enable PwPs to keep a real-time record of symptoms, which might improve the accuracy of symptom assessment and management and enable HCPs to better understand patterns of symptoms.

Finally, this review established that, to date, most mHealth interventions have focused only on motor symptoms of PD and quantitative assessment of outcomes, which has typically been achieved indirectly. At present, there are no mHealth app interventions that primarily aim to support PwPs and their HCPs during clinical encounters by collecting patient data, and few mHealth app interventions have been developed to remotely collect patient data and to be used independently by PwPs to inform clinical consultations (Ferreira et al. 2015;

Lakshminarayana et al. 2017). Additionally, development of such an intervention would support the direction of the Welsh government towards patient-centred care (Aylward et al. 2013) and exploitation of the power of digital technology in order to do so (Welsh Government 2015).

3.9 CONCLUSION

In summary, although there was limited available information regarding the perceptions of PwPs and their HCPs, this rapid review provides great insight into the motivators of and concerns about the currently studied mHealth interventions for PD. Additionally, the findings of this review provide a landscape, enabling the factors behind the acceptance and usability of smart device intervention for PD to be better understood. These factors could be useful for researchers and developers to improve the design of smart device interventions for PD by acknowledging users' perceptions and intentions to use and accept the interventions. Within its limitations, the findings of this review identified that the majority of mHealth interventions developed for PD so far have successfully enabled remote data collection in the form of motor symptom-monitoring interventions. Moreover, mHealth interventions appear to be an acceptable platform for delivering interventions in PD. This rapid review highlighted the early stages of the studies that are being conducted in this field, which might limit the conclusions that can be drawn. Currently, there is no mHealth intervention that primarily aims to be used within PD clinical settings to support PwPs and their HCPs during clinical encounters. The findings of this review highlight the potential clinical benefits resulting from the use of mHealth interventions, such as improving communication and supporting the decision-making process. However, there is a perceived lack of evidence base and proof of concept of clinical benefit resulting from the use of mHealth interventions for PD. Further research in this area is still needed, with a focus on feedback from all stakeholders in PD clinical settings, including both PwPs and HCPs, in the design and development of mHealth interventions to support the transfer of interventions into clinical practice.

Chapter 4: Use of iPad-based Pre-assessment Questionnaires in Parkinson's Disease Clinics: A Qualitative Study of Patients' Perceptions

This study was a follow-up to the prototype iPad-based app feasibility study mentioned in Chapter 1, which was conducted to gain a further understanding of the type of app that would be most useful and the potential uptake and possible outcomes of this type of intervention, including the benefits and disadvantages of, and barriers to, app use.

4.1 INTRODUCTION

Data collection regarding the patient's current health status is an essential part of the clinical review process. Traditionally, in the hospital setting, clinical consultation for PwPs relied on physical examination and patients' diaries (Todorova et al. 2014). As mentioned in Chapter 1, several PD-specific PROMs scales have been developed to facilitate the identification and recognition of PD symptoms, such as MD-UPDRS and NMSQuest (Chaudhuri et al. 2006; Goetz et al. 2008). However, the use of these scales within routine clinical practice is limited because of the time burden for consultations and the inefficient delivery of these scales (Todorova et al. 2014).

In two recent studies that evaluated users' perceptions of the routine use of PD-specific PROMs (e.g., PDQ-39) within clinical practice, the use of an electronic version was suggested for more efficient use (Neff et al. 2018; Damman et al. 2019). For example, Neff and colleagues conducted a qualitative case study design to evaluate the integration of the paper-based form of the PDQ-39 scale into routine clinical practice in one neurology clinic in the USA. This study reported that after 100 PwPs had completed the scale before the clinic visit, eight of them and three carers were interviewed individually to assess their experiences (Neff et al. 2018). This study found that the routine use of paper versions of PDQ-39 within clinical neurological practice was found to be useful by both PwPs and their carers (Neff et al. 2018). Several potential advantages of using the PDQ-39 scale in routine clinical practice were reported, such as helping PwPs focus during clinical consultations, reminding them about their most concerning issues, and tracking their progress over time. The use of an electronic form of PDQ-39 was suggested to improve the usability and integration of this scale into clinical practice

(Neff et al. 2018). However, this study included a small sample size (n = 11) and only reported the positive impact of using the PDQ-39 scale in routine clinical practice, which limited the generalisability and affected the evidence of the study's findings.

Similarly, the routine use of PROMs scales during clinical consultations was found to be useful and acceptable in a mixed-method study design (interview (n = 13)/survey (n = 113)) conducted by Damman et al. (2019) in the Netherlands. In this study, 94.5% of the surveyed PwPs reported a positive impact of using PROMs routinely during consultations. Several other benefits were reported, such as identifying and prioritising the main symptoms of concern, discussing them during consultations, and improving decisions regarding treatment choice. In addition, 74.2% of PwPs were able to comprehend and interpret the PROMs data correctly. The need for training was also reported for the proper use of PROMs scales within clinical practice (Damman et al. 2019). However, this study included a small sample size in both phases and from a single site in the Amsterdam area (n = 13, n = 113), which limits the generalisability of the findings. Therefore, this study's findings need to be interpreted with caution. In addition, perceptions may differ in other regions of the world. Nevertheless, this study offers some useful insights and feedback for further investigation.

Technology advances offer alternative, easy, and flexible tools to collect PROMs in a clinical setting, e.g., through smartphones, tablets (e.g., iPads), and computers. As mentioned in Chapter 1, patients' acceptance of technology use in healthcare has been shown for several health conditions, such as heart failure, oncology, hand surgery, and rheumatology (Hall et al. 2014; Kaka et al. 2015; Yaffe et al. 2015; Wallwiener et al. 2017). Additionally, as demonstrated in Chapter 3, most of the available research on technology for PD has tended to focus on quantitative assessment of outcomes, such as data extraction, accuracy, and reliability of the technology. There is little attention paid to users' perceptions, preferences, and use of technology. Only two studies reported PwPs' acceptance of technology use (Duroseau et al. 2017; AlMahadin et al. 2020). AlMahadin and colleagues (2020) conducted three focus group discussions with 12 PwPs to explore their needs and preferences towards wearable technology used to support the diagnosis of PD in the UK. Although the small sample size limits how well

this study can be generalised to the greater population, users' positive perspective on wearable devices was clearly noted especially if they were engaged in early design stages of the device (AlMahadin et al. 2020).

Perceptions regarding technology use within healthcare were also assessed through a cross-sectional survey, in which 65 out of 109 PwPs who completed the survey expressed less favourable views towards using technology (Duroseau et al. 2017). The patients' age appeared to be a factor in their acceptance of using technology, and 75-year-old patients showed less interest in using technology that aimed to improve their communication with HCPs or enhance their understanding of their healthcare needs (Duroseau et al. 2017). In addition to patients' age, other studies reported that various factors, including perceived usefulness of technology and perceived ease of use, might affect patients' acceptance (Maguire et al. 2015; Besse et al. 2016).

Several studies that have investigated patients' perceptions have focused on wearable sensors that quantify movement variables through internal sensors (e.g., accelerometers and gyroscopes that integrate with digital devices, garments, or accessories) (Adams et al. 2017; Ozanne et al. 2018). In a study by Ozanne et al. (2018), two focus group discussions (n = 15) were conducted to explore the perception of PwPs towards the use of wearable sensors to support PD monitoring and management. The participants in this study reported a positive attitude towards the sensors. They valued the potential benefits of enhancing the treatment effect more than the possible inconvenience of wearing them. However, the participants also reported several concerns about sensors, such as the need for training and clear instructions for use, the lack of options that support interactive communication between patients and HCPs, the lack of personal integrity, privacy of the collected data, and the user-friendliness of the devices (Ozanne et al. 2018). This study concluded that perceiving the benefits of sensor use is key to improving its usability and acceptance (Ozanne et al. 2018).

The use of multiple wearable sensors in a clinic and at home was found feasible and well accepted by 16 PwPs in the study by Adams et al. (2017). This study assessed the feasibility of using multiple wearable self-adhesive sensors in both clinical and home settings over two days.

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Most participants found the sensors comfortable and easy to use (n = 42/56, n = 50/56). However, the most reported concern was regarding the sensors' designs (n = 31/56) (Adams et al. 2017). Nevertheless, both studies are limited in their scale (small sample size) and with a short study duration, which impacts the evidence of these studies and limits the generalisability of their findings. However, since the digital data collection tools (e-PROMs) are not the same type as the wearable devices used in previous studies, these findings prove useful in demonstrating the importance of evaluating patients' perceptions regarding innovative technologies to improve the usability and acceptance of these interventions.

The implementation of digital devices as data collection tools in clinical settings may be associated with resistance from patients (Nilsen et al. 2016). The patient's acceptance may be particularly important when an innovative tool is applied to managing a chronic condition in older people who may be less acquainted with modern technology. Besides patient acceptance, patient characteristics, the content of these new tools, the level of security and privacy of these tools, the patient's experience in using technology, and how the technology fits the patient's needs are the most crucial factors that can affect engagement with health technology (Hardiker and Grant 2011). Hence, the developers of these new tools need to consider all of these factors before the development and implementation of these methods in clinical settings.

Although the majority of PwPs in a feasibility study conducted by Mohamed et al. (2016) reported a positive experience after using the app, several suggestions were made to improve the design and format of this app. This highlighted the importance of engaging the users of the intervention in the early development stages, but this was not considered by the developers of the prototype iPad-based app. Exploring users' perceptions and how they will react to the new technology and innovation are crucial and likely to affect its acceptability and eventual success within clinical settings (Yardley et al. 2015).

To benefit from this technology and successfully implement the iPad app at PD clinics, it is essential to understand PwPs' thoughts and opinions regarding the electronic collection of

PROMs and the iPad app. Thus, in the first stage of this thesis, a series of focus groups with PwPs and their carers were conducted.

4.2 AIMS OF THIS STUDY

To date, no study has sought to explore the views and preferences of PwPs and their carers around an app that aims to collect their information through PROMs to aid their clinical consultations in PD clinic settings.

- The main aim of this study was to explore the perception of using technology and an iPad app as a data collection tool for PwPs prior to their consultations with HCPs. This included exploration of:

(1) Previous experiences of data collection processes in PD clinical settings, previous experiences of using technology, and preferences for using an iPad app and its features;

(2) The perceived acceptability/non-acceptability of the iPad app, alongside any suggestions to improve the app features and contents; and

(3) The perceived pros and cons of the app, including any benefits of its use or barriers to using it, include views on the time and place PwPs might find using this app most useful.

4.3 METHODOLOGY

A schematic diagram shows the method used in this study in Figure 4.1.

4.3.1 Study design

As mentioned in Section 2.3, the design of the first phase of this thesis was a qualitative focus group study to explore participants' perceptions of and views on the utility of an iPad-based app to collect patient data in a hospital clinic. The focus groups were conducted in different community meeting groups and PD support groups throughout Cardiff. The focus group method was chosen over the individual interview because it allows flexibility for discussion among different groups of people and reports on different experiences (Kitzinger 1995).

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According to Lederman (1990), focus group discussions have several advantages compared to individual interviews in eliciting insight into participants' thoughts.

The focus group discussions were chosen for this phase of the project for the following reasons:

- They encourage participation in peer interaction and minimise inconvenience to participants. After one participant has answered a question, the rest of the group can express their agreement or disagreement by adding extra information or explaining why they disagree (Lederman 1990).

- The flexible structure of focus groups allows the researcher to explore unexpected themes if they arise and cover the topic in more depth in a limited amount of time (Krueger and Casey 2000).

- A focus group that includes a group of people who share a common issue will trigger a more dynamic interaction between participants when discussing the issue, and the data generated from these groups are often more productive and more profound than from an individual interview (Lederman 1990; Kitzinger 1995).

Since the main aim of the focus group discussion is to explore the reasons behind the participants' responses, the data gathered from this kind of discussion will allow the researcher to understand not only what the people think but also why they think it (Kitzinger 1995; Powell and Single 1996). Furthermore, the discussion within the focus groups allows participants to re-evaluate their own thoughts and behaviours, which is important when exploring older peoples' thoughts on using technology (Gibbs 1997).

It should, however, be noted that focus group discussion requires better preparation and planning of the place itself (e.g., where the discussion will take place, setting records, providing refreshments), and elaborating on the findings, since it will probably provide more complex data than an individual interview. Table 4.1 presents some potential disadvantages of focus groups based on Morgan et al. (1998) and Krueger and Casey (2000), along with some notes on these in relation to the context of the current study.

Table 4.1: Disadvantages of focus group discussions based on Morgan et al. (1998) and Krueger and Casey (2000)

Disadvantages	Commentary
1. The researcher has less control over the collected data. 2. Being in a group might affect individual group members' behaviour (groupthink). 3. It demands interviewers be carefully trained in how to deal with one or several group members dominating the discussion. 4. It takes effort to assemble the groups. 5. The discussion should be conducted in an environment that facilitates the discussion. In health-related topics, pre-existing groups can overcome issues relating to confidentiality and the disclosure of potentially stigmatising conditions that participants may find uncomfortable in stranger groups. However, there may be conditions in which disclosure is more comfortable in stranger groups.	1. The aim of this study was to explore the participants' views so, the researcher was happy to be directed by what was important to them in regard to technology use. 2. The researcher tried to minimise the impact of groupthink during the discussion by re-asking and encouraging individual members to speak out. 3. The researcher received the required training. 4. The researcher could tap into pre-formed groups to minimise the effort to assemble a new group. 5. As above, using pre-formed groups was suitable for conditions such as PD, as the PwPs may experience sensitive issues and may not feel comfortable raising them during discussions in stranger groups. This helped PwPs avoid embarrassment and dishonest responses.

However, despite these potential issues, focus group discussions were considered the best method to address this phase of the thesis because older participants are much more likely to feel uncomfortable and hesitant when answering questions related to technology use (Mitzner et al. 2010). Lederman saw focus group discussions as less threatening than other qualitative methods because of the presence of support between group members, so participants may feel more secure with people they already know, and that could encourage shy participants to contribute (Lederman 1990).

There was no minimum number of focus groups to be conducted in this study; the initial plan was to conduct five to six focus groups that would include between five and six participants, as this is seen as an optimal size for research (Morgan et al. 1998). According to Morgan et al. (1998) and Krueger and Casey (2000), a well-designed focus group consists of between six and twelve participants and lasts between one and two hours. The main goal regarding the size of

a focus group is to include enough participants to ensure diversity in the provided information, although large groups may create an uncomfortable environment for participants to share their views and beliefs. However, mini-focus groups that include between three and four participants are also useful if participants have specialised knowledge or shared experiences regarding the topic under discussion (Morgan et al. 1998; Krueger and Casey 2000). Morgan et al. (1998) advocated that three to six different focus groups are sufficient to reach theoretical saturation (occurring when data happens so repeatedly that the researcher can anticipate it and the collection of more data appears to have no additional value). Therefore, the exact number of focus groups to be conducted is dependent on the data that emerges and whether the theoretical saturation has been reached.

Study was approved by Cardiff School of Pharmacy and Pharmaceutical Sciences Research Ethics Committee

- The PD participants and their carers were recruited from various Parkinson's UK local support and research interest groups throughout South Wales.
- Participant information sheet and invitation letter to the study were provided to each participant.

- Written informed consent was obtained from all participants.
- Focus groups were conducted using topic guide.
- Focus group discussion were audio-recorded.
- Recordings were transcribed verbatim.

Data analysis was conducted via a thematic approach. Inductive and deductive methods were used, via coding, to identify main themes and sub-themes.

Figure 4.1: A schematic diagram to show the method of this study

4.3.2. Development of the focus group topic guide

A topic guide that provides a protocol for the focus group discussions was used to address this phase's aim (see Appendices 4.1 and 4.2). Two separate topic guides were originally created for PwPs and their carers and people without a diagnosis of PD.

First, the development of a topic guide was initially informed by the discussions between the full research team (three undergraduate students from the Pharmacy School at Cardiff University working on this topic part of their final year research project, and the researcher's lead supervisors), using the findings of the iPad-based app feasibility study (e.g., to identify wider views in the technology use and suggestions to improve the app) (Mohamed et al. 2016). The developed topic guide covered general questions about using technology and the participants' experience of it in their daily lives; questions about using an iPad device to collect PROMs in the hospital; and more specific questions about the iPad app (see Appendix 4.1). This topic guide included a list of open-ended and follow-up questions to facilitate discussions with the PwPs and their carers. Open-ended questions were used at the beginning of each focus group to encourage participants to contribute and avoid bias or undue influence on participants' thinking (Lederman 1990). Follow-up questions were used carefully to elicit more information.

Second, the first version of the topic guide for the PwPs and their carers was piloted by three undergraduate students (via conducting a test focus group with the PwPs and their carers) to refine the questions used and identify areas where questions were not asked (Samuel et al. 2016). Third, the researcher reviewed the findings of a qualitative pilot study conducted by undergraduate students. It was noticed that most of the negative perceptions towards the use of the prototype app were because the main purpose behind the development of the app was not explained and clarified during the discussion. Therefore, the researcher made a slight modification to the topic guide in order to provide a clearer background and context (see Appendix 4.1).

In addition, the pilot test demonstrated that the topic guide would successfully elicit the required information, and no significant changes were required. After that, this thesis's

research team (researcher and project supervisors) decided to use the modified topic guide that the researcher generated to conduct the work at this stage.

It should be noted that the researcher also adapted this final version of the topic guide to be suitable for use with people without a diagnosis of PD. This involved a slight modification to the questions (e.g., to generalise the questions related to PD to other chronic health conditions) to facilitate general discussion about technology use within an older population (see Appendix 4.2). As described in Section 2.4, this work was conducted purely as a learning process for the researcher to gain and develop essential skills and experiences to facilitate the conduction of the focus group discussion with the target study population (PwPs). As such, the results of this 'training series of focus groups' are not included in this chapter.

4.3.3 Sampling considerations, participants, and recruitment

Merriam (2009) suggested that purposive sampling is the most appropriate method of sampling in qualitative research since the analysis of this kind of research is focused on answering questions regarding how people think or how people interact with each other within the group. According to Merriam, purposive sampling encourages the researcher to select information-rich participants related to the investigated phenomena. She explains the processes of purposive sampling (2009). The first step is to determine the eligibility criteria according to the aims of the research. Given this study's aim to understand what the older population thinks about using technology within hospital clinics, it was also important to recruit participants who adequately represented the target age population of PD. The following eligibility criteria were therefore deemed important for selecting participants:

1) People aged 60 years or over who have been diagnosed with PD; and
2) Carers for people with PD with no age restriction.

Being aged 60 or over was included in the first category of participants since most people diagnosed with PD are at the average age of 60 or above (NICE 2017). However, people who were less than 60 years old in the first category were excluded from the study.

The second step was to determine the type of sampling that the researcher intended to use. The purposive method includes different sampling types, including typical, unique, maximum variation, convenience, and snowball sampling (Merriam 2009; Palinkas et al. 2015). Convenience sampling was used for this study. This method has drawbacks, as it limits generalisability and potential bias in the selection of the participants. However, it involves recruiting participants who are easily accessible to the researcher and identifying hard-to-reach participants (e.g., community-based older people) while giving them autonomy and time to decide whether to participate. Purposive convenience sampling was used in this study to invite relevant participants from established meeting groups. The PwPs and their carers were recruited from the established Parkinson's Cafe meeting group from local Parkinson's UK support and research interest groups throughout Wales (Local groups | Parkinson's UK). These groups' organisers were asked to forward the information pack regarding the study (participant information sheet, invitation letter, and consent form) to their group members (see Appendices 4.2, 4.3, and 4.7).

Recruitment into the study utilised a combination of many approaches. Recruitment emails were submitted to the staff organisers of these groups with an invitation letter and information sheet attached, and they were asked to identify suitable participants who met the inclusion criteria given above and provide them with the study information pack (see Appendices 4.3 and 4.4). Where possible, the researcher spoke to or met the group organisers to provide them with further explanations and discussed the logistics of conducting the focus group discussions.

The group staff organisers acted as gatekeepers for this study; they introduced the study to their group members using the information pack provided. Where the group organisers granted permission to conduct the focus group discussion, the researcher arranged the date, time, and place to hold the discussion.

4.3.4 ETHICAL CONSIDERATIONS

This study was approved by the Cardiff University School of Pharmacy and Pharmaceutical Sciences Ethics Committee (see Appendix 4.5). The initial approval was in relation to PwPs and carers. The focus group participants were invited to participate via a preapproved invitation

letter and a participant information sheet, as discussed above (see Appendices 4.3 and 4.4). It should be noted that an amendment approval was also sought and received from the same committee to run the practice focus groups with older people without a PD diagnosis (see Appendix 4.6 and Section 2.4).

In addition, each participant was asked to sign and date the preapproved consent forms before each focus group session (see Appendix 4.7). The recorded data and transcripts were stored in a secure cabinet in the Redwood Building at Cardiff University, and data used for analysis or publication were anonymised.

4.3.5 DATA collection

A minimum of two researchers were present at each focus group discussion, one moderator and one note taker, to maximise the validity and quality of the collected data (Krueger and Casey 2000). These roles were interchangeable between the researcher and the undergraduate student to allow the undergraduate student to gain more experience in this type of research.

Krueger and Casey (2000) listed the following functions of the focus group moderator:

- To encourage all focus group members to participate and contribute.
- To direct the discussion by asking open questions and probing for details.
- To maintain the flow of the conversation.
- To ensure that all participants contribute either with positive or negative comments.
- To avoid giving personal opinions, showing too much approval, and influencing the participants with their own opinions.

Also, Krueger and Casey (2000) described the key functions of the note taker as follows:

- To record the session (e.g., whether by audio or videotape).
- To observe participants' body language and non-verbal signs.
- To take comprehensive notes during the discussion that will aid the transcription process.

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Setting the scene: To provide a natural environment for the participants, all focus group discussions were conducted at the same venue where the group usually met, as it was felt that these were convenient for participants to gain a high level of engagement. As suggested by Morgan (1988), at the beginning of each focus group discussion, the researcher introduced herself and the undergraduate student, explained the aims of the study, and rechecked that the participants were still willing to participate. She then verified this by asking them to complete and sign a consent form (see Appendix 4.7) before beginning the discussion. The focus group topic guide was used to guide the discussion. All the discussions were audio-recorded using a digital voice recorder. At the close of the discussion, the participants were asked to give additional opinions, and no further information was added. In addition, refreshments were served in all groups.

The focus group's digital audio recordings were transcribed verbatim after each session, with non-verbal communication recorded using assistant moderator notes by the researcher and the undergraduate student. The audio recordings were transcribed by both the researcher and an undergraduate student, and each one transcribed one audio equally. Also, any data that could identify participants in the focus group discussion were anonymised on the transcript (see example in Appendix 4.8). Then, to check the undergrad student's transcripts' accuracy, the researcher listened to the audio recordings while reading the transcripts. This also helped the researcher become more immersed in the data. Another colleague reviewed all transcripts to ensure their quality.

The transcribed data were coded to simplify the analysis, and themes were identified within the coded data using inductive and deductive approaches.

4.3.6 DATA analysis

Thematic analysis was performed, where two separate approaches were used to identify themes or patterns within the data, specifically, the theoretical or deductive 'top-down' approach and the inductive 'bottom-up' approach (a hybrid approach) (Braun and Clarke 2006; Babbie 2013). A hybrid thematic analysis approach is widely used as a qualitative analytic method in the literature (Fereday and Muir-Cochrane 2006; Ligurgo et al. 2018; Xu and Zammit

2020). The researcher had no experience living or working with PwPs and so may not fully understand their experiences or the psychosocial context of their condition or the use of technology, which allows and facilitates the use of the inductive approach during the data analysis process.

Initially, the data were deductively analysed using a topic guide to determine the pre-established areas of interest. Then, the inductive approach was used to discover any new patterns or themes within the data, and the deductive approach was used to confirm or reject the anticipated themes (Babbie 2013). Likewise, the inductive approach was used to identify any new themes that would be relevant to the electronic data collection. The thematic analysis was done manually by the researcher through printing codes; no software was used. The thematic analysis procedure was carried out through several steps, as shown in Figure 4.2.

In addition, a content analysis approach was used to utilise a descriptive approach (e.g., quantitative inferences) in both coding and interpretation of the data (Vaismoradi et al. 2013; Bengtsson 2016; Erlingsson and Brysiewicz 2017). Using content analysis helped the researcher quantify and examine the presences, meanings, and relationships of words and concepts and made inferences about the findings within the data. According to (Vaismoradi et al. 2013), both content analysis and thematic analysis share the same purpose of analytically examining qualitative data, and they are often used interchangeably in the literature. The key difference between the two approaches lies in the possibility of quantifying data in content analysis through assessing the frequency of different themes and categories (Vaismoradi et al. 2013).
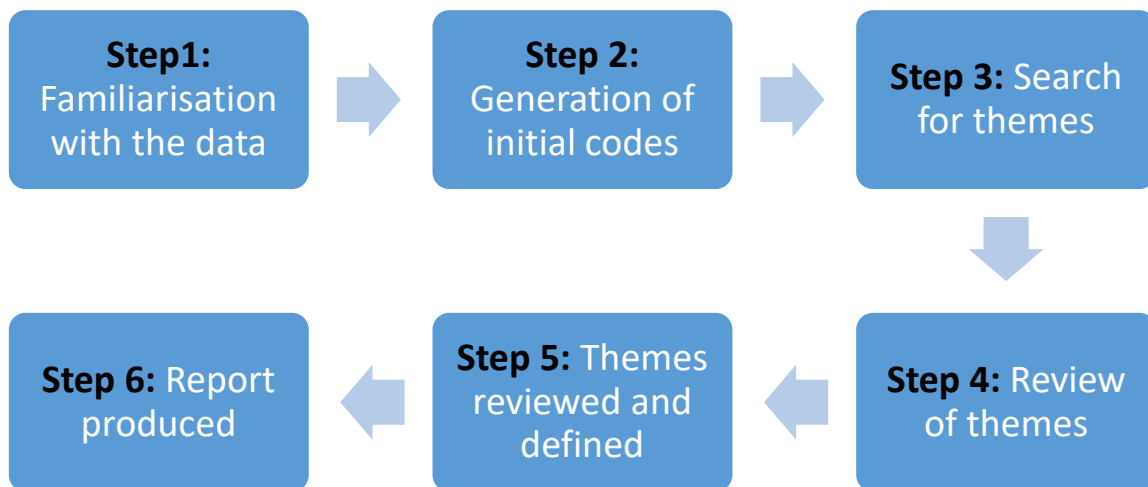
Figure 4.2: The steps of thematic analysis (adapted from Braun and Clarke 2006)

Both inductive and deductive approaches were applied during the data analysis, based on the section of data to be analysed (Ligurgo et al. 2018; Xu and Zammit 2020). For example, a deductive approach was taken where the researcher sought to identify specific information relating to the attitudes, values about technology use in general, views relating to the app, and suggestions for improvements of the app by participants, so these questions were asked directly during the focus group discussion. It was important, however, not to limit the findings to these specific aspects, as participants may express views relating to important yet unanticipated topics, which would provide a greater understanding of the research area. As such, for inductive analysis, the researcher used the detailed reading of the raw data, line by line, to identify codes and develop themes regarding the participants' views and beliefs on wider aspects of the topic, in particular aspects which they were not asked about directly during the group discussion. In this stage, the coding of data was generated solely from the data itself, enabling the development of data-specific themes (Braun and Clarke 2006).

This process was challenging, as it was difficult to be completely detached from previous preconceptions and theoretical views. Hence, it is possible that unintentional analytical bias may have existed, despite measures taken to minimise this possibility (Braun and Clarke 2006).

Nevertheless, the researcher was transparent and reflexive (e.g., critically self-reflective about her own preconceptions) and let the data drive the coding to minimise any potential bias.

After being printed, the transcripts were read and re-read by the researcher to familiarise herself with and immerse herself in the data. Then, researcher started to highlight and annotate each portion of the text and generated the initial codes. After the coding process, researcher tried to understand the following questions in order to identify the themes: 'What is being described? How is it understood? What does it mean? And why?'. This helped to group the codes depending on their focus and meaning, where each group was a potential theme or subtheme.

A schematic diagram was created in an MS Word® document in order to visually observe the relationships between codes, themes, and subthemes. Then, the researcher and the researcher's supervisors reviewed the themes that emerged to modify and finalise them to accurately represent the data's essence. An example of the analysis process is shown in Table 4.2. The final stage of thematic analysis was the generation of the findings as a report, with illustrative quotations selected to represent each theme, as shown in the results section (4.4). An example of the developed themes is shown in Figure 4.3.

Table 4.2: An example of the analysis process

Approach	Codes	Subtheme	Theme
Deductive	'Font size'; 'big screen'; 'one question per page'; 'frequent answers'; 'comment box'	Suggestions for improvement	The use of the iPad app
Inductive	'Did you ask the clinicians'; 'if I'm told by my clinicians'	Recommendation from HCPs	Facilitators to use technology and app

4.4. RESULTS

Focus groups were conducted between August 2016 and December 2017. A total of eight focus group discussions were included in the data analysis involving 47 participants. The focus group discussions lasted between 35 to 50 minutes and included 24 participants who had PD (43%) and 23 who were carers (41%). However, other demographic data (e.g., stage of the disease, gender, and ethnicity) were not collected in this study. The age range of the participants was

31–84 years and in line with inclusion and exclusion criteria, the PwPs were over 60 and younger participants were all carers. The details of the focus group participants are shown in Table 4.3.

Table 4.3: Characteristics of the focus group participants

Focus group number	Total participants	Number of PwP	Number of carers	Age range (years)	Participants Initials
G1	7	4	3	31–65	P1, P2, P3, P4, C1, C2, C3
G2	3	2	1	49–67	P1, P2, C1
G3	6	2	4	65–80	P1, P2, C1, C2, C3, C4
G4	7	2	5	51–84	P1, P2, C1, C2, C3, C4, C5
G5	5	1	4	68–87	P1, C1, C2, C3, C4
G6	9	6	3	59 - 84	P1, P2, P3, P4, P5, P6, C1, C2, C3
G7	7	5	2	70 - 78	P1, P2, P3, P4, P5, C1, C2
G8	3	2	1	64 - 71	P1, P2, C1

G: group number; P: PwP; C: carer for PwP. The number represents the order of participants in each group, for example, G1P1 means the first participant with PD in the first focus group).

Based on the data collected during the focus group discussions and thematic analysis of the participant responses, three key themes emerged: barriers to the use of technology and apps, facilitators to the use of technology and apps, and the prototype iPad-based app. Each theme contained relevant subthemes, as shown in Figure 4.3. As explained in Section 2.3, in order to gain a further understanding of the findings, some of the qualitative data were described and presented using quantitative terms. However, there was no quantitative analysis conducted in this study; it was simply integrating quantitative terms in qualitative data reporting. This was done to describe the extent to which a specific phenomenon was generated as an outcome (Maxwell 2010; Monrouxe and Rees 2020).

Barriers to Use Technology and App	Facilitators to use technology and App	The prototype iPad-based app
• Concerns about technology and app • Logistics (clinics waiting area and time). • Health-related barriers.	• Importance of Technology. • Technology readiness. • Need for Training and assistance. • Recommendations from HCPs. • Feeding back to patients.	• Perceived benefits of the prototype iPad app. • The content of the prototype iPad app. • Suggestions for improvement.

Figure 4.3: Identified themes and sub-themes

1.   **Barriers to technology and app use**

Throughout all the focus groups, the participants mentioned a number of perceived and possible barriers to using technology in general and the iPad app in particular. Three subthemes emerged under this theme: concerns about technology and the app, logistics, and health-related barriers.

1.1 Concerns about technology and iPad app

The participants expressed several elements that were often identified as a cause for concern in relation to misuse and mistrust of technology use in clinical settings. These included age gap, privacy, and confidentiality concerns, lack of previous knowledge and education in technology use, physiological factors, and, more specifically, the impact of technology on the current nature of consultation.

1.1.1   Age gap

The majority of participants in this study acknowledged that age was a crucial factor in their level of technology use. Many of the participants reported that some older people were not

very familiar with the use of technology, and they felt that their age could restrict their ability

to utilise technology and derive any benefit from it:

> *I am just an old-fashioned technophobe. G1, P1*

> *We [older people] cannot use them [technology] like the younger people use them, so its age could be an advantage compared to the older generation. G5, C3*

On the other hand, some of the participants did not consider age to be a barrier to themselves;

they thought that age might be an obstacle to technology use among older people in general.

> *My husband, he is over 70, and does not use technology, but I do, and I would like to know more about technology. G4, C2*

There was agreement among all participants that young people who had grown up with

technology and appeared to know how to use it would find it easy to accept, adopt, and use

technology, such as an iPad.

> *I suppose if you were fairly young, they would be able to cope with technology as an iPad. It is just the older generation. G5, C1*

1.1.2   Lack of previous education in technology use

The lack of previous education and knowledge regarding how to use technology was

mentioned as a barrier to its effective use. Several participants emphasised that they were

limited to basic technology use due to a lack of education and knowledge. As one of the

participants stated:

> *We did not have computers at school, so what I know is what I've picked up as I've gone along, and I'm not brilliant at it really. G7, P1*

> *I never had any education in these things [technology]. G3, P1*

1.1.3   Privacy and confidentiality concerns

Some of the participants were anxious about the security and confidentiality of electronically held data. Lack of trust in who had the right to access their personal and medical data and under what circumstances was reported by a few participants. For example, one of the participants explained the vulnerability of electronically held data and how hackers or unauthorised users could exploit it.

> *There is always a security issue, is not there, with anything that is stored electronically…somebody getting access to it that shouldn't be accessing it. G1, P1*

On the other hand, most of the focus group participants had no concerns about the security or confidentiality of their medical data; however, concerns regarding the security of financial data were highlighted. This suggests that the medical data were perceived differently, as security was less likely to concern the participants.

> *I worry about security in terms of banking, and I do not bank with the computer; the finance would make me worry, but knowledge about medical matters would not worry me too much. G7, P5*

1.1.4   Psychological factors

Some participants in all focus groups expressed their concerns about using technology for various reasons, such as a sense of pressure, anxiety, fear, and hatred of technology. However, these psychological factors could be related to older age or a lack of previous knowledge, which could sometimes lead to fear of doing something wrong and potentially ruining the device. As a result, older people tend to hesitate to use technology. For example, a few of the participants listed fear as compromising their willingness.

> *I find it very intimidating, quite seriously, and it is a bit psychological. Once you turn on the fear of 'Oh I cannot do it', it escalates, so I tend now to not even want to try. G6, P2*

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Some of the participants described how using technology in clinical settings may increase their anxiety levels, as attending clinics can be stressful in itself.

> *You are always a bit stressed when you go to see a consultant; my mum, whenever she has to go to appointments, she gets very anxious. G4, C1*

In addition, some of the participants expressed their feelings of dislike regarding the idea of using technology, even though some recognised the advantages of using it.

> *I do not like computers; it is handy; it is quick, but it is not as good as [you think]. I think they are time-wasting things. G4, C3*

1.1.5 The impact of technology on the current nature of consultation

Embedding technology in hospital clinics would change the current data collection method, so some of the participants were not in favour of using it to support and facilitate data collection within clinical settings. They were concerned about losing valuable face-to-face time with HCPs, and they viewed direct contact with HCPs as a superior option for them. They felt anxious that the iPad app tool would have a negative impact on their care and their relationships with HCPs.

> *I think the personal relationship, which I have built up with my Parkinson's nurse over the past five years, is more important; she is getting [more] information because she knows what I am doing and what I can do, which I am not sure a machine will necessarily do. I would hate to lose any of the contacts I have with the Parkinson's nurse. I think I would rather tell [my symptoms] to the Parkinson's nurse than put it on the machine. G7, P4*

1.2 Logistics

1.2.1 Clinic waiting times

In practical terms, the patients would likely be asked to use the prototype iPad app to complete the questionnaires while waiting in the waiting area at PD clinics. This was decided after a

discussion with staff from a local PD clinic in the Cardiff area to facilitate the integration of the collected data with the patients' database (EHRs) in the clinic. Therefore, the participants were asked about their opinions about using mHealth technology, such as the iPad-based app, while waiting for their appointment. Participants across all focus groups narrated different experiences of waiting times, depending on which clinic they attended and where they were on the clinic lists, ranging from no wait to a wait of up to an hour. Some of the participants were worried about having sufficient time to complete the content of the iPad app correctly.

> *As long as they allow time between patients; otherwise, you're going to rush it, and you're not going to give the correct information. G4, C3*

The participants suggested that to overcome these challenges, patients would have to turn up earlier to their appointments to allow enough time to complete the app and to avoid any disturbance of the clinic's workflow.

> *I think if they have given them an appointment time, say they have given them an appointment at 2 o'clock, they will spend 15 minutes on the iPad because 12 minutes was an average, so they would need to get called in earlier to do [the] app before they see the consultant. Because the only thing with clinics, if one person is running late, then the whole clinic is running late. G5, C2*

On the other hand, some of the participants had no concerns about the time needed to complete the iPad app. This was either because they usually arrived earlier than their appointment time, so they had to wait a long time, or they would let their carers complete the app instead of them.

> *You would have plenty of time to use it [iPad app] if you come in earlier and wait. G6, P5*
> *We would have time to do it if the carer did it. G4, P2*

1.2.2 Clinic waiting areas

Regarding the waiting area, where the participants would be likely to use the iPad, participants' responses varied from no concerns at all to concerns over the lack of privacy. For example, one of the participants with no concerns about using the app in the waiting room environment said:

> *I would not have a problem with it; I would just sit in a quiet corner and do it [use an iPad to input data]. G1, P2*

However, other participants expressed concerns about their ability to use the iPad app in the waiting clinic area due to distractions and crowdedness.

> *Yesterday, I went in to see the consultant, but outside in the waiting room, it was quite busy. You would not be able to concentrate then. G6, C3*

Another participant believed that the clinic waiting area was not a suitable environment to use the iPad to input data because of the lack of privacy and confidentiality of such an area, especially for people with a hearing impairment:

> *I think the privacy side of that, if you are asking somebody out loud in a waiting room would not be good; it is noisy. If you have got someone who is hard of hearing, it would not be appropriate. G3, C4*

1.3 Health-related barriers

Participants across all focus groups mentioned a number of health-related issues that older PwPs were more likely to have, which could affect their ability to use technology such as an iPad app. Concerns were expressed about the nature of PD itself and its symptoms, such as tremors, cognitive impairment, and dexterity issues that would make interacting with and using the iPad app interface difficult for users.

> *My immediate reaction was that it would be very difficult for a lot of Parkinson's patients, for somebody with a tremor [to use technology such as an iPad]. G2, C1*

The participants also mentioned other symptoms related to PD motor symptoms as a potential barrier to the effective use of technology. This includes tremors, feelings of weakness, or not having enough strength to press the right keys or to double press keys.

> *They would not press the right keys. If they were shaking, they would be pressing the wrong keys. G5, C1*

> *They [PwPs] have not got enough strength to press. G3, C4*

Another potential barrier to technology use related to PD symptoms is the decline in cognitive functions (e.g., thinking and memory problems), as mentioned by the participants.

> *The memory problems, really. If you are using a laptop or whatever you have to remember, don't you, your passwords, and all the rest of it. G3, C2*

The cognitive functions in PD usually decline gradually and worsen over time (Broeders et al. 2013). and some of the participants emphasised that the PD stages would affect the ability of PwPs to use technology. For example, PwPs with an advanced stage of PD would not be able to use technology compared to when they were in the early stages of the condition.

> *When she [wife] first had Parkinson's, she used to use the computer a lot, but as she deteriorated, her use of the computer deteriorated. First, certainly with memory, she was finding it difficult to remember what programmes to find what she wanted. G3, C2*

Moreover, the participants reported that due to PD, they found it more difficult to use their hands, which may impact the use of technology.

> *Also, [we] need to note the fact that some people with Parkinson's, their manual dexterity is not very good. My left hand is virtually useless, so it is just the dexterity in general. G7, P2*

2. Facilitators to technology and app use

This theme reflects participants' views on factors that could facilitate the future use and implementation of technology in clinical settings. Key subthemes included the importance of technology use, technology readiness, the need for training and support, recommendations from HCPs, and feeding back to patients.

2.1 Perceived usefulness and importance of technology

The perceived usefulness and importance of a digital device or service would influence perception towards, uptake, and engagement with new technology interventions. The general concept of using technology to improve the data collection process in clinical settings was viewed positively by the participants. Participants who did not feel the usefulness or need for technology, recognise its importance, or see any advantages over current strategies already employed for their care services were less likely to perceive mHealth interventions as useful or important and therefore did not use them. However, during the discussion, the participants recognised, acknowledged, and emphasised the usefulness and importance of using technology within clinical settings. For example, one of the participants said that using technology within clinics would have a positive impact on streamlining the data exchange process between HCPs and standardised documentation, which would have a significant impact on managing their condition by different HCPs.

> *If it is going to make things more universal, so every part of the care that you are getting, every practitioner sees what the situation is with a particular disease. G8, C1*

Some of the participants added that using technology to collect patients' data within clinics would facilitate the collection and access of data by HCPs, which could give HCPs sufficient time to focus on managing patients.

> *It would be more time-efficient, and there would be quick access to data if needed for treating patients; it is in the right direction. G1, C2*

Yet another participant described the importance of using technology to save patients' records.

> *I think it is an important tool nowadays because paper records, as we found out with other things, disappear, and they get lost. G8, P1*

Even though technology has not been widely used among older people, participants expressed their willingness to use technology to learn about new developments and to keep up-to-date with modern life. The willingness to learn how to use technology, such as an iPad app, can facilitate the adoption and usability of such an intervention.

> *A friend of mine once told me that the older generation should not be left behind. Our generation must learn technology to keep up with new developments. G6, P5*

2.2 Technology readiness

Previous experience with technology correlates to technological readiness, which is defined as the participant's capabilities in using different types of digital devices like computers and smartphones (Khatun et al. 2016). Therefore, having previous experience with technology (mHealth technology) could act as a facilitating factor for future adoption and use of the mHealth app. Indeed, some participants seemed very ready to use technology. They described their current use of a smartphone, computer, and tablet or iPad during the discussion and expressed confidence in learning how to use these devices for health-related purposes. In line with this, those who reported owning smartphones or digital devices also commented on online activities, such as sending and receiving emails, shopping online, and using Facebook and Skype for social reasons.

> *My mother is now 83, and she has an iPhone and an iPad. On a good day, she can email; she can certainly get an email. So, for her, it is a good thing when it works. G6, C2*

Another participant described how he was ready to use or comfortable using technology.

> *I used an iPad at least since bed [since I wake up] probably at least two to three hours a day for Facebook and mail and internet searching for medical matters and so on. So, I am very comfortable using the iPad. G8, P1*

2.3 Need for training and assistance

There was agreement among all participants regarding the need for training in how to use mHealth technology to collect their data in clinical settings. Providing patients with adequate training would facilitate and positively impact their willingness to use technology. The majority of participants stated that they would need someone to be present to train patients and to explain the process of what they should do, particularly if they were first time users.

> *I think the first time you are introduced to this, somebody needs to explain it to you and show you how to use it, whether that is the consultant or a nurse in the waiting room. Once you have had an explanation of what to do, the next time I do not think you need it, but the first time, yes. You need some explanation as to why it is being done. G3, C2*

On the other hand, providing training would be insufficient in some cases, such as for patients with cognitive or severe physical impairment. Therefore, providing and offering assistance to use mHealth technology seems essential to facilitate the adaptation and usability of such technology within clinical settings. Some of the participants stated that there would be a need to provide ad hoc assistance to facilitate the use of mHealth technology (iPad app) rather than providing extra training in how to use it. This support could be offered by either one of the team members at the clinic or the patient's carer. As one of the participants stated, older adults, especially PwPs, might need some help to input their data using this technology (iPad app) because of their memory problems or the physical symptoms of PD.

> *I think the actual process of doing it would be very simple, but maybe not for people with tremors. You have to accept that people with Parkinson's may have signs of*

dementia: Mum certainly has, and she would struggle to fill that in without help, but she would never be there without somebody anyway. G6, C2

2.4 Recommendations from HCPs

Some of the participants emphasised the importance of knowing their HCPs' views on the use of technology for them to use it, as they valued their opinions and recommendations. The trust that patients have in HCPs' advice could facilitate mHealth technology (iPad app) adoption and use, and involving HCPs could play a vital role in successfully integrating and using technology within clinical settings. Indeed, it was apparent that some of the participants were willing to use technology such as the iPad app only if their HCPs recommended it.

If I am assured by the clinician that it is [technology/iPad app] of value, I am happy to go with it. G7, P5

2.5 Feeding back to patients

The mHealth technology intervention that summarises users' data and provides supplementary reports was most appreciated, as described in Chapter 3. This would help patients make sense of their disease conditions, track their progress, and further engage in their care. Providing patients with such an information summary and acknowledging that they would use the intervention during their clinical visits would encourage mHealth technology (iPad app) use. A few of the participants expressed the importance of providing them with a summary report of their performance after using mHealth technology, such as the iPad app, within clinical settings.

The patients, once they fill that in [app questionnaires], would like to be acknowledged on what they have done. G2, P1

It would be nice if you could have a printout as well so that you can compare it with the next one you do. G8, C1

However, the participants had no preference regarding the format or the ways to receive the feedback—as a printed form or an electronic form were acceptable.

> *Either hard copy or electronic copy email back to me. It would be nice if you have one to compare it with the next one you do. G8, C1*

3. The prototype iPad-based app

As mentioned in Chapter 1, the prototype iPad-based app included three sections: the EQ-5D quality of life questionnaire, NMSQuest (this covers all the NMS domains), and the two-finger tapping test. The three subthemes were identified that described the participants' perceptions; these included the perceived benefits of the prototype iPad app use, the iPad app's content, and suggestions to improve the app.

3.1 Perceived benefits of the iPad app

Despite several concerns regarding technology use in general, most participants responded positively to the use of the prototype iPad-based app. They anticipated several benefits of an app that would aid consultations by providing more information regarding the patient's condition, helping them focus before their consultations, focusing consultations on their needs, and tracking their progress. The most common anticipated benefit was improving communication with HCPs, as providing HCPs with more relevant information might help them better understand the patient's condition.

> *Sometimes when you go to the doctor, they do not look at your records; they ask you what you are doing there…The quickest thing would be to glance down this thing [iPad app] and trying to ask the patients and get to know all the details through conversation. G4, C3, C7*

In addition, the iPad app could improve and focus consultations on the problems that the patients might have or might want to discuss with the HCPs.

> *I do not get asked these questions in the past in the clinic; they wait for me to volunteer information. That at least gives an indication of all the problems you are likely to be facing, so they can then ask questions about it. G8, P1*

Also, some of the participants emphasised that using the iPad app to input their data electronically could lower their anxiety levels by providing a way to answer questions that would otherwise be embarrassing.

> *You can ask questions that are potentially embarrassing, and you are just talking to a machine, whereas you might be too frightened to raise it with the specialist. G2, P1*

The participants also felt that the app could help them focus and remember the main issues of concern they wanted to discuss with HCPs before their consultations. Also, it would allow them to organise their thoughts and be prepared for discussion with the HCPs.

> *It covers things you might forget you actually want to say when you go into the consultant. G1, P2*

Another participant added a further explanation:

> *If you were answering these questions and when you are sitting in front of the consultant, you do not always answer correctly; you have got a better chance of organising your thoughts really. G4, C2*

In addition, according to some of the participants, the prototype iPad app would offer an opportunity to track the progression of the disease.

> *They could bring up your answers from last time and see if there is any deterioration. G2, P1*

3.2 Content of the iPad app

The different sections of the iPad app were widely accepted among participants. The majority of participants found the health rating scale in the EQ-5D questionnaire section too subjective and felt it would depend on the patient's psychological condition.

> *I have always got a problem when I am asked on a scale of 1 to 10 or 1 to 100. I end up picking a number out of thin air, say, I will go for 50 today. You do not really know if you are picking the right number. And I think that the state of your health is more a psychological thing than a physical thing. G6, P1*

In contrast, the participants were impressed with the NMSQuest section on the app; they felt that this section covered all the issues they encountered with their condition. As one of the participants said:

> *They are good. A lot of these things you know I can see happen to me—falling and things like that. G1, P3*

In addition, there was agreement among participants on the value of the tapping test sections. Participants described how it would help to predict their condition, generate a number and give a different scale every time they visited the clinic. As one of the participants said:

> *I think the tapping test would be good; it would be different every time, and give a scale. G1, P2*

3.3 Suggestions for improvement

The participants made several suggestions to improve the app's features, which would facilitate the process of electronic data collection at the clinics. Table 4.4 shows some of the example quotations from participants; the superscript numbers in the text below are related to each quotation.

The most common suggestion was the need for enlarging font size or placing only one question per page[1], the inclusion of frequency ranges on the NMSQuest questionnaire answers rather

than 'Yes' and 'No' answers[2], and adding general questions regarding medications[3]. Other suggestions included adding a section with general questions that would be completed by the patient's[4] carer, improving the app's general instructions[5], and adding a flagging system or comment box to enable patients to rate the top three symptoms on the NMSQuest section that they wished to discuss with consultants[6]. Since scrolling up and down was problematic for some participants, several participants suggested a swipe action mimicking turning the pages of book[7]. A final suggestion was having remote access to the app so patients could complete the app at home before the clinic appointment[8].

Table 4.4: Suggestions and some of the example quotes from the focus group participants

Features	Suggestions	*Q. no.	No. of participants who made this suggestion	Example quotes from participants
Functionality	Enlarge font size of the app	1	30	*'I think that screen size needs to be bigger.' G4, C3*
	Frequency ranges on NMSQuest	2	15	*'I think it's a good idea but just have some sort of question to say how variable the situation is. To have some flexibility to say how variable the symptoms are. Because it's not definitive is it?' G4, C2*
	Flagging system	6	6, to enable patients to prioritise the most important thing they want to discuss during consultation.	*'With your emails, you get a list of emails, and some you can flag the most important one I'd like to talk about.' G8, P2*
	A swipe action to move across the app sections	7	6	*'Maybe for older people it would be good if it was a big set of questions on one page rather than having to slide up and downturn over a leaf, that kind of thing.' G2, P2*
	Remote access to the app	8	6, as the iPad app was developed to be used in clinical settings.	*'You could do it from home before you go and then they've got the information there, and it would probably be a bit easier and more relaxed doing it.' G4, C1*
Contents	Medication section	3	12	*'Medication is a minefield.' G5, C2*
	Carer section	4	8	*'I believe that it's vital that the carer has some input to the discussion with the clinician. I think it (carer section) is a consideration.' G2, C1*
	App general instructions	5	7	*'Instruction at the beginning saying how to navigate the app and questions on the screen, scroll through and hit.' G5, C1* *'[General instructions] because moving down isn't explained.' G2, P1*

*Q.no. (Quote number)

4.5 Discussion

This is the first study to explore the perceptions of PwPs and their carers regarding the preference for and acceptance of an iPad-based app that aims to collect patient data (e.g., NMSQuest, EQ-5D quality of life questionnaire, and finger tapping test) to feed into consultations in PD clinical settings. This study provides useful information regarding the value of using digital technology and an iPad-based app for PwPs as a new data collection tool in hospital clinical settings instead of paper documents. Furthermore, this study provides an in-depth exploration of what PwPs and their carers think about the use of technology, the facilitators, and barriers to using it in clinical settings, and the required features to redesign the iPad app, as well as the acceptability of the iPad-based app and its potential benefits in collecting patient data through PROMs.

The findings of this study highlight the varied responses towards the use of iPad apps and technology, and this is consistent with previous studies that explored older peoples' perceptions regarding the use of technologies (Mitzner et al. 2010; Hall et al. 2014; Yaffe et al. 2015; Wallwiener et al. 2017). The previous studies focused on using a broad range of technologies in various settings, such as home, work, and health. However, this study focused on using an mHealth device (iPad-based app) in PD clinical settings. The importance of using technology and an iPad app to improve the data collection process in clinical settings was highlighted throughout all the focus group discussions. This could be a promising indicator for mHealth technology (iPad app) adoption, usage, and implementation within PD clinical settings.

Some of the themes found (e.g., potential benefits, the importance of technology, and potential barriers or concerns regarding technology use) in this study are consistent with the findings of previous studies that investigated technology use among older people and heart failure patients (Hall et al. 2014; Vaportzis et al. 2017a; Cajita et al. 2018). Even though previous studies have focused on older people's perceptions of telecare and technology use in general,

it appears that the attitudes and perceptions of older people, either with chronic health conditions or without, towards technology use are similar (Hall et al. 2014; Cajita et al. 2017; Vaportzis et al. 2017b; Spann and Stewart 2018). Additionally, the physical impact of PD, such as tremor and dexterity issues, could also play an essential role in PwPs' attitudes and perceptions towards the use of mHealth technology (iPad app) so app designers should consider that during the development process.

As mentioned earlier, the participants recognised the importance of using technology, such as the prototype iPad-based app, in clinical settings to facilitate data gathering and communication with HCPs. This is similar to the findings of Vaportize et al. (2017) and Hall et al. (2014), whose work emphasised the need for older people to adopt technology to move on with their new lifestyles and communicate better with their surroundings. Furthermore, the participants in Hall et al.'s (2014) and Cajita et al.'s (2018) studies reported the usefulness of using mHealth technology to manage heart failure symptoms, which was in line with the findings of this present study. The PwPs highlighted the potential uses of the proposed iPad app to identify and manage their PD symptoms.

In comparison with the current conventional methods of collecting patients' data at hospital clinics using paper documents, the participants throughout all the focus groups mentioned several benefits of the use of technology to replace paper-based systems to collect data. This includes improving access to health records, which could result in saving HCPs' time during regular consultations, providing an early indication of a deteriorating condition, and facilitating data exchange between healthcare institutions and care providers, which could result in improving the management of the patients' conditions. These findings are consistent with the perceptions of older people with heart failure regarding the use of mHealth technology to manage disease symptoms, as reported by Hall et al. (2014) and Cajita et al. (2018). Furthermore, these findings supported the Welsh government's vision regarding the digital transformation of health services (Welsh Government 2015).

Chapter 4   **Perceptions of HCPs on the use of e-PROMs app in PD clinical settings**

As mentioned previously, the participants' perceptions of electronic data collection by using mHealth technology varied widely between the focus groups; however, it was noticed that the negative responses regarding technology use were related to the participants' lack of understanding of how the data are currently collected. These participants' poor knowledge of the current process for data collection at hospital clinics needs to be addressed and clarified to facilitate the future adoption and use of technology within PD clinical settings. As such, patients may find greater acceptability in using mHealth technology intervention to support data collection if an explanation about the currently used system for data collection and documentation in clinical settings, which is mostly mixed systems (paper and electronic), is provided in advance.

In terms of technology readiness, the participants expressed different levels of confidence in using technology, which was in line with the findings by Cajita et al. (2018). Some of the participants in this study were very confident in their ability to use mHealth technologies, and unsurprisingly, they expressed a positive attitude towards technology and the prototype iPad-based app for PD. Similarly, Cajita et al. (2018) reported that older people with heart failure who expressed a high level of confidence in using technology expressed a positive attitude towards mHealth technology and were more likely to have the intention to use it for health-related purposes.

In line with Cajita et al. (2018), this study's participants expressed the need for training in the use of mHealth technology to realise the full potential of the technology and the prototype iPad-based app within clinic settings. This indicates that training could improve older people's self-efficacy in using mHealth technology (Cajita et al. 2018). Therefore, providing PwPs with essential training seems to be an influential factor that facilitates the acceptance and use of such apps in PD clinical settings.

Providing training sessions might not be sufficient for some PwPs, especially those who suffer from severe physical (tremors) and cognitive impairment. Offering support for the use of

mHealth technology seems important. This finding is in line with Cajita et al.'s (2018) study, which reported that older people with heart failure who suffered from cognitive impairment might require support when they first use mHealth technology.

Support for using mHealth technology could be provided by either the clinical teams at the PD clinics or the carers of PwPs. The carers of the PwPs in this study suggested that they could provide the necessary support to help them use the iPad app. Consideration of these factors (tailoring training and offering technical support) will facilitate the acceptance and implementation of the prototype iPad-based app in PD clinical settings, resulting in improved usability of the app.

Although the participants emphasised the advantages of using technology in clinical practice, they also expressed multiple concerns about it. This included age gap, impact on clinical consultation, privacy and confidentiality issues, lack of previous education, and physiological factors.

The findings of this study suggest that users' age might impact adoption and intention to accept and use technology, which is in line with previous studies (Heart and Kalderon 2013; Byambasuren et al. 2020). Byambasuren et al. (2020) reported that patients' old age was the most frequently reported barrier to mHealth app use in general clinical practice. Another study that demonstrated the role of age in the acceptance of health-related technology among older people over the age of 60 found that age negatively impacted users' intention to use technology (Heart and Kalderon 2013). In addition, a few of the participants in the current study expected that older people would be less likely to be able to use technology than younger people. Given that PD is most frequently linked with advanced age (Reeve et al. 2014), this is an important finding.

The current study's findings also report that modern technologies, such as smartphones and iPads, are adopted by older people with PD. Regardless of age, they would selectively adopt technologies that are perceived as beneficial to them. This could highlight misconceptions about the ability and willingness of older people regarding technology use. Indeed, a previous

study also demonstrated that the myths about older people's ability to use IT are overgeneralised, and any challenge older people might have in this regard can be managed through user-friendly design and providing training and instruction (Wandke et al. 2012).

The lack of knowledge/education on technology use was mentioned as a concern regarding the effective use and adoption of mHealth technology in the current study. This is in line with the qualitative study by Cajita et al. (2018), who found that people over the age of 60 mostly reported a lack of knowledge as a barrier to using mobile technology to support them in the management of heart failure. Despite this lack of knowledge, some participants in the current study reported a willingness to learn how to use mHealth technology. This could facilitate the future use and implementation of mHealth technology in PD clinical settings.

Other perceived concerns about mHealth technology use in PD clinical settings were also reported by participants, such as the loss of valuable face-to-face interaction with HCPs (this related to the fear of losing the human and physical interaction with their clinicians), problems with the security of the collected information and anxiety about and fear of technology. In contrast to the current study findings, a recent qualitative focus group study that explored PwPs' perceptions of wearable technology use to support the current assessment methods in PD clinical settings in the UK reported no concern about technology use (AlMahadin et al. 2020). Indeed, no concerns about privacy issues, lack of knowledge on technology use, fear and discomfort regarding technology use, and lack of personal interaction were reported by 12 PwPs in the AlMahadin et al. (2020) study. However, this study included a very small sample size (n = 12), and the included participant was a user of wearable technology (e.g., smartwatch), which would impact the generalisability and validity of this study findings. Nevertheless, these findings are interesting because of the conflicting perspectives between the PwPs in the current study and the AlMahadin et al. (2020) study. This suggests that the concerns mentioned in the current study might be a temporary barrier to mHealth technology use. The acceptance and adoption of technology may not be fully related to these concerns. Therefore, the early understanding and addressing of these barriers can maximise the potential of mHealth technology use within clinical settings.

Chapter 4   Perceptions of HCPs on the use of e-PROMs app in PD clinical settings

The prototype iPad-based app was initially developed to be used in PD clinical settings in order to facilitate the transformation of collected data into patients' EHRs. Participants were asked about their perceptions of using this intervention within the waiting clinic area. The participants' perceptions of the clinic waiting room and the time required to utilise the iPad app varied widely throughout the focus group discussions. As might be expected, there were different prior experiences of waiting rooms and times, which affected the participants' attitudes towards completing the iPad process in such a setting. Participants reported that the noise levels in the waiting room might result in a lack of concentration, in addition to privacy concerns. Similar to other research (Patel et al. 2015), the time that patients spent waiting in primary care settings was found to vary.

In contrast with the current study findings, the Patel study participants reported no concerns regarding the use of mHealth technology (tablet app that aimed to assess decision making in medical treatment) in the waiting room. However, this study was conducted in the USA, in different clinical settings, and with younger patients (average age 43). Therefore, the patients' experiences with the waiting area would be different from the current study, and these findings need to be cautiously interpreted.

PwPs might require additional time to use mHealth technology, as their ability to use it could be impacted by their PD conditions (e.g., tremors), which could negatively impact the clinic workflow. However, some suggestions were mentioned in the current study, including the provision of a stylus pen, asking patients to arrive earlier than their appointment time, and offering the remote access option to patients to use the prototype app before coming to a clinic (offering an at-home option). These suggestions might affect the successful adoption and use of mHealth technology in clinical settings; however, remote access to the app or at-home option is a different and wider approach to collect patients' data. Additional research is needed to understand patients' perceptions and preferences towards remote data collection versus clinic settings to develop a platform that meets technical standards and regulations for this different context.

Chapter 4   Perceptions of HCPs on the use of e-PROMs app in PD clinical settings

The participants in the current study mentioned several health-related conditions that could hinder them from using mHealth technology. The PwPs and their carers highlighted the negative consequences of PD symptoms, such as tremors and cognitive impairment, and expected that these symptoms might affect their ability to use technology. This is in line with previous studies that reported concerns about age-related health issues, such as vision, hearing, cognitive, and physical impairment, for the effective adoption and use of technology among older people with heart failure and older people in general (Cajita et al. 2018; Wildenbos et al. 2019). These findings emphasised the need to develop mHealth technology that fits the requirements and expectations of older people and ensures that the design of the intervention should accommodate these health-related issues. For example, the design guidelines for mHealth app interfaces emphasise the need to recognise the relevance of cognitive skills and minimise the cognitive load on users during the development process of mHealth technology for older people (Ruzic and Sanfod 2017).

The participants in the current study responded positively to the prototype iPad app. They thought it would help them improve their knowledge about PD, assist the management of their condition, overcome the barriers of asking embarrassing questions, and prevent them from forgetting to ask important questions during consultations, improving their communication with HCPs. A similar mHealth system to the one proposed in the current study was found to have a positive impact on patients attending primary care settings. Patel et al. (2015) found that integrating the tablet system (which aimed to collect PROMs and provide healthcare information) into clinical practice was acceptable and useful to support decision making and improve communication with HCPs. According to TAM (Davis 1993) and UTAUT (Venkatesh et al. 2003), the perception of usefulness has been highlighted consistently as a major factor influencing technology acceptance and use. Consequently, this indicates that it is essential to focus on perceived usefulness within the promotion of the mHealth technology app.

The mHealth intervention design is one of the essential factors that determines whether patients are willing to use the intervention. This study's findings provided unique insights into PwPs' and their carers' needs and perceptions that would help the developers of the prototype

iPad-based app refine and improve the format and content of the app. The participants mentioned several suggestions, such as enlarging font size, adding sections regarding carers and PD medications, and improving the app's general instruction and navigation options. See Appendix 4.9 for further details regarding suggestions that would help app developers change the app features and design to improve the future acceptance and use of the app.

While e-PROM tools have been used in different clinical practices, such as oncology and orthopaedic settings, no evidence has been found of the existing use of a similar iPad-based app used as a data collection tool and successfully implemented in routine clinical practice in PD clinical settings (Abernethy et al. 2009; Malhotra et al. 2016). The only use of e-PROMs in a PD clinical setting was the ICHOM system mentioned in Chapter 1 (a computer system, where a health assistant was responsible for collecting patients' information using ICHOM standard PROMs set within a PD clinical setting (Arora et al. 2017)). Therefore, the current study results provide a positive preliminary indicator of the PwPs' and their carers' perceptions of the potential acceptance and usability of the iPad-based app upon implementation in PD clinics. However, further studies are still needed to explore their perceptions after implementing the mHealth app at the clinic to validate the findings of the current study.

Finally, the recommendations and involvement of HCPs in developing and implementing technology (iPad-based app) within clinical practice seemed to be essential to improve its acceptability and use by the patients. A few of the participants in the current study reported interest in using the proposed app if their HCPs informed them about it and endorsed its use. A previous study reported similar findings (Wallwiener et al. 2017), reporting that involving HCPs and patients in the first phase of developing e-PROMs would facilitate the implementation process and improve patients' compliance with the device (Wallwiener et al. 2017). Therefore, it would be essential to explore the usefulness of using technology and this app with a wider range of HCPs at PD clinics before implementing it in PD clinical settings. Exploring the features and use of an app with a range of HCPs might highlight the most needed data to improve patients' management processes in clinical settings.

4.6 STUDY STRENGTHS AND LIMITATIONS

This study's strength was the fact that it involved a varied sample of participants, including PwPs and their carers, which allowed the perceptions of the older people towards technology use and the iPad-based app to be explored in greater depth. Although the study had a low response rate at the beginning of the recruitment process, assistance was sought from a member of a patient and public involvement (PPI) group who helped identify the reasons and the potential solutions. It was found that some of the people may have had difficulty understanding the nature of the project and what was required from them. As a result, and based on a recommendation from the PPI community member, the participant information sheet was redesigned (providing further explanation about the purpose of the iPad app use), which resulted in an improved response rate.

There are a number of limitations to consider. First, most of the focus group participants owned smart devices, meaning that this sample may not be representative of the wider population. However, even though the majority of participants were technology owners, they seemed to be relatively unfamiliar with the technology. Therefore, they may have expressed different views and needs regarding using technology and the iPad-based app compared to people who are more familiar with technology use. Those who are more familiar with technology may have different experiences with technology use compared to the majority of this study's participants, and may therefore express different needs and preferences regarding an iPad-based app.

Second, all the participants and their carers were recruited from Parkinson's UK local support groups, so this sample's perceptions may not be representative of the general PD population, such as those with young-onset PD. Even though this study's findings may not be generalisable, they can provide a helpful indication of the views of people with late-onset PD (when the PD affects people at the age of 60 or over) regarding perceptions and acceptance of technology use in PD clinical settings. Although data saturation was achieved (the collected data achieved strong repetition of themes, no new insights were obtained, and no issues were found related to mHealth technology use), the findings are limited to those views obtained

from this specific sample population. The research may not have captured the full story. Despite this, the valuable information obtained provides useful insights into the views of PwPs, and this can be built on in further research. In particular, the perspective of HCPs requires consideration in order to understand the full picture, and patients' views can help provide the context for such a study.

4.7 IMPLICATIONS

The findings of this study have the following implications: First, there is a need for more information to be gathered and used during patients' consultations with clinicians, especially in PD clinical settings, to improve the quality of clinical consultations and support the orientation towards the patient-centred care model. Second, there is a need to provide a knowledge base to app designers and developers about PwP's needs and preferences for the desired app design and features for future use in clinics to improve and ensure the adoption and usability of the app by target users. This study's novelty was that it focused more on the needs and preferences of older people with PD and their carers regarding the use of technology and the development of an iPad-based app. Third: it provides evidence that supports previous knowledge on the effect of the perceived usefulness of mHealth technology, and this is an essential factor influencing technology acceptance and usage. Finally: it allows a better understanding of the potential barriers to and facilitators of collecting PROMs electronically by using an iPad-based app in clinical settings, which should be considered during the app's development and implementation phase to enhance its acceptance and usability.

4.8 CONCLUSION

This study was the first to explore the perceptions and preferences of PwPs and their carers regarding using mHealth technology, such as an iPad-based app that aims to gather patient data (PROMs) to aid consultations with HCPs in hospital clinic settings. Participants acknowledged the importance of the iPad-based app and its use as a data collection tool to regain a sense of control over their consultations. However, potential barriers to technology use within the clinic environment and suggestions to improve the app's design and content have been identified. These findings highlight that establishing a supportive atmosphere to

implement the app as a data collection tool within hospital clinics is critical for the successful implementation of the app in the current service. Among several identified barriers, particularly the allocated place and time to use the app, were issues of concern to the participants. Therefore, sufficient attention must be paid to the infrastructure and logistics during the implementation phase of app within PD clinical settings.

Even though, the participants appreciated the use of technology and the app, and they felt that the app could be beneficial to both HCPs and PwPs. Further studies to explore PwPs' perceptions are still needed after implementing the intervention to validate the findings of this study.

It is worth noting that users' participation in the design process of mHealth technology for PD is a crucial aspect of user acceptance. That includes creating additional features for the mHealth app, such as the carer section and medication section, which could be appealing to PwPs. This study's findings can help redesign a high-quality mHealth app with a high level of PwPs' and their carers' acceptance by considering their needs and perceptions and involving them in the design process.

4.9 Summary of this Chapter

1. This qualitative focus group study explored PwPs and their carers' perceptions regarding the use of mHealth technology (prototype iPad-based app) to assist data collection in PD clinical practice.

2. Potential facilitators of and barriers to mHealth technology adoption and use were identified that could help guide the development and implementation of future mHealth interventions for PD.

3. The findings suggest that PwPs and their carers are willing to use mHealth technology, such as the prototype iPad-based app. However, this was with conditions, e.g., providing adequate training and offering support and recognising and addressing the PD health-related issues during the design process.

4. Future researchers seeking to develop and implement mHealth-based interventions for PD should address the people- and technology-related barriers and take advantage of

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potential facilitators' influence, such as HCPs' recommendations to promote mHealth technology adoption and usage.

5. Moving forward, as the prototype iPad-based app was developed for use within PD clinical settings, it seemed important to explore the perceptions of HCPs. Therefore, the following chapter (Chapter 5) presents findings from a mixed-method study with HCPs who are dealing and working with PwPs.

Chapter 5: Use of mHealth technology (e-PROMs) in Parkinson's disease clinics: A mixed-methods study of staff's perceptions.

5.1 INTRODUCTION

In addition to the in-depth exploration of the concerns faced by PwPs and their carers as end users of the iPad-based app (e-PROMs tool), it is important to gain an understanding of the context in which the e-PROMs tool might be used and its potential impact on routine practice (Craig 2008). The findings from Chapter 3 suggest exploring HCPs' views regarding the potential use of an iPad-based app (e-PROMs tool) in routine practice. As discussed previously (Chapter 1), using PROMs has the potential to improve the quality and efficiency of the care provided to patients (Etkind et al. 2015; O'Connell et al. 2018). However, evidence regarding their actual use in PD clinical settings is limited, as is evidence of their impact on the quality of the provided care and outcomes. For this reason, it is important to understand the actual use of PD-specific PROMs from people running PD clinics.

As described in Chapter 1, PROMs are well accepted and widely used in routine practice within a range of health conditions, such as oncology, orthopaedic surgeries, and palliative care (Bennett et al. 2012; Collins et al. 2015; Howell et al. 2015; NHS Digital. 2017; Rotenstein et al. 2017). A qualitative review study reported positive perceptions of HCPs from a wide range of health conditions, such as mental health, oncology, palliative care, acute care, and depression, regarding the use of PROMs to improve quality of care (Boyce et al. 2014). The HCPs only valued the use of PROMs if their impact on clinical decision making was evident. The use of technology has also been suggested to enhance and facilitate the use of PROMs within clinical practice (Boyce et al. 2014).

Within routine PD practice, the use of PROMs is limited (Todorova et al. 2014). However, their use in clinical research studies is common as a primary or secondary outcome measure to evaluate adherence to treatment and the effectiveness of interventions (Mitchell et al. 2000; Deuschl et al. 2006; Bostantjopoulou et al. 2013; Lakshminarayana et al. 2017; Hannink et al. 2019). The PDQ39 (Jenkinson et al. 1997) and UPDRS-III (Goetz 2003) were used as the main outcome measures in a randomised trial to assess the effectiveness of deep brain stimulation

on patients with advanced PD and were successful variables in evaluating the health-related quality of life and severity of motor symptoms after this surgical procedure (Deuschl et al. 2006). The PDQ-39 and NMSS (Chaudhuri et al. 2007) were also used as secondary outcomes in a study that assessed the impact of a smartphone app for patient self-management that aimed to improve treatment adherence and the quality of clinical consultation (Lakshminarayana et al. 2017).

Despite the evidence on the use of PD-specific PROMs in clinical studies, less evidence has been found regarding the use and implementation of these scales in clinical practice. As mentioned in the first chapter, interest in using PD-specific PROMs within PD clinical settings is growing, but little attention has been paid to the perceptions of HCPs. After a scoping search, only two studies were found that explored the perceptions of HCPs regarding the use of paper forms of PROMs to assess the quality of life among PwPs and improve quality of care. For example, a semi-structured interview-based study was conducted with 14 HCPs (n = 7 neurologists and n = 7 physiotherapists), which revealed that most HCPs had a positive attitude towards using PROMs in medical encounters with patients (Damman et al. 2019). The use of PROMs enables HCPs to track PD progression over time, has the potential to support shared decision making, and facilitates communication with PwPs (Damman et al. 2019).

The use of PDQ-39 was seen as valuable by four HCPs (a neurologist, a physical therapist, an occupational therapist, and a speech and language pathologist) in another qualitative interview study conducted in the USA (Neff et al.2018). Using the paper-based form of the PDQ-39 was found to have the potential to focus the consultation on the symptoms of most concern to the PwP, and it was successfully integrated within a busy neurological clinic (Neff et al. 2018). Employing a digital tool to facilitate the utilisation of PD-specific PROMs within clinical practice was also suggested in this study (Neff et al. 2018). These studies were conducted in the Netherlands (Damman et al. 2019) and the USA (Neff et al. 2018), so the perceptions may be different in other regions of the world, which limits the generalisability of the findings of these studies.

Chapter 5   **Perceptions of HCPs on the use of e-PROMs app in PD clinical settings**

Only one study was found that highlighted the implementation processes of a web form of the ICHOM PD standard set (e-PROMs) in a PD clinic operated by a PDNS (Arora et al. 2017). This study was conducted as a short-term project to identify the main factors that might affect the ICHOM standard set's long-term use, potential benefits, and any concerns (Arora et al. 2017). A small delay within the clinic was reported after piloting the ICHOM PD standard set within clinical practice because data collection happened outside the clinic time. The PDNSs may take a longer time to obtain data and act on it, which leads to a small delay between patients' clinic appointments (Arora et al. 2017). However, several benefits were also identified, including enhancement of the consultation's quality by focusing on the patients' needs and empowering PwPs by stimulating patient-clinician conversation and helping patients structure their thinking prior to their consultations (Arora et al. 2017).

According to the findings of the Arora et al. (2017) case study, for the e-PROMs tool to be effective in clinical practice, a number of factors need to be considered: e-PROMs must be easy to use, and there must be close collaboration with HCPs to ensure engagement of patients and HCPs for long-term use. It is also crucial to maintain IT support and engagement to resolve any practical issues with the system interface (Arora et al. 2017; O'Connell et al. 2018). Even though the use of the ICHOM PD standard set was shown to be feasible in clinical practice, this was only demonstrated in one health board in Wales, UK; as such, the findings may not be the same with different health boards. The findings from O'Connell et al.'s (2018) study show that implementing and using the e-PROMs tool on a national scale will take time due to the differences in the existing IT infrastructure across health boards in Wales.

Even though previous studies have shown that the majority of HCPs have positive perceptions of digital technology to support the use and collection of PROMs in routine clinical practice, several concerns have also been highlighted (Wu et al. 2016; Arora et al. 2017). Concerns about implementing e-PROMs in clinical practice were related to the quality of patient-clinician interactions, disruption of clinical workflow, IT problems and adequate support, and whether the outcomes' data would be clinically useful (Wu et al. 2016; Arora et al. 2017).

Chapter 5   **Perceptions of HCPs on the use of e-PROMs app in PD clinical settings**

While a range of individual studies have been conducted to evaluate the use of PD-specific PROMs in clinical practice (Arora et al. 2017; Neff et al. 2018; Damman et al. 2019), to date, there are no high-quality generalisable studies that definitively describe the perceived usefulness, benefits, and concerns of involving HCPs to facilitate the development and implementation of an electronic tool (e-PROMs) within clinical practice. For example, in Wu et al.'s (2016) study, 12 medical and radiation oncology clinicians were interviewed to evaluate the Patient-Viewpoint system, which is an electronic tool used to collect PROMs within oncology clinical practice. Despite the positive opinions about the system, the clinicians were concerned about the impact of incorporating it into their workflow. However, no further explanations were provided to support these findings (Wu et al. 2016).

Another semi-structured interview study involved five HCPs (internal medicine practitioner, general practitioner, a psychiatrist, and two nurse practitioners) in primary care settings to evaluate their perceptions of tablet-based personalised healthcare information exchange systems in clinical settings to support the clinical encounter (Patel et al. 2015). Four out of five HCPs expressed their willingness to incorporate the tablet system into their clinic. The tablet system had potential benefits to improve clinical workflow, patient health knowledge, PROMs collection, and patient-HCPs communication. However, HCPs expressed their concern about the privacy and security of data collected using the tablet-based system (Patel et al. 2015). Both above-mentioned studies were conducted in the USA and included a small sample size, which would affect the validity and generalisability of their findings in other geographical areas. Therefore, these studies should not be interpreted as representative of HCPs across specialties, clinics, or regions globally.

The findings of the early-phase study of an iPad-based app (e-PROMs app) that aimed to support PwPs in a clinical setting showed that the five HCPs involved (geriatricians and PDNSs) perceived the app positively and described the potential to improve patient care by using this app (Mohamed et al. 2016). The HCPs also revealed their concerns about the intervention, including the ability of PwPs to use the app without assistance and the additional workload on the clinical team and resources (Mohamed et al. 2016). However, a need and suggestion for

further exploration of HCPs' perceptions were also reported in this feasibility study and in Chapter 4 of this thesis.

Collectively, then, engaging HCPs in the development of an mHealth app intervention would provide an opportunity to identify, understand, and minimise the potential concerns regarding its implementation in a clinical setting, as well as being essential to the successful adoption and use of such intervention tools (Patel et al. 2015; Alhamid et al. 2016). In addition, HCPs may also have a vital role in encouraging the use of an e-PROMs tool for PwPs, as PwPs respect and trust HCPs' opinions as a source of information (Keating et al. 2004). Therefore, this study is intended to provide a general explanation of the opinions, beliefs, and concerns of HCPs regarding using an e-PROMs tool in PD clinics.

5.2 AIMS OF THIS STUDY

To date, no study has sought to explore the views and preferences of HCPs who are working in PD regarding the development of an mHealth tool, such as an iPad-based app, that aims to collect PD-specific PROMs before patients' clinical consultations.

- The primary aim of this study was to explore the views of staff working in PD regarding the use of mHealth technology and an iPad-based app to collect PD-specific PROMs prior to patients' consultations. This involved the exploration of:
    - Previous experiences of data collection processes in PD clinics;
    - The type of data used during consultations;
    - The perceived acceptability of the e-PROMs app; and
    - The potential advantages and disadvantages of, and facilitators and barriers to, iPad-based app use.
- A secondary aim of this study was to explore HCPs' views on the following:
    - For which type of patient (at a different stage of disease) and at what point of the consultation cycle they believe the e-PROMs app could be most useful.
    - Whether support might be needed for the use of an e-PROMs app in PD services, and their perceptions of training needs to use it.

5.3 METHODOLOGY

5.3.1 STUDY DESIGN

Given that the literature highlights a need for richer explanations and understanding of the perception and role of HCPs for the successful development, integration, and use of an e-PROMs tool within clinical practice, the management of PD requires the involvement of an MDT involving a wide range of HCPs. A mixed-methods approach was best suited to allow divergent views to be collected and analysed. According to Creswell and Plano Clark (2007, p. 5), a mixed-methods approach is:

> A research design with philosophical assumptions as well as methods of inquiry. As a methodology, it involves a philosophical assumption that guides the direction of collecting and analysing a mixture of quantitative and qualitative approaches in many phases of the research process. As a method, it focuses on collecting, analysing, and mixing both quantitative and qualitative approaches; in combination, it provides a better understanding of research problems than either approach alone. (Creswell and Plano Clark 2007)

Mixed-methods studies can be designed as convergent, sequential, explanatory, or sequential exploratory studies (Creswell 2015). In sequential research, the use of qualitative and quantitative approaches is conducted in phases. These depend on the research questions, so researchers would have the flexibility to choose either one to start with to best answer the research question and explain the findings. In the explanatory study, the researcher begins with quantitative methods and then uses qualitative methods to help explain the results in more depth. In contrast, in an exploratory design, the researcher first uses the qualitative method to explore the research problems. Then the findings of the first phase are used to conduct the second quantitative phase. In convergent design, however, the priority is to conduct and analyse both qualitative and quantitative approaches simultaneously to merge and compare the results of both approaches (Creswell 2015).

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The mixed-methods approach allows for further exploration of a topic by combining the strengths of the different methods to better understand the research questions and reduce the limitations and restrictions of undertaking a qualitative or quantitative method alone (Burke Johnson and Onwuegbuzie 2004).

This mixed-methods study was conducted in an explanatory sequential manner—Phase I, quantitative (cross-sectional questionnaire), followed by Phase II, qualitative (semi-structured interviews). This method allowed the data to be collected iteratively, and the findings from Phase I were used to inform Phase II. This enhanced understanding and in-depth exploration of the topic under research.

The first phase commenced with a self-complete questionnaire administered to PD health professionals to determine numerical and generalisable data related to respondents' reported previous use of PD-specific PROMs and anticipated future use of e-PROMs. Then, the findings from Phase I were used to inform Phase II, where qualitative, face-to-face, semi-structured interviews with a wide range of HCPs were used to explore their perceptions of PROMs and e-PROMs at PD clinics in more detail. A schematic diagram of the method used in this study is shown in Figure 5.1.

Phase I (cross-sectional questionnaire)

Study was approved by Cardiff School of Pharmacy and Pharmaceutical Sciences Research Ethics Committee.

Questionnaire adminstred to the PDNS who attend the PDNSA conference 2018.

Data was analysed using descriptive analysis, specifically frequency and percentage of response.

Phase II (semi-structured interviews)

Study was approved by both Cardiff School of Pharmacy and Pharmaceutical Sciences Research Ethics Committee and NHS ethical approval and R&D approval from each of the sites.

HCPS including geriatricians, neurologists, specialists pharmacists, physiotherapists, speech and language therapists, occupational therapists, and PDNS were recruited from three NHS sites; CVUHB, Aneurin Bevan University LHB, and ABMU. Participant information sheet with invitation letter to the study were provided to each participant.

Written informed consent obtained from all participants, face-face interview conducted using topic guide.

Interviews were audio-recorded then transcribed verbatim.

Data analyssis conducted via using of the Consolidated Framework for Implementation Research.

Figure 5.1: Study design overview for mixed-method explanatory study of perceptions of HCPs regarding the use of e-PROMs tool (Further details on operationalisation are provided in the following sections)

5.3.2   PHASE I CROSS-SECTIONAL QUESTIONNAIRE

5.3.2.1 SAMPLING CONSIDERATIONS, PARTICIPANTS, AND RECRUITMENT

To ensure that the data collected provided a broad view of the opinions and attitudes of the target population when administering questionnaires, convenience and purposive sampling were used. Convenience and purposive sampling are forms of non-probability sampling and were used to identify participants who were easily accessible and information-rich for the researcher (see Chapter 4, Section 4.3).

The intention was to administer the first phase questionnaire to a varied sample of HCPs, but this was not possible for several reasons. Initially, the researcher contacted several groups with PD staff members to help with questionnaire distribution, such as Parkinson's UK Excellence Network dataset, but no responses were obtained. A discussion between the research team (researcher and lead supervisors) and a local PD neurologist contact took place to discuss the recruitment options and targeting the PDNSs only. Based on the findings of Chapter 4, where the participants mentioned that they saw their PDNSs more often than other HCPs, as well as the views of the neurologist, it was agreed that the PDNSs would be the most appropriate group to target for this phase of the study. This is supported by other research, which suggests that PDNSs are the most accessible and reachable health professionals for PwPs in relation to the management of their PD (NICE 2017).

Despite being accessible to patients, PDNSs are still a relatively hard-to-reach research population. Based on the Parkinson's UK database, there are not enough Parkinson's nurse specialists employed in Wales (22 PDNSs are working in Wales), and they are widely spread geographically (UK Parkinson's Excellence Network Mailbox 2020). The Parkinson's Disease Nurse Specialists Association (PDNSA) conference runs annually and is an opportunity for specialist PDNSs and allied HCPs working in the field of PD management from across the UK to come together (PDNSA 2020). As such, it afforded the researcher ready and easy access to this hard-to-reach population.

As an added advantage, the research team agreed that the in-person distribution and collection of the questionnaire would be the best method to ensure enough responses, compared to the online distribution of the questionnaire, especially for such a hard-to-reach population. In 2013, a study conducted by Szolnoki and Hoffmann found that face-to-face surveys yielded the best results when compared to online and telephone surveys. As such, the conference provided the ideal opportunity to recruit participants for Phase I. The PDNSs who attended the PDNSA conference in November 2018 from across the UK were selected as potential participants for this phase of the study.

5.3.2.2 Questionnaire design

Design: The cross-sectional questionnaire was used to quantify the perceived usefulness and acceptance of using an e-PROMs tool within PD clinics in the first phase of this mixed-methods study. Creswell (2003) defined a survey as a quantitative type of research that yields a numeric description of the attitudes, trends, or views of a population by studying a sample of that population. According to De Vaus (2002), the questionnaire is the most common technique for data collection in the survey method (De Vaus 2002).

 A quick and easy self-complete questionnaire was designed to be administered to PDNSs across the UK. The questionnaire was designed to collect both quantitative and qualitative data to determine precise and numerical data related to PDNSs' perceptions of using the e-PROMs tool. This method was chosen to gain a good understanding of the PDNSs' opinions, which could then help inform the second phase of this study by enabling a deeper exploration of the findings to obtain the most valuable data possible (Creswell 2017). This was not intended as a formal, validated tool, but rather as an opportunity to lead the researcher towards a better understanding of the perceptions of e-PROMs use in PD clinical practice.

Development of initial draft: One of the main aims of this first phase was to explore the feasibility and acceptability of e-PROMs use among PDNSs. The questionnaire was designed to explore their perceptions. Collaboration between the research team (researcher and lead supervisors) and an undergraduate student from the School of Pharmacy and Pharmaceutical Sciences at Cardiff University (as part of her final year research project) took place to formulate

the questionnaire by using the findings from the previous study (see Chapter 4, Section 4), in addition to having a thorough understanding of the literature regarding the potential advantages and concerns about the integration of the e-PROMs tool in clinical practice (see Chapter 1, Section 3).

The questionnaire consisted of two sections (see Appendix 5.1) with 18 different questions, including open and closed questions, such as 'Yes' and 'No', and multiple choice questions to facilitate the ease of completion through the use of predominantly quantitative questions (Kumar 2014). In addition, as some of the questions were not exhaustive, free text boxes were provided to collect qualitative data and enable respondents to provide further comments they wished to make about PROMs and e-PROMs. The questionnaire was also designed to be short while still gathering the desired data, and was administered using both online and paper forms to help increase the response rate (Edwards et al. 2009).

The first section of the questionnaire included one question to determine the geographical area in which the respondents (PDNSs) worked. This was done to identify and distinguish the opinions of PDNSs working in the Wales area versus other geographic regions. Then, respondents were asked to indicate their reported use, frequency, advantages, and concerns towards PD-specific PROMs in practice (seven questions). This was done to identify and understand the current situation and perceptions of using the paper-based form of PROMs in practice. The second section comprised 10 questions related to digital collection and use of PROMs (e-PROMS). This section allowed respondents to report their perceptions of the potential benefits, concerns, and content, the best time and place to use the e-PROMs tool, and future interest in using such an intervention in practice. All questions were developed based on earlier findings (Chapter 4) or the wider literature. Additionally, the questionnaire gathered information to recruit potential participants for Phase II of this mixed-methods study, with those interested in participating in Phase II asked to provide contact details.

Review and piloting: Once the initial questionnaire was completed, it was reviewed by the full research team. It was then piloted by one of the PDNSs (who was working in the Wales area and was not planning to attend the PDNS Association conference). The PDNSs completed and

reviewed the questionnaire for general flow and face validity (Babbie, 2015), and advised that an estimate completion time of 5–10 minutes was reasonable based on the content. It was not possible to pilot a larger sample due to the relatively small size of the study population (a large pilot sample would have further reduced the final numbers eligible to complete the questionnaire) and the challenges in accessing PDNSs to participate in the pilot. No changes were necessitated after the review/pilot test, so the questionnaire used and distributed was unchanged. Unfortunately, it was not possible to conduct a Cronbach's alpha reliability test due to logistical challenges, such the restricted available time between obtaining ethical approval and the upcoming annual conference date. The final version was produced as both a paper copy and an identical electronic version to enable rapid completion of the questionnaire during the conference.

Other study paperwork: A concise and easy-to-read participant information sheet, including the purpose of this questionnaire and the targeted participants, was developed and provided to each participant prior to taking part (see Appendix 5.2). Consent for participation was implied when the PDNSs completed and returned the questionnaire to the researchers.

5.3.2.3 QUESTIONNAIRE ADMINISTRATION

As previously explained, recruitment occurred at the PDNSA annual conference. Permission was obtained from the association for the researcher(s) to be present to recruit for the study. During the coffee and lunch breaks of the conference, the attendees who were PDNSs were approached by the researchers, who explained the purpose of the questionnaire and handed them the PIS (see Appendix 5.2). The potential participants were invited to complete the questionnaire as either a paper or online version. At the very start of the day, the questionnaire was made available to attendees who wished to complete it at a more convenient time, returning it to the researchers at any point during the conference. The questionnaire was short, and after getting feedback from the research team and PDNSs, it took each participant approximately 5–10 minutes to complete.

5.3.2.4 Ethical considerations

Phase I of this mixed-methods study was approved by the Cardiff University School of Pharmacy and Pharmaceutical Sciences Ethics Committee (see Appendix 5.3). The participants were invited using the pre-approved participant information sheet, as explained above (see Appendix 5.2). Consent to complete the questionnaire was obtained verbally when the participants returned the completed questionnaire. The data were anonymous, and the participants were asked if they would be willing to take part in the following phase of this study, which would then be conducted across Wales by the main researcher. If they agreed, they were asked to provide their contact details at the end of the questionnaire. This identifiable information was dissociated from the survey and kept confidential, seen only by the research team.

5.3.2.5 Data handling

The data from the returned questionnaires were inputted into the IBM SPSS® statistics data editor version 25 [SPSS] for statistical analysis. To check the validity of the inputted data, a 10% sample was taken, and repeated until no error was found (Babbie 2015). If no response was made to the mandatory questions, the questionnaire was removed from the analysis. All returned questionnaires were anonymised, and a separate code was given for each response to questions that had multiple choices. There were no identified missing values to consider.

The qualitative written comments that were provided in the free text 'other-please specify' boxes of the questionnaire were input verbatim into Microsoft Excel 2013® version 15.0.5127.1000 (MS Excel). Then, the questionnaire code and the number of questions were written next to each comment for qualitative analysis.

5.3.2.6 Data analysis

The analysis of the questionnaire was conducted using two separate methods according to the nature of the data. The quantitative data were analysed using descriptive statistics. The data obtained from the questionnaire were a mix of nominal and ordinal non-parametric data, as the data did not fit normal distribution. It is essential to use and select the appropriate

statistical tests and exclude tests such as median, standard deviation, and percentile (Stevens 1946). Thus, percentage and frequency of responses were calculated for each question, and comparisons were made based on geographical location and the routine use of the PROMs tool by using Chi-square tests. Trends and differences in the data were observed and commented upon using the supporting qualitative data.

The qualitative data from the free format questions were coded and analysed using thematic analysis. A deductive approach was used to look for key themes that were expected to arise, as well as content analysis to enable quantitative inference in the data reported and presentation (Braun and Clarke 2006; Erlingsson and Brysiewicz 2017). In addition, a constant comparison between all questionnaire responses was undertaken to identify any new themes.

5.3.3 PHASE II QUALITATIVE METHOD

Informed by the consolidated framework for implementation research (CFIR) and the results from Phase I (the questionnaire), semi-structured face-to-face interviews were sequentially conducted with a wide range of HCPs to explore the feasibility and acceptability of using an e-PROMs tool and to determine the value of using it in PD clinical practice. This phase allowed further exploration of the findings from the questionnaire and other areas of interest.

A qualitative interview method was chosen for this phase of this mixed-methods study to allow the researcher to gain a more in-depth understanding of the topic from the perspective of the targeted individuals (Green and Thorogood 2013). Qualitative methods enable the exploration and description of more personal responses, experiences, or beliefs from individuals compared to quantitative methods (Babbie 2015). Interviews are defined as 'a method to gather descriptions of the life-world of the interviewee with respect to interpretation of the meaning of the described topic' (Kvale 1983, p. 174).

The interview allowed for flexible interaction between the researcher and HCPs, which led to the collection of rich and detailed data (Bryman 2008). In reality, HCPs' experiences and perceptions of using the e-PROMs tool in their clinical practice were unlikely to be similar and

exploring these differences would help in understanding and visualising their needs to develop a successful app to collect PROMs.

There are three ways to conduct an interview study: structured, semi-structured, and unstructured. The structured interview is a rigid structure in which a set of questions need to be defined in advance to help generate quantitative data (May 2001; Whiting 2008). The semi-structured interview is more flexible, where the interviewer follows a list of questions, but these can be changed to adapt to the data that emerges during the interview (Patton 2002). In contrast, in unstructured interviews, there is no order of questions—the interviewer relies on the interviewee to tell their story, and the interviewer just asks questions to clarify and explore specific situations in more detail (May 2001; Gillham 2005).

In-depth semi-structured interviews were chosen to give HCPs the freedom to describe their experiences or beliefs and any concerns that they felt were relevant in responding to a set of questions. They also gave the researcher the freedom to deviate from these questions to further explore any concerns raised (King et al. 2010). The researcher followed a set of steps introduced by Smith (1995) to distinguish the semi-structured interview from other types of interview (Smith 1995):

- Preparing a list of questions (topic guide);
- Establishing a relationship with the targeted interviewee;
- Asking questions in any order to follow the dialogue of the conversations with the interviewee; and
- Asking follow-up questions to further probe areas of interest raised during the interview.

Semi-structured interviews were conducted face-to-face. Although face-to-face interviews could have led to delays in agreeing on a convenient date and time with interviewees (HCPs), who needed to prioritise their patients, they helped the researcher gather both verbal and visual data that allowed thicker descriptions and interpretations (Opdenakker 2006). It also helped the researcher explore the similarities and differences of HCPs' perceptions in more depth than other methods (i.e., telephone interviews), understand their needs, ask for

clarification, and generate a consensus of suggestions for a future e-PROMs app (Kendall et al. 2009). The duration of telephone interviews is often shorter, which results in a lack of relationship between interviewer and interviewee (personal contact), which might lead to the collection of less detailed data. This in turn might affect the development of the report (Irvine 2011).

5.3.3.1 Consolidated framework for implementation research (CFIR)

As mentioned above, Phase II of this mixed-methods study was informed by the CFIR and the findings of the questionnaire. The CFIR is a conceptual framework that helps identify factors that might affect the effectiveness and implementation of a particular innovation. The CFIR consists of five main domains, which cover 39 constructs (Damschroder et al. 2009):

1. The **intervention characteristics** domain is related to the main aspects of interventions that might influence the successful use and implementation of an intervention and includes eight constructs.

2. The **outer settings** domain is related to the factors outside the organisation that might influence the implementation of an intervention and includes four constructs.

3. The **inner settings** domain is related to factors inside the organisation that might influence implementation and includes 14 constructs.

4. The **characteristic of the individual** domain is related to factors that explain the individuals' attitudes, actions, ability, and behaviours towards the intervention and includes five constructs.

5. The **process of implementation** domain is related to strategy features that might influence the effective implementation process and includes eight constructs.

The CFIR is a flexible framework that researchers can apply and tailor to any healthcare delivery intervention design and context being studied (Damschroder et al. 2009). Researchers can apply this framework at any stage of implementation to assess their interventions, for example, before, during, or after implementation (Kirk et al. 2015).

As previously discussed, this study's main aim was to explore the perceptions of different HCPs (PD MDT) regarding the use and implementation of an e-PROMs tool within PD clinical practice.

This could lead to the collection of different views, so a systematic approach was required. The CFIR framework was chosen to guide the collection and analysis of this study phase's data, as it provides a systematic structure and guidance for evaluating the implementation of a complex innovation in healthcare services. If used during the initial stages of implementation or pre-implementation, the CFIR can generate outcomes that could inform developers on improvements to the intervention's development and implementation. In addition, this framework promotes the consistent use of constructs, systematic analysis, and organisation of findings (Damschroder et al. 2009).

Since its publication in 2009, over 300 published articles have cited the CFIR framework (CFIR team centre 2021). Several studies have demonstrated the usefulness of the CFIR to guide implementation across numerous health services, such as internet patient-provider communication and PROMs use in palliative care (Varsi et al. 2015; Pinto et al. 2018).

5.3.3.2 Development of interview topic guide

The interview topic guide was developed to explore how PD-specific PROMs are used in clinical practice, the perceptions of HCPs towards the use of an e-PROMs tool, and the factors that might affect the implementation of e-PROMs. The findings from the questionnaire phase of this study (i.e., routine use of PROMs, potential advantages, and concerns) and the list of Damschroder's CFIR domains were used to develop the questions of the topic guide (see Appendix 5.4). Figure 5.2 shows how the CFIR framework provided guidance for developing the topic guide. Based on the relevance to the aims of this phase, the researcher tried to pre-identify the CFIR construct, as recommended by Damschroder et al. (2009). For this phase, the CFIR domains aligned with the following items: intervention characteristics (e-PROMs tool); outer setting (NHS Health Board); inner setting (HCPs' practice); individuals (HCPs and PwPs); and process (factors of developing and integrating the e-PROMs tool to the current service).

The researcher used all CFIR domains to develop the topic guide. The topic guide covered general questions about the routine use of PD-specific PROMs, perceived acceptability of the e-PROMs app, perceived advantages and disadvantages, factors that might affect its implementation in the PD clinic, useful app features, and HCPs' training needs in relation to

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the app. As described in Chapter 1, Section 1.10, the prototype iPad-based app was developed for use in the PD clinic, but the researcher could still collect and analyse any suggestions relating to home use if raised during the discussion. The same topic guide was used with all HCPs. Because the HCPs had varying specialities, they were first asked whether they had ever used PD-specific PROMs to confirm whether their participation in this study was relevant.

The topic guide was reviewed by the researcher's supervisors and piloted with two HCPs (neurologist and PDNS). Pilot interviews help a researcher to check the flow of the interviews, identify any need to redesign or reword the questions of the topic guide, determine the estimated time of the interviews, and familiarise themselves with the topic guide to help the interview flow more freely (Babbie 2015). The two pilot interviews ran smoothly and allowed the researcher to obtain the necessary data in relation to the participants' perceptions without any changes required. The results from these interviews were then included in the final analysis.

5.3.3.3 Sampling considerations, participants, and recruitment

The convenience and snowball sampling types of the purposive sampling strategy, in which participants are selected depending on the characteristics of the study's target populations, were used to allow for divergent views to emerge (Patton 2002). The purposive sampling method was used to invite the HCPs who were known to the research team (supervisors and researcher) to take part in the interviews, and to act as gatekeepers to aid the recruitment process of this study. This method helped to identify the hard-to-reach HCPs while giving them the autonomy and time they needed to decide whether to participate. Snowball sampling was used to facilitate access to a wider selection of HCPs, with participants recommending the study to other HCPs who met the study target population. The participants contacted other potential participants and passed the study information pack on to them (comprising the invitation letter, the participant information sheet, and the consent form), inviting them to contact the researcher if they were interested (Babbie 2015).

Chapter 5   Perceptions of HCPs on the use of e-PROMs app in PD clinical settings

HCPs were recruited from three different health boards across Wales (Cardiff and Vale University Health Board, Aneurin Bevan University Health Board, and Abertawe Bro Morgannwg University Health Board). The sample aimed to include geriatricians, neurologists, specialist pharmacists, physiotherapists, speech and language therapists, occupational therapists, and PDNSs who were currently working in PD/care of the elderly clinics in Wales.
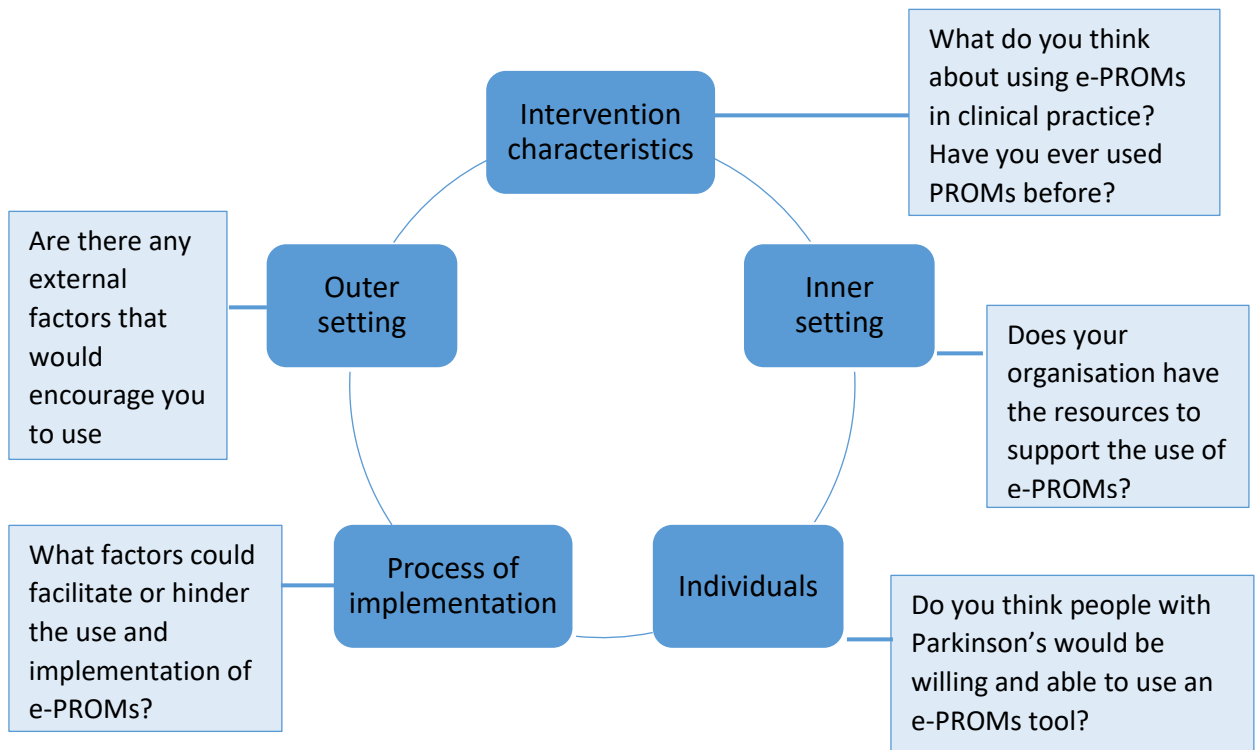
Figure 5.2: Approach to topic guide questions using CFIR domains

Recruitment into this phase utilised a combination of many approaches. Invitation emails were submitted to the previously known HCPs in each health board via the NHS Wales global email system with the information sheet attached (see Appendices 5.5 & 5.6). These explained the study aims and objectives, invited them to participate in the study, and discussed their anticipated role as gatekeepers. An agreement was reached once the interviews were conducted, after the HCPs had agreed on a suitable date, time, and place. The HCPs who

agreed to act as gatekeepers then introduced the study to further participants who met the study target criteria (i.e., working in PD/care of elderly clinics in Wales– PDNS/ neurologist/geriatrician) using the provided information pack (participant information sheet, invitation letter, and consent form). The interested HCPs were then encouraged to contact the researcher via telephone or email to arrange for the interview. All interested HCPs chose to contact the researcher directly by email, and almost all interviews were conducted at HCPs' clinics.

Before conducting the study, it was difficult to state the sample size, and the aim of the recruitment was to recruit HCPs until theoretical saturation had been achieved (i.e., when there was a strong repetition of data and themes) (Corbin and Strauss 2008).

5.3.3.4 Ethical considerations

This study phase was approved by the Cardiff University School of Pharmacy and Pharmaceutical Sciences Ethics Committee (see Appendix 5.8), and NHS ethical approval and research and development (R&D) approval from each of the sites was also granted (18/HCRW/0011, Appendixes 5.9). The participants were invited by using the pre-approved invitation letter and participant information sheet, as discussed above (see Appendices 5.6 and 5.7).

Each participant was asked to sign and date the pre-approved consent form at the beginning of the interview (see Appendix 5.10). The informed consent confirmed that the participant had read and understood the information sheet, that participation was voluntary, that they had agreed for the interviews to be audio recorded, and that anonymised quotations could be used in the researcher's thesis and publications. The recorded data and transcripts were stored in a secure cabinet in the Redwood Building at Cardiff University.

5.3.3.5 Data collection

Interviews were conducted at HCPs' clinics, which was convenient for them. To ensure that the flow of the interviews was not interrupted, they were conducted either at the beginning

or the end of the routine clinics (based on the interviewees' preference). This helped avoid distractions and ensured the high quality of the recordings (King et al. 2010).

At the interview, the researcher introduced herself, and briefly explained the purpose and structure of the interview and key topics to aid HCPs' understanding and make them feel more comfortable (Kvale 2007). It also gave the HCPs an opportunity to ask questions about the study. The HCPs were then provided with a consent form to sign and date (see Appendix 5.10). The researcher explained that the interview was confidential and that only the research team (researcher and lead supervisors) would have access to the data. The researcher also explained how the collected data would be anonymised, stored securely, and retained for one year at Cardiff University. After the necessary permission was obtained, the interviews were started, and audio recordings began.

A reputable transcription company was used to help the researcher transcribe half of the interview audio files, which were sent electronically by uploading the files to a secure server used by the transcription company. The rest of the interview audio files were transcribed by the researcher. As described in Chapter 4, the audio files were transcribed verbatim, but any information that could identify HCPs in the transcripts was anonymised (see example in Appendix 5.11). The researcher checked that the transcription company had a confidentiality agreement and was approved by Cardiff University to ensure that HCPs' information and interview data were protected. Once the transcription had been completed, the transcripts were sent to the researcher. To check their accuracy, the researcher listened to the audio recordings while reading the transcripts. This also helped the researcher become more immersed in the data.

5.3.3.6 Data management

In accordance with the Data Protection Act 1998, all the transcripts and audio files were securely stored on a Cardiff University password protected server. In accordance with Cardiff University research data policies, all consent forms, transcripts, and audio files will be kept securely for one year, after which they will be deleted.

5.3.3.7 Data analysis

To ensure that adequate data were collected for analysis, the HCPs were interviewed until data saturation was reached. Data saturation occurred when no new data or themes were raised for at least the final three interviews (Francis et al. 2010). Data were analysed using the framework analysis approach (Srivastava and Thomson 2009) to guide the relevance of the CFIR domains. The framework analysis allowed the researcher flexibility to conduct the analysis alongside the data collection process so that the analysis was started as soon as the first interview was conducted, and it continued concurrently with the data collection process. Content analysis was also used to make sense of the meanings in the data and to analyse the texts within its context (Erlingsson and Brysiewicz 2017). The CFIR informed the framework analysis of the data. The framework analysis was done in five steps, as recommended by Ritchie and Spencer (1994) and Warner et al. (2018).

- Familiarisation: The researcher read the transcripts several times to familiarise herself with the collected data, ensure awareness of the key ideas and recurrent data, and take note of them.
- Thematic framework: A template of codes was developed using the notes from the familiarisation step. The software package NVivo (NVivo 11) was used to help create the coding tree.
- Indexing: The identified codes were then systematically applied to all transcripts.
- Charting: The transcripts were charted into themes and organised by CFIR domains using an MS Word document.
- Mapping and interpretation: This step helped to interpret the data as a whole, as explained in the results section.

All the transcripts were analysed by the researcher, and the codes and themes were reviewed several times to reduce potential biases and facilitate interpretation of the findings. The quality of the analysis was then reviewed and checked by the researcher's supervisors. An example of the developed themes is shown in Table 5.1 as an illustration (full results are shown and explained in Section 5.4).

Table 5.1: An example of analysis leading to themes and corresponding CFIR domains

Codes	Themes	CFIR Domains
Guide consultation, improve communication, prioritise clinic list	Potential advantages	Intervention (e-PROMs/PROMs)
Culture, depends on individual service	Teamwork	Inner setting
Additional staff required/ No money	Resources	Outer setting
Great fan of PROMs/ It is good to use if I have the time	Attitude towards PROMs	Individual (HCP/Patients)
Make it accessible across the board, privacy in the waiting room	Consideration for implementation	Process of implementation

5.4 RESULTS

The results are presented in two phases: (i) first phase—quantitative analysis (questionnaire) and (ii) second phase—qualitative analysis (semi-structured interviews).

5.4.1 Phase I – Questionnaire to determine the perception of PDNSs on the utility of technology to collect PD-specific PROMs

In this phase, as mentioned in Section 5.3.2, the questionnaire was designed to collect both quantitative and qualitative data to allow a deep understanding of PDNSs' perceptions. Even though there was very little qualitative data (from the free text comments) analysis, the researcher included it to provide some context and help understand participants' responses.

5.4.1.1 Response rate

Of a potential participant pool of 90 conference attendees, 67 questionnaires were returned. Of these, two were excluded, and 65 were included in the analysis, providing an overall response rate of 72.2%. Of these, 94% (n= 61/65) of participants were from England and 9% (n=6/65) from Wales. Commentary on the response rates in relation to nationality and presenting data in regard to the Wales area are provided in Section 5.5.

5.4.1.2 PROMs

Regarding the previous use of the PD-specific PROMs, 76.9% (n = 50/65) of participants had used some form of PROMs previously (78 % (n = 46/59) of England-based vs 67% (n = 4/6) of Wales-based respondents). Among the 76.9% of participants who had used PROMs, only 50.8% (n = 33/65) had used them in their routine clinics (England 29/59, Wales 4/6). Those who had routinely collected PROMs indicated how often they used them by choosing from four different time scales, as shown in Figure 5.3.
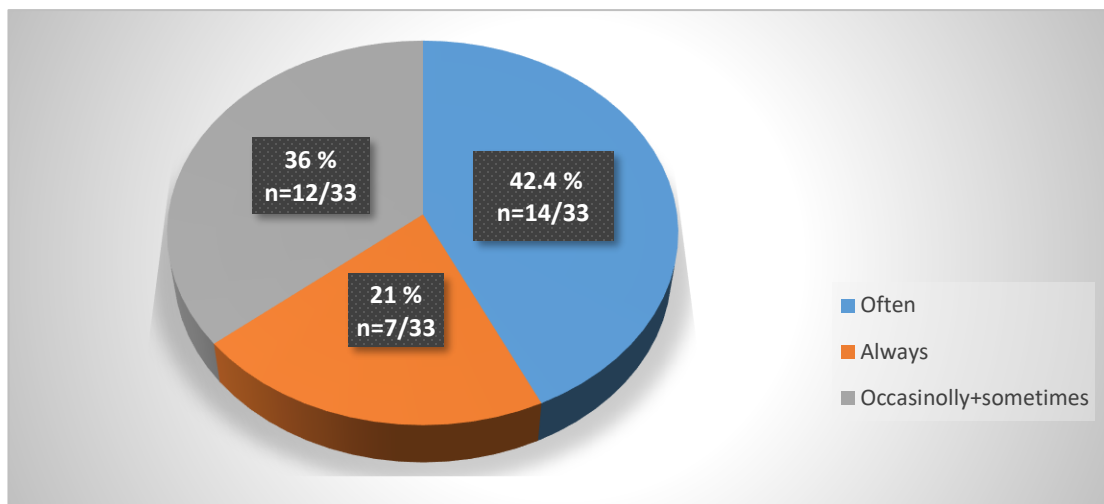
Figure 5.3: Pie chart showing the questionnaire responses of the PDNSs on their reported frequency of routine PROMs collection within clinical practice. *The values of occasionally (12%, n = 4/33) and sometimes (24%, n = 8/33) were combined since the meanings of the two words are quite similar

Among those who had used PD-specific PROMs previously, the UPDRs were the most used, and the SCOPA-AUT was the least used, with 86% of participants using more than one type of PROMs scale. Table 5.2 shows the type of PROMs and the corresponding frequency and percentage. Table 5.3 shows the type of PD-specific PROMs among those who routinely used PROMs and the corresponding frequency and percentage. In addition, participants reported the use of other types of PROMs that were not PD specific and were not included in the possible answers to this question. These were the MOCA (n = 2), Beck's depression scale (n =

1), the QUIP scale (n = 1), GDS (n = 1), ICD (n = 1), the Falls scale (n = 1), and the hospital

admission scale (n = 1).

Table 5.2: Types of PD-specific PROMs previously used by respondents, shown as corresponding frequency and percentage (n = 50)

	PROMs	N	Percent
	Used UPDRS	40	80 %
	Used PDQ-39	30	60 %
	Used NMSS	29	58 %
	Used HY Scale	23	46 %
	Used NMS Quest	20	40 %
	Used PDQ-8	18	36 %
	Other	8	16 %
	Used SCOPA-AUT	2	4 %

Table 5.3: Types of PD-specific PROMs used **routinely,** shown as corresponding frequency and percentage (n = 33)

	PROMs	N	Percent of 'yes' answers to routine use of PROMs question (n= 33)
	Routinely used UPDRS	25	76 %
	Routinely usedPDQ-39	20	61 %
	Routinely used NMSS	20	61 %
	Routinely used HY Scale	17	52 %
	Routinely used NMS Quest	17	52 %
	Routinely usedPDQ-8	12	36 %
	Routinely used Other	6	18 %
	Routinely used SCOPA-AUT	1	3 %

The PDNSs were asked about the types of PROMs scales that they thought needed to be used routinely during the clinical consultation. Almost all PDNSs identified PROMs scales that related to nonmotor symptoms (91%, n = 59/65) as a necessity during clinic consultation. The other suggested PROMs scales were selected to varying degrees by the respondents: 80% (n = 52/65) agreed that scales related to motor symptoms should be routinely used; the values for the other two given options were cognition (74%, n = 48/65) and psychosis (57%, n = 37/65). In addition, some respondents added 'other 'options of scales that were important to be

collected routinely. These were related to driving test (n = 3), depression (n = 2), sleep (n = 1), quality of life (n = 1), and carer burden (n = 1).

Overall, 78.5% (n = 51/65) of the participants indicated that PD-specific PROMs were an acceptable approach in measuring the patient's perception of their own health, and only 3.1% (n = 2/65) thought they were not, while 18.5% (n = 12/65) remained unsure). There was no relationship between the PDNSs who used PROMs in their routine clinics and those who did not use them as to whether they thought it was an acceptable approach (p = 0.781).

In addition, 86.2% (n = 56/65) of the participants thought that the PD-specific PROMs would be beneficial for PwPs, only 1.5% (n = 1/65) thought they were not, and 12.3% (n = 8/65) remained unsure. Again, there was no relationship between the PDNSs who had routinely used PROMs and those who had not as to whether they thought they were beneficial for PwPs (p = 0.413). Further explanations were provided by participants, and they mentioned several potential advantages of using PROMs, such as providing a good starting point for conversations with the HCPs (n = 12), encouraging patients to open up and discuss their symptoms (n = 10), helping patients focus during consultation (n = 11), providing useful tools to monitor outcomes and identify unmet needs at an individual and service level (n = 8), providing standardised outcomes to identify issues and respond proactively (n = 11), and enabling comparisons to be made at later reviews (n = 11). The respondents also thought that using PROMs could provide an easy and structured approach to understanding the individual patient's needs and concerns, as each patient will view their condition differently (n = 12). It could also help HCPs discover what concerns the patients the most and allow them to tailor the consultation towards this (n = 10). However, PDNSs expressed concern that it could add extra work for them (n = 10). Further explorations of the potential advantages and concerns will be discussed in Phase II of this section.

5.4.1.3 e-PROMS

The PDNs were asked to indicate, using a tick box, their perceptions, and potential advantages of collecting the PROMs data digitally. Figure 5.4 shows the potential advantages of e-PROMs

and the corresponding frequency and percentage. In addition, participants mentioned other potential advantages of using the e-PROMs tool, such as it being more beneficial for research and complex therapies (e.g., Duodopa®, deep brain stimulation, and apomorphine) (n = 15), and the benefits of going paperless for medical records (n = 10).
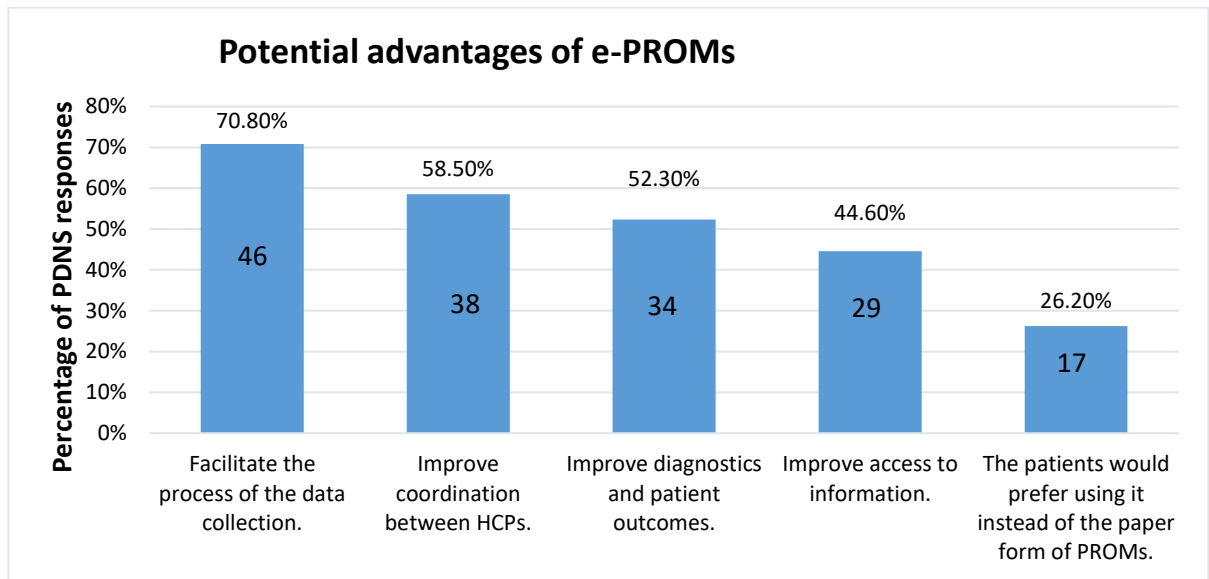
Figure 5.4: Potential advantages of e-PROMs and the corresponding frequency percentage (n = 65)

However, several concerns were also highlighted by some of the participants. These included increased workload, negative impact on clinics' workflow (e.g., delayed clinics and clinics overrun), lack of IT infrastructure (e.g., no EHR system at the clinics), extra time requirements, and the difficulty of data collection. Figure 5.5 shows the potential concerns regarding the use of e-PROMs and the corresponding percentage. Other concerns were also reported by participants, including the security of the collected data and possible data breaches (n = 8), patients' age (n = 10), and patients' dexterity issues (n = 14).
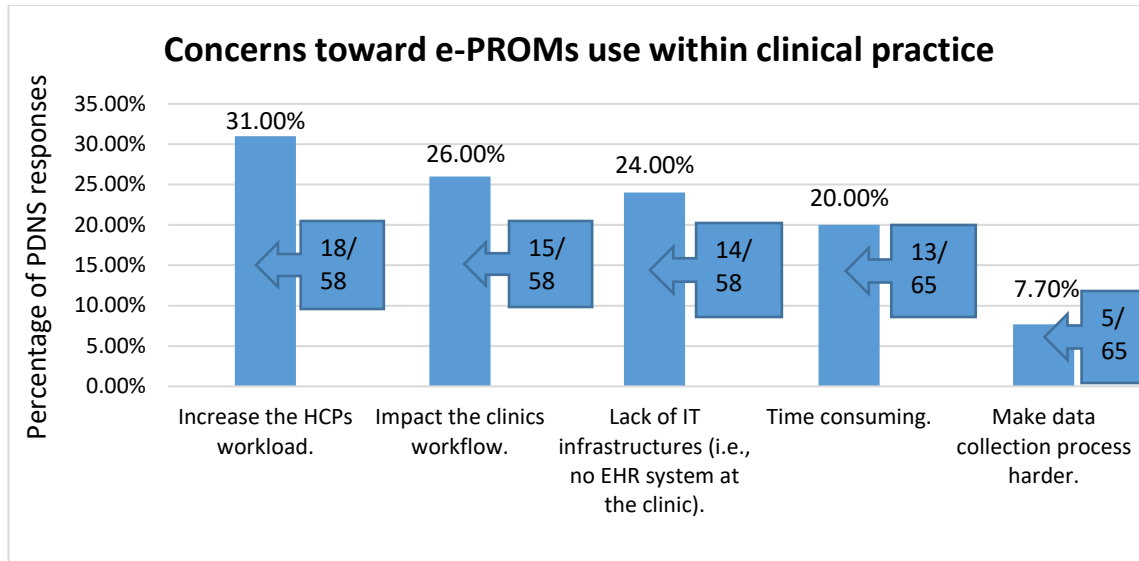
Figure 5.5: Potential concerns about using e-PROMs and the corresponding frequency and percentage

The participants mentioned other barriers that could prevent patients from using the technology to input their data, such as dexterity issues, privacy issues, and IT-illiterate patients needing training. There was an equal percentage of participants whose concerns would and would not prevent them from using the e-PROMs (36.9%, n = 24/65 each) and around a quarter (26.2%, n = 17/65) who were unsure. A slightly higher number of participants (n = 14) who did not routinely collect PROMs were more concerned about using e-PROMs than those who did (n = 10).

In total, 58.5% (n = 38/65) of participants thought that the use of e-PROMs would have a positive impact on communication between the patients (improve communication) and HCPs, 13.8% (n = 9/65) did not think it would have an impact, and 27.7% (n = 18/65) were unsure. Twice as many participants who did not routinely use PROMs thought that e-PROMs would not influence communication between patients and HCPs (n = 15), compared to those who did routinely use PROMs (n = 32). Further explanations were provided by the participants regarding how the e-PROMs would affect communication, such as promoting discussion (n = 8), providing a platform for further exploration of symptoms (n = 10), reducing the repetition of data (n = 15), and enabling a more seamless service (n = 11). However, not all the

participants thought that the e-PROMs would have a positive impact on communication, believing HCPs would be too busy looking at a screen to look at the patient, and it would be time consuming and detract from consultation time (n = 5).

Participants believed that the e-PROMs would be beneficial for all members of the PD MDT, as well as the PDNSs (97%, n = 63/65), including physiotherapists (88%, n = 57/65), occupational therapists (88%, n = 57/65), speech and language therapists (85%, n = 55/65), and specialist doctors (79%, n = 51/65). Participants mentioned other clinicians not in the MDT who would benefit from using e-PROMs, such as dieticians (n = 6), the mental health team (n = 10), and the psychology and psychiatry teams (n = 10).

The e-PROMs tool was initially developed to be used in clinical settings, while patients are waiting for their appointment. Some of the participants in Chapter 4 reported suggestions for at-home use of the intervention, so it seemed essential to explore PDNSs' perceptions of this. A total of 55.4% (n = 36/65) of participants suggested that the data be collected before the patients came for their appointment, while 40.0% (n = 26/65) preferred while the patients were waiting for their appointment. Other suggestions included during the consultation or whatever worked best for the patient on an individual basis. Participants who chose the option of completion before the patient's appointment were asked to state a time frame. Responses varied from a few days to three weeks prior to the appointment, as shown in Figure 5.6.
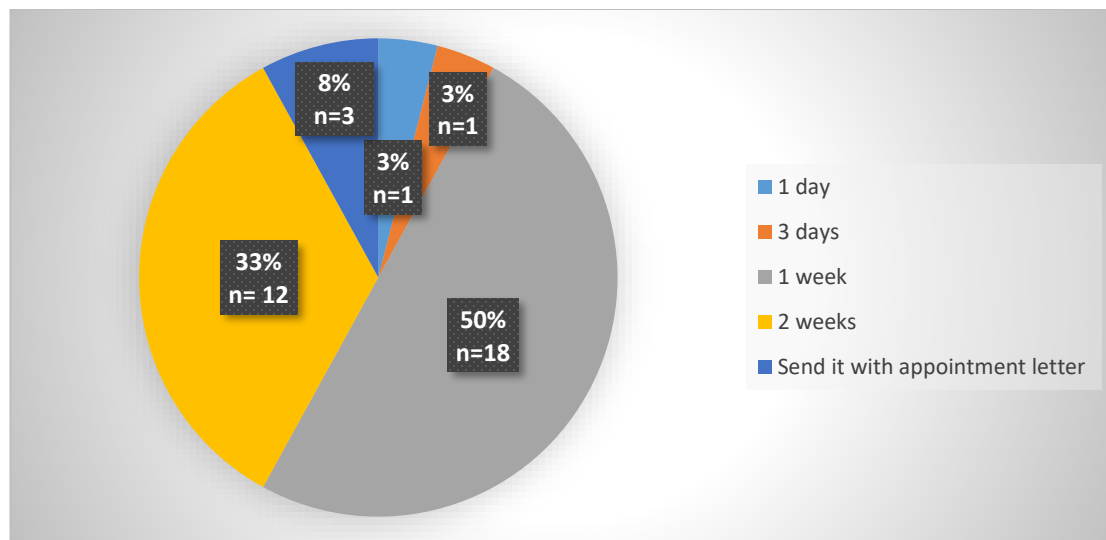
Figure 5.6: The most effective time to collect e-PROMs during the consultation cycle according to the PDNSs' perceptions (days/ weeks; prior to the consultation) (n = 36)

Regarding the required training for HCPs and patients on using e-PROMs, 86.2% (n = 56/65) of participants thought that HCPs would need training on how to use e-PROMs, 9.2% (n = 6/65) thought training was not required, and 4.6% (n = 3/65) remained unsure. There was a slightly lower percentage of participants who considered training essential for PwPs (81.5%, n = 53/65), 6.2% (n = 4/65) did not, and 12.3% (n = 8/65) were unsure. The participants chose the appropriate methods to provide training for both patients and HCPs with suggestions for other methods, such as clear verbal instructions, as shown in Figure 5.7.
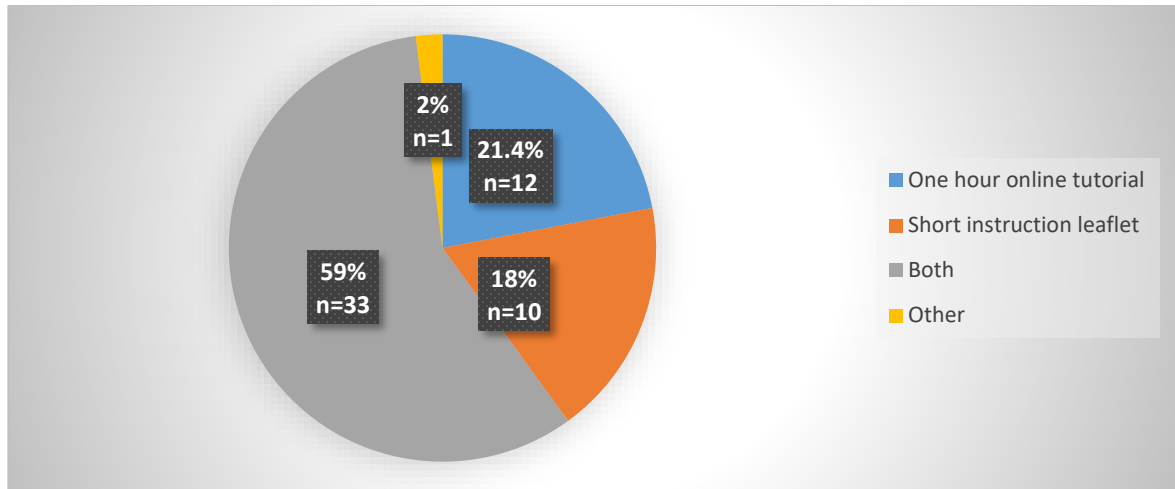
Figure 5.7: The response of PNDS to the proposed methods for appropriate training for HCPs with corresponding percentages (n = 56)

Of all respondents, 76.9% (n = 50/65) were interested in using e-PROMs tool in their routine practice, 3.1% (n = 2/65) were not, and 20% (n = 13/65) were unsure (England 46/59, Wales 4/6).

5.4.2   Phase II – Semi-structured interviews exploring HCPs' perceptions of e-PROMs in PD clinics

This section describes the results of the qualitative interviews with HCPs. Interviews aimed to explore and better understand how PD-specific PROMs were used in PD clinics and identify key considerations for future development and implementation of the tool. Some of the identified themes and subthemes were discussed more extensively during the interviews than others, which may explain the unequal representation of the narrative of these themes. This was also to present sufficient depth and detail that conveyed the richness and complexity of the collected data.

As mentioned in Chapter 2, Section 2.3, to gain an understanding of the findings, some of the qualitative data were described and presented using quantitative inferences, such as 'the majority' and 'a few' (Maxwell 2010; Monrouxe and Rees 2020).

5.4.2.1 Participants

In this study, 16 HCPs (three through direct contact and 13 through snowball sampling) were interviewed between January 2019 and April 2019. At this point, it was determined that the sample represented different specialities with strong repetition of data and themes and that the study aims had been achieved (Bowen 2008; King and Horrocks 2010; Malterud et al. 2015). All HCPs chose to be interviewed in their clinics at three different NHS sites: (i) Cardiff and Vale University Health Board (UHB) (n = 9), (ii) Abertawe Bro Morgannwg UHB (n = 2), and (iii) Aneurin Bevan UHB (n = 5) (see Table 5.4). In order to maintain anonymity, the location of each HCP was excluded. The average duration of the interviews was 30 minutes (range: 15–44 minutes).

Table 5.4: Sample characteristics of HCPs

Participant ID	Occupation	Clinics
C1 (Neuro)	Neurologist	Movement disorder
C2 (Nurse)	PD nurse specialists	Care of elderly
C3 (Geria)	Geriatrician	Care of elderly/PD clinics
C4 (Physio)	Physiotherapists	Care of elderly
C5 (nurse)	PD nurse specialists	Care of elderly
C6 (Physio)	Physiotherapists	Education programme for PwPs
C7 (Nurse)	PD nurse specialists	Care of elderly/PD clinics
C8 (Neuro)	Neurologist	Movement disorder
C9 (Geria)	Geriatrician	Care of elderly/movement disorder
C10 (Nurse)	PD nurse specialists	Care of elderly/ movement disorder
C11 (Nurse)	PD nurse specialists	Care of elderly/PD clinics
C12 (Pharma)	PD specialist pharmacists	Care of elderly/ PD clinics
C13 (Geria)	Geriatrician	Care of elderly/PD clinics
C14 (OT)	Occupational therapists	Parkinson's day programme
C15 (S&LT)	Language and speech therapists	Private clinics
C16 (Geria)	Geriatrician	Care of elderly/movement disorder

5.4.2.2 Interview findings

The findings are presented according to the five CFIR domains: (i) intervention characteristics (PROMs/e-PROMs), (ii) outer setting, (iii) inner setting, (iv) individuals (HCPs/PwPs), and (v) implementation (see Figure 5.8), with no distinct differences between HCPs. Main themes and

subthemes will be discussed in more detail under each domain below. HCPs are identified with 'C' followed by their identification numbers and abbreviations of occupations, as listed in Table 5.4 (e.g., C1 (Neuro) is Clinician 1, neurologist).
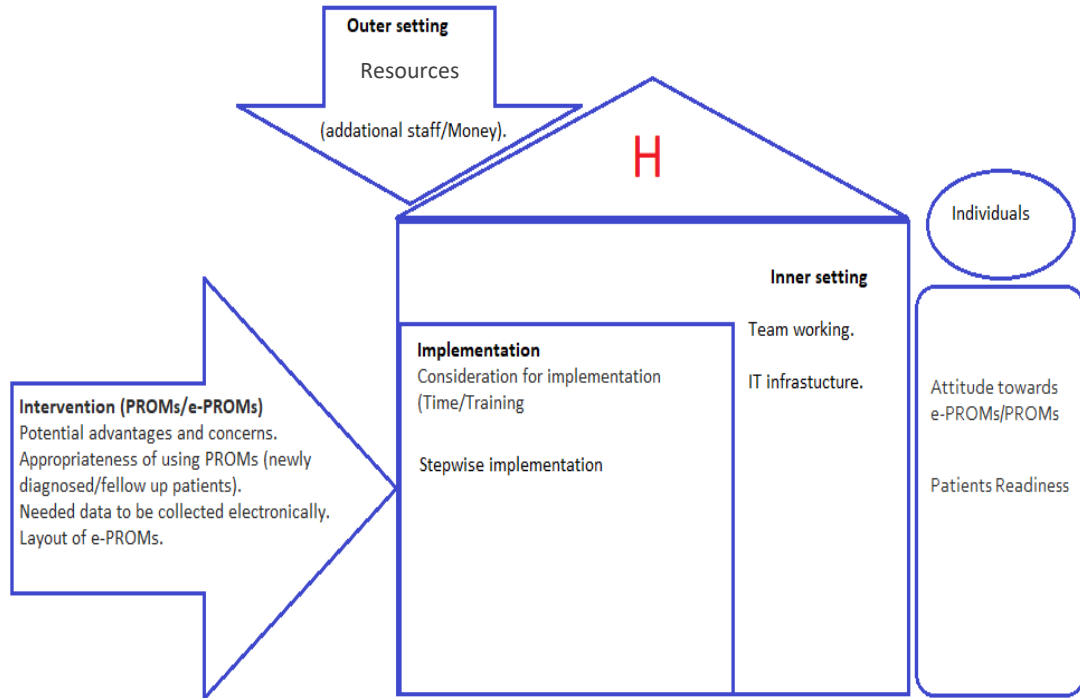
Figure 5.8: Main themes and subthemes based on the CFIR domains

1.   Intervention characteristics

This theme reflects the views of HCPs on PD-specific PROMs and the e-PROMs tool as an intervention to aid consultations with PwPs. Although this domain involves eight constructs (intervention source, evidence strength and quality, relative advantage, adaptability, trialability, complexity, design quality and packaging, and cost of the intervention; (Damschroder et al. 2009), the findings of this study align with just five of these constructs. Included were (1) intervention source (previous use of PROMs/ perceptions of HCPs about the intervention), (2) relative advantages (HCPs' perceived advantages of using the intervention), (3) complexity (concerns or perceived difficulties of the intervention), (4) adaptability (HCPs' perceptions of how the intervention can be adapted to fit the clinic needs (appropriateness of

using e-PROMS)), and (5) design (content of the e-PROMs tool and suggestions for the necessary data collection and layout of the e-PROMs tool).

1.1 Previous use of PD-specific PROMs: It was evident from the data that the majority of HCPs had previously used some sort of PD-specific PROMs in their clinical practice. The physiotherapists had used PROMs frequently, as the nature of their jobs required them to do so.

> *We do two programmes, and each of those we do assessments at the beginning, assessments at the end, with lots of PROMs and physical outcome measures. So those run fairly continuously. C6 (Physio)*

The other allied health therapists, including occupational therapists and speech and language therapists, reported that they used PROMs more frequently, but they did this by asking the PROMs questions during routine encounters with PwPs rather than collecting the data in advance. The pre-clinical use of PROMs/e-PROMs might adversely affect encounters with PwPs.

> *For us as speech therapists, part of collecting the data [PROMs data] is an opportunity to informally assess their communication [via asking these questions]. So, the way that they answer the questions will give us information about maybe their cognitive skills, their understanding, and their word finding. C15 (S&LT)*

The rest of the HCPs, including neurologists, geriatricians, and PDNSs, reported using PROMs occasionally. They provided further explanations regarding how and when they used PD-specific PROMs in their clinical practice for a range of reasons.

If their consultations with PwPs led them to use the PROMs:

> *I would use them really if I thought the consultation was heading in the direction where I thought they may be useful. I cannot see the merit in routinely collecting [PROMs] on everybody. C9 (Geria)*

If they had a patient with a complex PD condition (e.g., dementia or severe motor symptoms):

We have used NMSQuest in complex clinic patients when the patients are waiting, but in routine follow-up patients, we do not actually use PROMs. C3 (Geria)

If they were doing a research project:

Not routinely—if we are doing specific projects, sometimes we have medical students; they might be taking [PROMs] scales from patients. C9 (Geria)

Furthermore, some PDNSs and neurologists mentioned using PROMs in their clinical practice at least once a year to obtain a baseline assessment of their patients:

I generally do [a lot of PROMs] for cognitive, driving, Epworth sleep scale, MOCA, and anxiety bed depression scale on everybody at least once a year, but always at baseline and then follow up once a year. C10 (Nurse)

Another participant said:

Once a year, we do a full UPDRS, so sections one to four. So, they will have one appointment when we do that and one appointment when we do not. C1 (Neuro)

Only one of the PDNSs mentioned using PROMs routinely in her clinical practice:

Over the last few years, we have used PROMs, which are collected before they come in with me [while they were waiting for the appointment], and then I will have an electronic screening of that. C7 (Nurse)

Furthermore, most HCPs reported that they would prefer to use an electronic tool to support the collection of PROMs than the paper-based form. Participants felt that the electronic tool would improve the collection and storage process of the PROMs and provide them with easy access to the data.

I would prefer it [PROMs] in electronic form. If it is iPad or a tablet that just can be held to tick it when they are waiting, and it can be then transferred electronically to our database, that is far better than a paper trail. The problem with the paper trail to stay with the notes, we do not store the notes. The notes go everywhere for that patient,

wherever the patent goes in the hospital, so we may not have access to those questionnaires at the time. If it is electronically collected and stored, and we see the patient two weeks later, two months later, phone us up or have a telephone query, then we can look at it straight away. C3 (Geria)

Other participants further discussed their preference for electronic forms of PROMs by explaining the current working system at their clinics.

Most of the [PROMs] records at the moment are paper-based, but I think if it can be done digitally, that is easier in terms of storage and being able to access the data. C15 (S&LT)

1.2 Potential advantages: The HCPs anticipated several potential advantages of using PROMs/e-PROMs within clinical practice, emphasising the need to use them to aid the consultation and not to replace the actual clinical consultation with patients. Table 5.5 summarises the most commonly anticipated advantages mentioned by HCPs.

Table 5.5: Advantages of using PROMs/e-PROMs, as reported by HCPs

Advantages	Neuro	Geria	PDNS	Pharma	Physio	OT	S&LT
Better understanding of patients' symptoms/ Guide and plan consultations	✓	✓	✓	✓	✓	✓	✓
Prioritise clinic waiting list*	✓	✓	✓	✗	✗	✗	✗
Aiding and empowering PwPs	✓	✓	✓	✓	✓	✓	✗
Improve communication/ collaboration between MDT	✓	✓	✓	✓	✓	✓	✓
Improve health services	✓	✓	✓	✓	✓	✗	✓
Good for research purpose	✓	✓	✓	✓	✗	✗	✗

***** Prioritising PwPs on waiting lists for clinical appointments based on their current condition

1.2.1 Better understanding of patients' symptoms/Guide and plan consultations: There was agreement among all HCPs on using PD-specific PROMs/e-PROMs before the patients' clinic visits as a way to help them better understand the patients' symptoms, focus patients on their main problems, and highlight the main issue during the clinical visit.

> *I get the nonmotor score [nonmotor questionnaire] before they come into clinic, so I always have a look through that; it does give me an opportunity to say, 'Well, you've scored' or 'You've said here that there's X problems, there's some neuro problems or something like this. Tell me a bit about that in a bit more detail. C1 (Neuro)*

Another participant said that the PROMs/e-PROMs use would help to focus the consultation on the symptoms that most concern the patients.

> *That is really important because sometimes that comes out right at the end of the consultation [main concerning symptoms], and if you knew that up front, then that might change your diagnosis. C12 (Pharma)*

HCPs also mentioned that using a PROMs/e-PROMs tool could help track the progress of the disease.

> *It is a comparison to see how people are, so if they have deteriorated, it can identify particular functional difficulties that you can focus on. So, it is a way of monitoring any change really. C4 (Physio)*

Another participant said:

> *I think it is far more meaningful to be able to put what it is and what it was last year. So, you can see whether they are stable or not. C10 (Nurse)*

In addition, HCPs suggested that using the PROMs/e-PROMs tool could guide consultation with patients. They thought having further information about their patients in advance could help them organise the consultation based on the patients' needs.

> *We have talked all the way along from the beginning about ranking things, about saying this is important or this is unimportant, to try and get an idea about actually what the patient wants to talk about. The advantage of it is that you have covered a lot of the information before they come in. C8 (Neuro)*

The allied HCPs also suggested that using the PROMs/e-PROMs could help them during the preparation and organisation of the patient group sessions.

> *It basically helps us collect a baseline of information to then go on and decide what interventions we need to carry out to help them. C14 (OT)*

Additionally, some of the HCPs expected that using PROMs/e-PROMs could aid their decision making and patient management plan during the consultation.

> *Part of the management plan is trying to work out (a) what the problem is and (b) is there any therapy we are able to offer. So, in that sense, yes, of course, it guides onward management. I think the questionnaire by itself is not enough, but the questionnaire in the context of the clinical environment is useful to be able to plan the management strategy. C1 (Neuro)*

1.2.2 Prioritise clinic waiting list: A minority of HCPs (4) suggested that using PROMs/e-PROMs could help solve the issue of long clinic waiting lists, which would enable them to prioritise PwPs according to their disease status. However, this might require using the intervention in different settings outside clinical practice (i.e., at home) in order to utilise the collected data to prioritise clinic waiting lists.

It allows us to identify patients with low need who could perhaps say, 'Actually, I do not need to be seen this time,' or that they may just be happy with a telephone call or a Skype call. So, it opens lots of other avenues [for] working. C8 (Neuro)

Another participant provided a further explanation by giving an example of a new web programme they had started to pilot at their clinics called Patient Knows Best (PKB).

You can communicate with patients, so it reduces the burden in terms of phone calls and things through the PDNSs. There are certain patients, a very small number, who are very stable. The younger type of patient can communicate with PKB without coming to the clinic. So those are the advantages of PKB, but at the moment, we are still evaluating it. C3 (Geria)

In contrast, the majority of the HCPs were unsure how using PROMs/e-PROMs could, in practical terms, help with prioritising the clinic list because this would require time to utilise the data in making decisions, rather than simply seeing patients when their appointment time came around.

I am not so sure about that because at any point in time we have got about 70, 80, 100 patients on our waiting list. So, I cannot see how I would look at PROMs and then prioritise my waiting list. C13 (Geria)

Some participants were unsure and suggested piloting it first to see its actual impact in a real setting.

It is unlikely to do that, but if somebody is very stable, it is still difficult. I have not used them [PROMs/e-PROMs], so I could not tell you whether I might use it to delay a consultation or an appointment for the patient because they are so stable. I do not know; I would have to use it first to say that. C16 (Geria)

1.2.3 Aiding and empowering PwPs: HCPs explained how using PROMs/e-PROMs might empower patients during the consultation. HCPs anticipated that using PROMs/e-PROMs could help patients focus, remember their main issue, and relate it to the PD.

Could it focus the person on thinking before they get in [to the clinic] that this is a Parkinson's appointment, although there is a plethora of symptoms for Parkinson's? Are they motor or nonmotor? Are they psychological symptoms? Because a lot of people do not see their psychological or the nonmotor symptoms; they think of the motor symptoms. C11 (Nurse)

They also anticipated that using PROMs/e-PROMs could give patients a voice and enable them to speak during consultations.

I think they are useful to a certain extent, especially for those who do not tend to have a voice as much. Obviously, everybody is different, and you have got some people who know exactly what they want to say and exactly what they want to get out of the consultation. Then you have got, obviously, other people who do not really have any expectation of the consultation, and they are a little bit harder to help really. So, I think it might be useful for those people. C5 (Nurse)

HCPs also expected that the PROMs/e-PROMs could help patients understand their symptoms and educate them about their condition.

I think it is useful; it is an educational tool in a way. For example, some of our Parkinson's patients do not recognise that sleep is an issue, and it could be related to Parkinson's, or constipation, or some of their sexual dysfunction. So, all those things, it might serve to highlight some of those problems before the clinician has actually picked it up. How the patients respond and are aware that this could be obviously Parkinson's. C13 (Geria)

Additionally, HCPs anticipated that using PROMs/e-PROMs could give patients more control over their disease, which could support their self-management.

We are working towards much more self-management. Giving them [patients] the information they need and working on motivational interviewing and self-awareness. So, we are hoping that we have reduced all their problems, but we reckon that if the NMS score goes up, in other words, they have more NMS [problems], it actually shows that they're a lot more self-aware of what is part of the problem. So, they are more aware of what the Parkinson's is causing, so they can start managing it better. C6 (Physio)

1.2.4   Improve communication/collaboration between MDTs: The majority of HCPs felt that using PROMs/e-PROMs could enhance communication between members of the MDT through standardised assessment.

We have an MDT meeting after clinic, and we discuss our patients. I think it would standardise an assessment, really, because you have an element of an opinion, have not you, with each different clinician and some people might perceive somebody doing not very well at all. So, that would take that element out of it, I think, because it would only be the patient's point of view. C5 (Nurse)

In addition, some of the HCPs felt that it could open up further discussions.

I think it is communication of somebody's difficulties, and we do tend to talk a lot about the patients to work out the best strategies for them as well… [for example] is increasing the dopamine going to help in some way, or is there some alternative therapy that we need to use, or would physio be more appropriate in assessing, or do we need to have some other specialist input? So, should we get a urologist in if the bladder problems are particularly bad? C14 (OT) and C1 (Neuro)

In contrast, some HCPs stated that the communication between MDT members would depend on the systems used at each health board and whether they had a robust communication system between all HCPs. They felt that using PROMs/e-PROMs tool would not have any impact on the communication between HCPs.

That goes to individual services [communication among the MDT]. For example, in our service, any patients that have particular issues or problems, we discuss them proactively in the MDT meeting after clinic anyway. C13 (Geria)

1.2.5   Improve health services: In addition to impacting communication between MDT members (which may have a positive impact on health services), HCPs also described specific ways in which using PROMs/e-PROMs could improve the provided health services, which would facilitate the audit and evaluation of services.

In terms of clinical care, I think clinical services and people do service evaluation and service improvement projects, so it could be used in those contexts, for instance, how good are we of managing constipation, and then go through the NMSQuest and look at

the number of patients who have scored three or four or whatever, and then look at how many of those patients have gone on to be prescribed a laxative. C1 (Neuro)

Many HCPs agreed on the advantages of e-PROMs and described how they could improve the data collection and storage process. They suggested that the integrative nature of the e-PROMs tool with EHR would enable them to easily access data and track changes in the stability of patients' conditions in a timely fashion.

I think with electronic; you have got more potential to be able to click on it and say, 'What was this bit the last time?' It is quicker, and ultimately, time is a very scarce commodity in the NHS. C10 (Nurse)

1.2.6 Good for research purposes: Almost all HCPs, except for the allied health therapists, stated that the PROMs/e-PROMs tool would provide valuable data for research purposes in the future.

For research purposes, to be able to collect that kind of data is helpful if you are doing a trial of a new drug or something. Then, to be able to access PROMs electronically would be a big step forward. C12 (Pharma)

1.3 Concerns: Several concerns were reported by the HCPs regarding the use of PROMs/e-PROMs within PD clinics. Table 5.6 summarises the most reported concerns.

Table 5.6: Concerns about using PROMS/e-PROMs, as reported by HCPs

Concerns	Neuro	Geria	PDNS	Pharma	Physio	OT	S&LT
Clinic time frame	✓	✓	✓	✗	✓	✗	✗
Clinic workflow	✓	✓	✓	✓	✓	✗	✗
Patient satisfaction	✓	✓	✓	✓	✓	✗	✗

1.3.1 Clinic time frame: Some HCPs were concerned about using PROMs/e-PROMs within clinical practice. Patients have only 20 minutes with their HCPs in a follow-up appointment, so it would be difficult for HCPs to go through every aspect of PD within this limited time frame.

I think that in a 20-minute slot, nonmotor symptoms… answering it can be quite difficult because you are addressing a lot of other issues relating to Parkinson's, including motor symptoms and cognition assessment. C3 (Geria)

1.3.2 Clinic workflow: The majority of HCPs described their concerns regarding the use of PROMs/e-PROMs within clinical practice, which could potentially lengthen consultations and disturb clinic workflow. Nevertheless, they believed that the potential advantages of using PROMs outweighed these concerns.

It probably adds on time because when you are specifically screening people for lots of different things, they may answer affirmatively there, then you need to do something about that, and a 10-minute consultation when things are okay may turn into a sort of 40-minute consultation, and I think it is just the pressure on the clinic may not allow for that in a way. So, the problem then is that you have people waiting longer times. Even it is trying to focus on the key problems that they vocalise in a way. C9 (Geria)

A small number of HCPs were also concerned that the patients would need assistance to complete the PROMs, which would lead to a greater workload for them and disturb the workflow of the clinic.

[The patients might] need some sort of guidance or counselling or support to complete it. That might be an additional resource that you factor in because you might then find that the clinic nurse is spending their time doing this, rather than checking on the patient, taking their weight and all those, and booking them into the clinics. C13 (Geria)

1.3.3 Patient satisfaction: Most HCPs (all but two) expressed their concerns about the use of PROMs/e-PROMs and patient satisfaction. They felt that using PROMs may make patients worried about their face-to-face consultations.

I think anything that detracts you from face-to-face contact—anything that changes the conversation away from what the patient wants to talk about—you have to be a bit careful about. But I think the more we look at computers and bits of paper on our desk, the less happy the patients are likely to be with their 20 minutes of time. C8 (Neuro)

Some HCPs believed that using PROMs before patients' clinical appointments might have a negative impact on patients and heighten the patients' anxiety levels.

> *With the NMS, for instance, the questionnaire [made] them think that everything on that questionnaire is something that they are going to get, and then worry about it and increase their anxiety. Hallucinations, for instance, on the NMS. And they think. 'I haven't got them yet, but that might be coming', and then they are going to worry about it. C10 (Nurse)*

In contrast, one of the HCPs who did not express any concerns about patient satisfaction explained how using PROMs/e-PROMs can have a positive impact on patients by reassuring them about their health status.

> *I think if the patient is stable and they have very little NMS, I think that will give them encouragement and realise they are actually stable and they're doing well in their condition. I think it is positive as opposed to a negative because at the end of clinic, and if I say to them, 'You're doing extremely well, your disease is slow progressing,' they are thrilled to bits, and they feel much better leaving the clinic consultation. C2 (Nurse)*

1.4 Appropriateness of using PD-specific PROMs/e-PROMs intervention in clinic: Only the geriatricians and neurologists emphasised the need to select the right group of patients to complete the PD-specific PROMs or use the e-PROMs intervention before clinic. They reported that their clinics included a mixture of patients with different neurological conditions and PD disease stages, indicating the need to identify appropriate patients who would benefit from using the PD-specific PROMs/e-PROMs. More specifically, they emphasised the need to distinguish between patients who come for a new consultation (i.e., patients waiting for PD diagnosis confirmation) and those who come for a follow-up consultation (i.e., patients with a confirmed PD diagnosis). They felt that the patients who came for follow-up appointments would be the most appropriate group of patients to use the PD-specific PROMs.

> *I think it would be most helpful in our follow-up patients. With new patients, we do not even know if they have Parkinson's disease. So, it may not be very useful for new patients. C16 (Geria)*

1.5 Design of the E-PROMs intervention: The users' perceptions of the design of the e-PROMs intervention are of great importance, as they could influence the users' intention to use it. The HCPs described many suggestions and preferences regarding the e-PROMs tool design, which included both contents and functionality features, as described below.

1.5.1 Content of the intervention (need for data to be collected electronically): HCPs identified several PROMs that they believed would have to be included on the e-PROMs tool, such as scales related to motor, sleep, depression, anxiety, cognition, driving test, quality of life, daily activities, and carer burden. Their suggestions for the required PROMs varied according to their specialities. For example, occupational therapists asked to include PROMs that were related to MS, and neurologists asked for NMS, as they explained how their clinics already focused on the MS. However, there was agreement on the need to collect information about NMS at the beginning.

> *I think motor scales, cognition, it is really what we have on our initial assessment. Things like functional difficulties, strengths, needs, input with the environment, their social support, their leisure interests, quality of life, mood, that kind of thing really. C14 (OT)*

Some HCPs agreed on the need to collect NMS information, as the focus of their clinic was on the assessment of motor aspects of PD.

> *Traditionally, the motor side of things has been focused on. Increasingly, I think we see that most of what people complain about is a lot of the NMS. Certainly, I think if you are going [to] put anything in there, NMS would be helpful; sleep scale, I guess, some sort of measure of motor and NMS would be helpful. C9 (Geria)*

Another participant emphasised the need to collect NMS-related PROMs.

> *I think if you look at the literature, the stuff that is least [asked about during clinic], it is usually the nonmotor stuff that people find more difficult to talk about, and that they may not want to bring up themselves in clinics. C1 (Neuro)*

Most of the HCPs (except the allied health therapists) emphasised the need for the medication section to be involved in the e-PROMs tool.

> *The medication input [section], that is a big advantage of it. So, if someone has impulse control in five years and they are on dopaminergic agonist. Unless you knew that, or the patient told you or you scrolled through every letter, you are not going to know it. With this system [e-PROMs] that will be there, so it will be like a front page with that information [PROMs], that will be quite an important thing. C8 (Neuro)*

Another participant also reported the importance of adding a medication section with an additional marker for medication intake across the PROMs questionnaire.

> *We know the importance of medication in PD. And we used to think about motor symptoms having fluctuations; however, the nonmotor symptoms can fluctuate too and can be linked to medications. So, I personally think it could be helpful if there is a medication section and also say this wherever you said yes to a symptom. Does this vary or depend on the timing of your medication? How long ago did they take their tablet? Is their tablet due? C10 (Nurse)*

1.5.2 Layout of e-PROMs tool: The HCPs mentioned several suggestions for designing the e-PROMs tool. Table 5.7 shows their main suggestions.

Table 5.7: Main suggestions for functionality of the e-PROMs tool highlighted by the HCPs

Suggestions	Illustrative quotations
Simple and easy to use tool	*'It should be simple and easy to use because a lot of our patients are cognitively impaired.' C16 (Geria)*
Clear instructions page	*'I kind of do an information sheet for them to follow, so if they get stuck, they can follow that to help them.' C15 (S&LT)*
Short format of PROMs with 'Yes' and 'No' answers	*'Quite simple to use, not too long. A lot of people with Parkinson's have difficulty writing from micrographia. So, a tick box type thing is ideal, 'Yes/No' questions so that they're not put off by having to do any writing.' C14 (OT)*
Large font size with one question per page	*'I think you need it to be large and easily readable. I think it needs to be big and easy to see and simple with no wordy questions. Maybe even just one question on a screen.' C12 (Pharma)*
Ticking boxes or tapping instead of the swipe action to provide the answers and turn to the next page	*'I use PKGs [Parkinson's KinetiGraph motion sensor watch], and when we previously had the one that you had to press, the old type people found those easier than the new ones, which are brilliant, but you have to swipe. So, I think that tap is much easier.' C10 (Nurse)*
Highlight the main issues or have a final summary page	*'It's got to be easy to put the data, in and it's got to be easy to see the end results in whatever way that the data is summarised for the clinician or the specialist nurse to be able to look at it.' C1 (Neuro)*
Incorporating a mechanism to display the data from the e-PROMs tool to the existing system at the clinics (integrating the e-PROMs tool with the EHRs at the clinic)	*'It would be useful if we can get it on the screen once they have completed it, you know; we need to be able to save the questionnaire to make sure we've saved the data we've collected, and it will be useful to then collate that with the patient care database we have so it is there with that consultation. So, if we need to go back and look at it on different data in the future, then it's there for us to look at.' C16 (Geria)*

2. **Implementation process**

This theme reflects HCPs' views on the process required for successful implementation of the e-PROMs tool in PD clinics. Based on the CFIR, this domain includes four constructs: planning, engaging, executing, and reflecting and evaluating. Two key subthemes were identified that belonged to the planning construct (the degree to which a plan or method of behaviour and tasks are developed in advance for the proper implementation of an intervention): stepwise implementation and consideration for implementation.

2.1 Stepwise implementation: Almost half of the HCPs suggested introducing the e-PROMs tool gradually into PD clinics to demonstrate its positive or negative impact on services. They also suggested piloting it on a small scale to understand and avoid any issues that might appear during the final implementation.

> *I think the key when you introduce something like this [e-PROMs] is never to try and do it in the whole clinic. So, to say, 'Okay, for this clinic, we're just going to try doing it with two patients,' so that if it goes very wrong, it is only two appointments that are affected, and we are just going to do it just for the new patients. C1 (Neuro)*

Another participant provided more clarification regarding the advantages of the gradual implementation of e-PROMs by giving an example of a current system that had been used on her health board.

> *In the beginning, they built the ICHOM system [set of PROMs data] only for me within my clinic because it was a pilot to start with, even though it has continued to be used. It will roll out to all the consultants who see people with Parkinson's, but that is when we have actually purposely got it, so everyone will be able to use it if they want to use it in their clinical roles. C7 (Nurse)*

2.1.1 Consideration for proper implementation: The essential purpose of planning is to develop a course of action to promote and facilitate effective implementation by understanding the local capacity and capability of the clinic for using the intervention.

Chapter 5   **Perceptions of HCPs on the use of e-PROMs app in PD clinical settings**

Considering the stakeholders' needs and perspectives helps developers and researchers build appropriate strategies to tailor the intervention and simplify the implementation.

The HCPs mentioned several factors that needed to be considered during the implementation process of the e-PROMs tool in the PD clinics, such as the best time and place to use it, offering essential training, and providing feedback to patients.

2.1.2 Consider the appropriate time/place to deliver intervention: The views regarding the appropriate time and place to use the e-PROMs tool varied among HCPs. Most participants thought that before the patients' clinical appointments, while they were waiting in the waiting room, would be the best time to use the intervention.

> *I would have thought the best starting place [to use the e-PROMs tool] would be to ask them to do it in clinic to begin with and to get people happy and familiar and understand what is going on and why they are doing it. C1 (Neuro)*

In contrast, four of the HCPs thought that the at-home option would be most appropriate. They thought that the patients would prefer to have access to the e-PROMs tool outside the clinic environment to facilitate the collection of the PROMs.

> *Before [coming into clinic], because they [could not] learn the technology and focus on the clinic appointment at the same time. They would want to be familiar with that beforehand because they are already quite anxious coming into the clinic for one reason or another. C11 (Nurse)*

A few of the HCPs did not have any preference regarding the appropriate time and place to use the e-PROMs tool as long as there was an efficient mechanism to use it, either in the clinic environment or at home. They made suggestions to enable patients to use the e-PROMs tool in either way, then later decide which method would yield high patient engagement with the intervention.

> *I think it will be a mixed bag [at clinic settings/at-home settings]. Collecting data before they are coming into the room [at clinical settings] for any consultation*

will probably be more targeted and easier. Collecting it before the clinic [clinical visit] either electronically [or paper form], I think that we can try both routes and see which one is the best. I will say that we will try both these two routes over a three-and six-month period and see where we get the maximum response. C3 (Geria)

2.1.3 Consider training and explanation for proper implementation of intervention: Almost all HCPs agreed on the need for delivering appropriate training and explanations to promote the implementation and use of an e-PROMs intervention. Explaining the main purpose of developing and using the intervention and how it will be used for either patients or clinical staff was considered essential for promoting and facilitating future use and implementation in clinical settings.

Only four of the HCPs thought that the clinical staff would need to be trained on how to use the e-PROMs tool, and the remaining HCPs thought only the patients would need the training. They suggested that the intervention developers or researchers deliver a face-to-face training session to both patients and clinical staff.

For the patients, a five-minute, you know, face-to-face sitting next to them and showing them how the iPad [e-PROMs tool] works would probably be sufficient. For the nursing staff, you could have two hours or an hour to go through the training with them. C16 (Geria)

A participant who thought that only the clinical staff would need the training said:

I think the clinical staff definitely would need to know how to [use the e-PROMs tool] to know how to get through it. Even just basic things if the iPad shuts down or something like that midway through. So, the technical side, as well as the actual doing of the questionnaire. I think the patients are pretty tech savvy. They are good, as long as they've got support in the clinic. C1 (Neuro)

A participant who thought that only the patients would need the training commented:

For the existing staff, no, we would not need training [on how to use the e-PROMs tool]. They [patients] would certainly need training if it was an iPad. Some of them use iPads all the time, but some have never seen one. Those would definitely need training. C5 (Nurse)

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2.1.4 Providing patients with feedback about the collected data for proper implementation:

Providing patients with feedback or summary reports about their performance and the collected data was considered essential in promoting the use and implementation of an e-PROMs tool in the clinical settings. A few of the HCPs expressed this importance within PD clinics.

> *I think we need to move more to patients having access to the information as well. So the patients could track their progress. If it could be used to [provide] feedback and say, 'Okay, well, we changed your medication, and this is showing that you're managing around the house better—you have not fallen as much, you are feeling happier' to make sure we are not doing this for nothing—to make sure the information is used and usable. C12 (Pharma)*

3. Inner setting

This theme reflects HCPs' views on organisational factors that might affect the future use and implementation of the e-PROMs tool in PD clinics. Based on the CIFR, this domain includes five constructs: structural characteristics, networks and communications, culture, implementation climate, and readiness for implementation (Damschroder et al. 2009).

Two main subthemes were identified that belong to the following constructs:

- Implementation climate, which is the stakeholders' shared receptivity of involved individuals to an intervention use and the extent to which the use of the intervention will be supported and expected within the organization, **teamwork.**
- Networks and communications, which is the nature and quality of digital networks at the organisation, **IT infrastructure.**

3.1 Teamwork: Based on the HCPs' experience of culture within the organisation, encouraging and promoting teamwork seemed essential for the effective use and implementation of an e-PROMs tool. Four HCPs highlighted the importance of working as a team. Beside HCPs, a team including nursing staff, clinic receptionists, and IT department staff must be involved to use the e-PROMs in a successful manner.

I think a key feature of any clinic, any specialty, no matter what you do, is not so much whether the clinician likes the questionnaire or looks at the data, but having all the other staff in the clinic on board and understanding the [e-PROMs tool] questionnaire, which questionnaire they are doing. The mechanism of how to do it; if there is a problem with the iPad at all, it is the nursing staff or the receptionist or the healthcare assistant who are the ones left managing these problems. So, they need to be on board. C1 (Neuro)

Another participant described the importance of establishing teamwork within a clinic or organisation for the successful use and implementation of e-PROMs tool by providing an example of the existing e-PROMs system.

They have employed a team of people to promote e-PROMs. When I first set up, I had an IT guy who helped build the programme for our clinical workstation. So, they would come to the clinic sometimes to make sure of the smooth delivery of things. They also felt that they were part of a working team because they had built the programme and they wanted it to work as well. C7 (Nurse)

3.2 IT infrastructure: IT infrastructure is an essential 'core property' for successful implementation of a digital intervention in a clinical practice. Most of the HCPs highlighted that the IT resources and infrastructure within the health board would impact the future use and implementation of the tool. The participants reported that poor wi-fi signals and the limited number of available computers in clinics would negatively impact implementation.

It would depend on whether it was internet-supported, because if it were a wi-fi situation, we have got very, I mean, we have got very poor interment connections. Our computer systems are quite old. C10 (Nurse)

Another participant added:

More computers for a start [using the e-PROMs]. We have got one computer between three of us, but we do not have the wi-fi support really [to use the e-PROMs]. C14 (OT)

Some of the HCPs reported having adequate IT infrastructure within their health boards to successfully implement and use an e-PROMs tool.

> *I think we have enough computers. There is a computer in each office in the clinic. So, if the patient is given an iPad [e-PROMs] which could be connected to the computer in the clinic, no, I do not think we would face a problem with that. C16 (Geria)*

4. Individual characteristics

This theme reflects the views of how HCPs feel about the future use of e-PROMs and their perceptions of how PwPs might react to their use within clinics.

Based on the CIFR, this domain includes five constructs: knowledge and beliefs about the intervention, self-efficacy, individual stage of change, individual identification with the organisation, and other personal attributes (Damschroder et al. 2009).

Two main subthemes were identified that belonged to the following constructs:

- Knowledge and beliefs about the intervention (individual attitudes toward the intervention); attitude towards e-PROMs.
- Self-efficacy (individual belief in their capabilities to use an intervention, which might affect its implementation and use); patient readiness.

4.1 Attitude towards the future use of e-PROMs: Almost all HCPs were very positive regarding the future use of e-PROMs tool within their clinics. Despite their initially expressed concerns, they were clear about the benefits:

We are happy to use that [e-PROMs tool], much quicker than looking at the notes [patients' diaries], and we are keen to, so, it is really helpful. C9 (Geria)

Even though the allied health therapists were very positive about the use of e-PROMs, they expressed a preference to ask the patients PROMs questions during the clinical visit rather than having them complete the questions prior to their appointment.

I think it would probably make life easier, really. It would be useful to have, but we would be more likely to ask them rather than look at the electronic device, really. To be honest, we would be asking them how they were, rather than just looking at their information. C4 (Physio)

4.2 Patient readiness: The HCPs expressed their beliefs about PwPs' capabilities, which would impact the effective use and implementation of the e-PROMs tool. The HCPs shared their perceptions and feelings regarding PwPs' abilities and willingness.

I think, in general, Parkinson's patients are quite keen to be involved. I think anything that shows interest in their symptoms and gives them a way to convey what problems they have will be positively received. C12 (Pharma)

The HCPs tried to avoid generalisation when it came to patients' age and their ability to use the e-PROMs tool, and almost all the HCPs believed that many older patients would have the basic skills required.

Younger patients will do it far easier than older, but we should not underestimate older patients because lots of them email and are very good electronically. C2 (Nurse)

More so than age, HCPs believed that the disease status of the patients might affect their ability to use the e-PROMs tool in the clinics. The HCPs explained that PwPs might have tremors, cognitive impairment, dementia, and poor eyesight, which could prevent them from using the e-PROMs tool or make the interaction with tool interface very difficult.

I think, physically, our patients will find it difficult to use a device. Physically because of the tremors, rigidity, dyskinesia, and also the cognition. C16 (Geria)

5. Outer setting

Based on the CFIR, this domain includes four constructs: patient needs and resources, cosmopolitanism, peer pressure, and external policy and incentives (Damschroder et al. 2009).

Resources were identified by the HCPs as the main outer setting construct that might affect the future implementation and use of e-PROMs. This included the need to hire additional staff and financial support.

5.1 Additional staff: HCPs reported that, given the current staffing level at the PD clinics, the e-PROMs tool might add further stress for the clinical staff, and that might impact its successful implementation and use. As such, they suggested hiring additional staff to take on the responsibility of the e-PROMs tool.

> *In terms of the clinic and the clinic numbers, I think the difficulty is who would administer and who would assist people in those. We have one or two clinic nurses for 40 or more patients all morning, so they are very tied up with getting people in, getting them booked, doing routine assessments, and so adding a little bit more, it is just demographically challenging, I think, or logistically, I should say. C9 (Geria)*

A further illustration was provided by some of the HCPs, who explained how the loss of staff had directly affected the sustainability of using PROMs in the past.

> *We used to do those [PROMs] when we used to have a band of six nurses with us, and we used to get the nonmotor scores. We used to get the Epworth sleep scale before they came in, but unfortunately, that member of staff is not with us anymore. C11 (Nurse)*

5.2 Financial support: The lack of funding to acquire the IT infrastructure necessary for the successful use and implementation of an mHealth intervention was reported.

> *I think there is a lot of enthusiasm, and people are always open to the idea of technology. The limiting factor is always the money. So, you must sort of generate the fund yourself in a way. So, for an electronic database, we funded it through Parkinson's UK. The trust has not really picked up on the cost of that,*

because you can get by using paper notes. So, they are always going to choose the most cost-effective option even if it is not the most efficient option. So, I think, in theory and on paper, there's enthusiasm for technology in practice, and financially, there is less enthusiasm to throw money at it. C9 (Geria)

5.5 DISCUSSION

To the best of our knowledge, this is the first study to explore the views of HCPs who are working with PwPs regarding the development of a novel e-PROMs tool intervention that aims to collect PD-specific PROMs to aid patients' consultation in clinical settings. The aim of this study was to understand the views of HCPs on the value of this type of intervention, and to establish the format that HCPs expect to be most useful. This study also aimed to explore HCPs' perceptions of patients' willingness to use an e-PROMs tool, and its potential outcomes, and to identify whether HCPs would support the use of an e-PROMs tool in their routine clinical practice. It also explored the needs consideration in relation to the integration of an e-PROMs tool within PD clinical settings.

A mixed-methods approach was adopted using both questionnaires and semi-structured interviews. Together, these methodological approaches identified the views of HCPs regarding the future use of e-PROMs (i.e., the questionnaire identified the quantity of PDNSs who had previously used or collected PROMs and identified which were the most frequently used PROMs) and explored the acceptability and utility of discussing PROMs during a routine consultation (i.e., the interviews explored in more detail the potential benefits and concerns of e-PROMs alongside considerations for implementation).

Even though the researcher only collected and administered the Phase I questionnaire on one day of a two-day conference, the questionnaire achieved a high response rate from the PDNS conference attendees from across the UK (76.9%), providing good insight into their perceptions as key members of the PD MDT. Given that Wales has a low PDNS population (n = 22) (UK Parkinson's Excellence Network Mailbox 2020), the responses from Welsh nurses (n = 6) were considered sufficient to give insights about the perceptions of Welsh PDNSs towards PROMs/e-PROMs tool use in practice, although there may be some responder bias. Other PD

members or PDNSs who did not attend the conference might express different views, so the findings from the questionnaire should not be interpreted as representative of all HCPs. Although the number of responses from Wales was very small, it was important to include data related to Welsh PDNSs. The healthcare system is developed across four nations in the UK, leading to differences in practice and organisation (NHS 2019; Paul Worthington 2019). The scope of this thesis was to look for something that would fit and work in the Wales area. However, the identified numbers and values should not be interpreted as representative of PDNSs in Wales; they only provide insights into their perceptions toward e-PROMs tool use to understand their initial and potential attitudes to such a concept.

Following the questionnaire, 16 semi-structured interviews were conducted, and while this did not include all health boards in Wales, this sample represented a cross-section of HCPs who deal with PwPs. There was strong repetition of the data and themes, and the study aims were achieved. However, it was interesting to note that some of HCPs' perceptions were based on the facilities and infrastructures within their health boards. HCPs from other health boards in Wales or from different areas of the UK might express different views and preferences regarding the use and implementation of e-PROMs tool within PD clinical settings. For this reason, the findings of this study need to be interpreted cautiously.

It is important to understand the implementation process and needs involved in using an e-PROMs tool within PD clinical settings to address the knowledge-to-practice gap of using PROMs (Arora et al. 2017). Though interest in this field is growing, as presented by the feasibility studies of Mohammed et al. (2016) and Arora et al. (2017), the findings of this study would be a useful addition to the evidence base of stakeholders' perceptions (HCPs) towards an electronic PD-specific PROMs tool and the potential early benefits and concerns.

In the current study, both quantitative and qualitative findings showed that using e-PROMs prior to patients' consultation was useful to support the data collection process and clinical decision making, and to focus the consultation on the patients' needs. HCPs were receptive to the idea of using e-PROMs tool within PD clinical settings. Findings from both phases identified several benefits to PROMs gathering and use during patients' consultations. This appeared to

contribute to decision making and patient management, which is consistent with previous findings (Neff et al. 2018; Damman et al. 2019). These benefits were reflected in the format of the e-PROMs tool and considerations for implementation suggested by HCPs. Of note, Neff et al. (2018) and Damman et al. (2019) both found benefits of using the paper version of PD-specific PROMs, but in the current study, the focus was on both the paper and electronic use of PD-specific PROMs. Even though the HCPs in this study identified some potential concerns regarding the use of e-PROMs, they reported preference for an electronic version, which was perceived to have the potential for fast, easy access to patents' data.

Based on the TAM (Davis 1993) and UTAUT (Venkatesh et al. 2003), perceived benefits and need for a device are important with regard to intention to adopt and engage with technology. Participants who did not see the need for mHealth and did not see any advantages over current strategies were less likely to perceive the intervention as useful, and thus, did not use it. The HCPs in this study highlighted several potential benefits of the use of the e-PROMs tool, and this is a good indicator for future intention to use the intervention.

HCPs anticipated several advantages of using e-PROMs, including identifying specific issues that may concern patients, flagging and prioritising these issues for discussion, and focusing on these issues in consultation. These findings are consistent with previous studies that assessed the use of PROMs in oncology, PD, and palliative care practice (Wu et al. 2016; Pinto et al. 2018; Damman et al. 2019). They are also consistent with those from Chapter 3, which indicates that patients might benefit from an e-PROMs tool intervention to help them develop a basic understanding of their main issues prior to consultations. They might also benefit from an e-PROMs tool that would enable them to become more active and vocal during consultations by encouraging them to ask questions and make their main issues clear to HCPs, instead of passively relying on HCPs. It is important for patients to voice their concerns and provide adequate information for HCPs to formulate the correct management and prescribe or amend treatment for them.

Participants in this study expected that the e-PROMs tool would be a useful intervention only for patients who come for a follow-up appointment. Because new patients usually come to

neurological clinics to confirm their PD diagnosis, some may not have the condition, so asking them to use such an intervention (e-PROMs tool for PD) would be inappropriate. This finding might provide valuable information for the researchers and developers to consider during the implementation phase, and to perhaps limit its use to patients with a confirmed PD diagnosis.

Participants emphasised the need to link the e-PROMs tool with the existing EHR system in clinics to use the collected data in a more efficient manner during the consultation. Similarly, a previous study that evaluated the routine collection of PDQ39 in PD clinics suggested the use of an electronic version to facilitate and avoid the manual entry of data (Neff et al. 2018). Consistent with another study, participants expressed positive perceptions regarding the use of PROMs/e-PROMs, but only if they could use them during their daily interactions with patients (Pinto et al. 2018).

A notable finding of this study is that a few of the HCPs anticipated that using an e-PROMs tool might be useful to resolve the issue of long waiting lists at PD clinics, as it could help with prioritising patients based on their health status and identifying who would need to be seen. Even though this is an interesting finding, it needs to be interpreted with caution, as the perceptions of the included HCPs may not reflect those of a wider group of HCPs. In order to see the actual impact of the e-PROMs tool in prioritising the clinic waiting lists, it might be necessary to consider using the tool in settings other than the clinic to utilise the collected information in advance and ensure that PwPs with greater or more urgent needs get healthcare services first. This might benefit health boards by reducing the pressure on the demand for appointments.

Using an e-PROMs tool would generate a large dataset, and according to the HCPs in this study, this data might support and benefit future research, auditing, and service evaluation research. These findings are consistent with previous studies that reported clinicians' perceptions of e-PROMs for other chronic conditions (oncology palliative care and chronic kidney disease) (Pinto et al. 2018; Aiyegbusi et al. 2019). Despite the previous studies being focused on exploring the perceptions of an existing developed PROMs systems, there is a clear relationship between the HCPs' perceptions of the use of PROMs/e-PROMs in these studies and the current

study, as all of them focus on the use of PROMs/e-PROMs to support management of chronic conditions.

The findings of this study identified HCPs' concerns about the routine use of e-PROMs during clinical consultations, including limited consultation times and their effect on their workflow. These findings are consistent with previous studies that evaluated the use of PROMs in chiropractic, oncology, and palliative care clinics (Wu et al. 2016; Arora et al. 2017; Holmes et al. 2018; Pinto et al. 2018). In Arora et al.'s study, a small delay in the clinic was reported after implementing the ICHOM PD standard set, as the data were effectively collected outside HCPs' contact time. This concern could be overcome, and the issue resolved during the implementation phase of the e-PROMs tool if there is a necessity to use the tool in the clinical settings. For example, the patient could be asked to arrive for their appointment 15 minutes earlier to give them ample opportunity to use an e-PROMs tool before their consultation time. Additionally, as found in Chapter 4, the at-home option to use the tool (e-PROMs) was also suggested by participants to resolve the issue of distributing clinic workflow. All these suggestions were identified and reported in this study, as well as in Chapter 4; however, identifying one of them as the best method to use the intervention (e-PROMs) is beyond the remit of this thesis. Additional research is needed to further evaluate this after refining and redesigning the intervention and piloting it in practice.

The HCPs' perceived barriers to consultations were consistent with those of PwPs and carers, as described in Chapter 4. Similar to previous studies, the HCPs in this study were concerned about patient satisfaction, such as patients feeling bored or pressured by using the e-PROMs tool, which may lead to an increase in their anxiety level before consultations. Previous studies have shown that using PROMs in palliative care clinics could add to the patient burden (Bausewein et al. 2011; Antunes et al. 2014). Other concerns raised by two of the HCPs were the security and confidentiality of patient information, which were also concerns of PwPs and their carers, as described in Chapter 4. These concerns may negatively impact the adoption and use of interventions and pose a risk to successful implementation of the e-PROMs tool in practice. Privacy and security concerns are often cited as barriers to health information

technology and mHealth acceptance and use (Boonstra and Broekhuis 2010; Pinto et al. 2018). However, users may be less concerned about privacy and generally more willing to use mHealth technology when they perceive the potential benefits as outweighing the risks (Archer et al. 2011; Pinto et al. 2018; Spann and Stewart 2018). In a study exploring users' attitudes to a tablet system to assess patients and collect data in clinic waiting areas in primary care settings, the authors found that while 33% (27/81) of users expressed concerns about privacy, 67% (54/81) were extremely or very interested in using the system.

To reduce patients' concerns regarding confidentiality and privacy, sending a letter or verbally explaining beforehand how the submitted data from the e-PROMs tool would be securely stored and used could improve patients' intentions to use the intervention. A similar concern about privacy and confidentiality was reported in Arora et al.'s (2017) study, and these concerns were tackled by distributing leaflets in PD clinics detailing the changes and guaranteeing security measures. For instance, the system was password protected, and the login process for HCPs and patients was streamlined.

In agreement with the previous research, most HCPs in this study anticipated that they would find the IT infrastructure (i.e., no available computer, wi-fi, and no EHR), lack of funds, and insufficient staff on their health board to be potential barriers for the future implementation of the e-PROMs tool (Pinto et al. 2018). The lack of IT facilities, networks, and funding is usually reported in the literature as a barrier to the successful use and adoption of health information technology (Gesulga et al. 2017; Pinto et al. 2018). Successful implementation of an mHealth intervention will require financial support for the costs associated with acquiring the necessary infrastructure and operating the intervention.

The HCPs made several suggestions to refine the design of the e-PROMs tool. They were based on the perceived nature of current patient consultations and awareness of the difficulties that patients might face when trying to express their issues during consultations. Within the interviews, HCPs stated that the focus of patient consultations was on the motor aspects of PD, so they stated a preference for collecting the NMS information, which could map the consultations and lead to using more specific PROMs for a specific symptom. Additionally, the

Chapter 5   Perceptions of HCPs on the use of e-PROMs app in PD clinical settings

HCPs' suggestions of features and content for the e-PROMs tool were consistent with the features suggested by PwPs and carers in Chapter 4, including an easy-to-use tool, a large font size, one question per page, and clear instructions to help patients easily navigate and use the device. A section related to PD medications was also considered important. A previous study reported that an unsuitable or poorly designed e-PROMs tool could affect the successful implementation in clinical settings (Chih-Hung Chang 2007). This could be addressed by ensuring the e-PROMs tool is designed based on the end users' preferences and easy use in busy clinical settings.

The HCPs in the interview study reported that they had previously used PROMs to assist them during patients' consultations, and as a result, perceived that an e-PROMs tool would be a valuable intervention to improve collection, storage, and access of data. Similarly, despite reported concerns, the findings from the questionnaire study showed that 76.9% of the PDNSs (50/65) were interested in using an e-PROMs tool in their routine practice. Generally, the HCPs appeared to be receptive to the idea of using the tool in routine clinical practice to collect further information from patients, which is probably due to their appreciation of the difficulties faced by HCPs and PwPs during and between consultations. These findings are consistent with previous studies that reported HCPs' positive perceptions of and expectations regarding other types of mobile interventions for PD and other chronic conditions (Holmes et al. 2018; Neff et al. 2018; Pinto et al. 2018; Aiyegbusi et al. 2019; Damman et al. 2019).

The HCPs felt that they would require extra training to support the use of an e-PROMs tool for both clinical staff and PwPs. A brief introduction and training session on the practical aspects of the e-PROMs tool and its content were suggested. Consistent with a previous study, the HCPs in this study suggested the gradual introduction of the e-PROMs tool into clinical practice, piloting it on a small scale before rolling it out in the whole clinic (Pinto et al. 2018). The study by Arora et al. (2017) also emphasised the importance of the gradual implementation of e-PROMs in PD clinical settings to reduce the risk of destabilising the workflow of the clinics, and to facilitate the incremental understanding of its impact from the individual to the organisational level.

Chapter 5 <u>**Perceptions of HCPs on the use of e-PROMs app in PD clinical settings**</u>

Most of the HCPs in this study anticipated that PwPs would find it acceptable to use an e-PROMs tool before consultation, as they already brought paper-based tools to consultations to facilitate the process. They described how PwPs were keen to be involved in anything that could help them with their disease. However, patients who were unwilling or unable due to old age or physical disability pose a potential barrier to the use of technology in clinics to administer and collect PROMs. HCPs tried to avoid generalisations about age and anticipated that many patients would be willing to use an e-PROMs tool, though younger patients, who are more familiar with smart technology, were more likely to use the tool than older patients. Previous studies of clinicians' perceptions of mHealth interventions for a range of other chronic conditions have identified patients' age as a potential concern (Bostock et al. 2009; Aiyegbusi et al. 2019). However, the HCPs in the current study recognised that patients' age was only a temporary potential barrier to the use of technology, as a newly diagnosed patient who has grown up in the digital age would be more familiar and comfortable with the technology use. As reported in Chapter 4, older people highlighted that they did not want to be perceived as a burden when using technology (Spann and Stewart 2018). They were eager to learn and use mHealth technology if it was perceived as useful and used to support the management of their conditions (Spann and Stewart 2018).

HCPs were aware of the impact of PD symptoms (i.e., cognitive and tremors) and, as a result, perceived that patients might face difficulties in using e-PROMs. They anticipated the need to provide support and assistance. These findings are consistent with the previous findings in Chapter 4. Similar findings were reported by a previous study that assessed the use of e-PROMs in palliative care practice (Pinto et al. 2018). This is an important finding since most developed mHealth technologies for PD have excluded people with advanced stages of severe physical and cognitive impairment. For this reason, the perceptions of and need for mHealth use might be different for these PwPs and have not yet been explored.

It seems essential to consider physical, cognitive, and sensory impairment when developing mHealth technology for PD and for older people in general (Spann and Stewart 2018). Indeed, the current study only identified the potential negative impact of these symptoms on the

capability to use an e-PROMs tool. Further studies are still required to explore the perceptions and requirements of PwPs with severe physical and cognitive impairment, their carers, and their HCPs in the design and development processes of mHealth technology.

A vital step in improving the uptake and engagement of HCPs is to understand the multitude of ways e-PROMs can be used in PD clinical practice. These findings are encouraging, as the views and support of HCPs are crucial to the successful development and implementation of an e-PROMs tool and its use by both HCPs and PwPs.

5.6 STUDY STRENGTHS AND LIMITATIONS

A strength of this study is that the mixed-methods approach was used to derive benefits from both qualitative and quantitative methods and to minimise the limitations of using a single methodological approach. Within Phase I, PDNSs were recruited from a conference event that allowed the recruitment of high numbers of participants (PDNSs) who are usually hard to reach. The findings provided adequate insights from the PDNSs who attended the conference from across England and also had good insights from Wales, considering the small PDNS population there. Based on the information from the Parkinson's UK database, there are 321 PDNSs working in England and 22 PDNSs in Wales (UK Parkinson's Excellence Network Mailbox 2020).

Additionally, a diverse group of HCPs were recruited in Phase II, who had a variety of roles and settings, and no distinct differences in their perceptions were identified. The sample size was sufficient for this type of qualitative research, and data saturation was reached. However, this study has several limitations to consider.

First, due to logistical issues (i.e., time restrictions and difficulty identifying an appropriate channel to help with questionnaire distribution), the sample for the Phase I questionnaire was limited to the PDNSs who attended the conference, and only the PDNSs among all the PD MDT members. The findings are not necessarily representative of all PDNSs or all members of the PD MDT, and generalisability is limited. The PDNSs who did not attend the conference and other members of the PD MDT might have different perceptions regarding the use of

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PROMs/e-PROMs in PD clinical settings. Future research should consider these limitations to validate the findings of this study. Nevertheless, useful information was provided to facilitate further research in this area.

While recruitment through the conference restricted the population able to respond to the questionnaire, it was decided that this was an acceptable limitation due to the inhibitory logistical challenges of trying to recruit from all PD MDT members across the UK (e.g., availability of contact details, necessary extension of timescales, and the time restriction of this PhD project). By recruiting through the conference, sufficient data was obtained to provide a better understanding of some of the issues, which then informed the Phase II data collection, where a wider range of HCPs were involved. It is important to note this potential sampling bias when reading and interpreting the findings from Phase I.

As mentioned above, the sampling for Phase II included diverse members of the PD MDT working in Wales (i.e., neurologist, PDNS, physiotherapist, speech and language therapist, and occupational therapist) to improve the generalisability of the findings. Also, the questionnaire tool was designed to be quick to complete due to the assumed time restraints of it being used at a single event. Due to logistical limitations, for example, the restricted time between receiving ethics approval and administering the questionnaire, it was not possible to assess the Cronbach's alpha reliability of the questionnaire. However, an expert person (PDNS) read through the questionnaire and ensured that the questions effectively addressed the research questions (face validity). Consequently, the questions in the questionnaire may have included some amount of bias, as they were closed questions with options rather than allowing the participants to express their own views. Some questions were asked without the participants being given free text boxes to provide more detailed explanations. However, the Phase II interviews were later used to explore the data in more detail. Because of the limited duration available to conduct this study, as well restraints regarding distance and response to the participation request, all participating HCPs in Phase II were from South Wales, with no participants from North or West Wales, or England, which could affect the generalisability of the findings. Even though data saturation was reached within this sample, participants from

these other demographic areas may have different views regarding the use of e-PROMs due to variations in health board infrastructure and services provided (e.g., no EHR and possibly rural). Additionally, most HCPs had previous experience with PROMs, so the sample may have included HCPs with more favourable perceptions of an e-PROMs tool than those who had not used it before. For convenience, the interviews were conducted in the HCPs' workplace (before or after clinic), which could affect the data gathered because of distractions and disruptions by other staff members or the limited available time for interviews. Some of the interviews were quite short, lasting between 12 and 18 minutes. Finally, the researcher was aware of the potential impact of researcher bias and tried to minimise the risk of this bias using several methods, as explained in Chapter 2, section 2.4. For example, at the beginning of the interview, the researcher clarified that all opinions were valued (both positive and negative) to aid the development of an app that would be most useful for future use within PD clinical settings.

5.7 IMPLICATIONS

The findings of this study have several implications for the future development and implementation of an e-PROMs tool within PD clinical practice, which would be a valuable addition to the evidence base. First, this study provided further evidence of the psychosocial context that underpins the needs and preferences of HCPs regarding an e-PROMs tool. The HCPs corroborated the presence of barriers to collecting PROMs before consultations and the difficulties that PwPs have when trying to explain their main issues during consultations. HCPs highlighted the importance of developing interventions that enable the collection of data that meet patients' needs in order to optimise patient care and focus the consultation.

Second, exploration of the perceptions of HCPs on the content of an e-PROMs tool indicated that they anticipate it will be useful for both them and their patients. This provides further justification for the future development of such a tool. HCPs also suggested further features for the e-PROMs tool that would benefit app designers and developers. Importantly, this study suggests that HCPs would support the implementation and use of an e-PROMs tool in clinical practice, which provides further justification for its development.

The findings identified potential barriers to the uptake of the e-PROMs tool, such as increased workload for HCPs, short consultation time, and poor IT infrastructure. These potential barriers should be considered before and during the implementation phase of the e-PROMs tool to optimise its uptake, usability, and usefulness. Finally, this study adds to the preliminary body of work conducted for this thesis, which completes the first phase of intervention development outlined by the MRC framework (Craig et al., 2008). Consideration of the findings of this body of work suggests that it is prudent to begin development of an app intervention that aims to meet the information needs of patients and their relatives, followed by exploratory research on the acceptability and feasibility of this type of intervention.

5.8 CONCLUSION AND FUTURE WORK

This was the first study to explore the perceptions of PD HCPs regarding an e-PROMs tool that aims to collect patients' data to aid their consultation in clinical settings. The use of a PD-specific e-PROMs tool has the potential to enhance healthcare on different levels. On the patient level, the use of an e-PROMs tool prior to consultation might improve their perceptions and understanding of their main concerns and target problem areas, improve patients' engagement in their care, and help them assess the outcome of therapy. On the HCP level, it might focus the consultation on patients' needs or main issues, provide them with timely data that may guide patient management, and support decision making. On the service level, it might improve patient care in general and improve clinical datasets for audit and treatment evaluation research.

Overall, the perceptions related to the future development and use of an e-PROMs tool to support patient care in PD clinics were encouraging and optimistic. The e-PROMs offer several advantages over paper-based collection of PROMs. The HCPs in this study reported a preference for e-PROMs over paper-based methods due to their potential to improve collection, storage, and access of data. Concerns regarding e-PROMs have been reported, and suggestions are provided to overcome the concerns.

The key considerations and recommendations for the development and implementation phases of the e-PROMs tool were identified. For successful uptake of the e-PROMs tool in PD

clinical practice, it is crucial to ensure that the collected data are regularly fed back to HCPs to act on the information and provide feedback to patients. This can be facilitated by linking the e-PROMs tool to the existing EHR system in the PD clinic and by providing HCPs with sufficient time and resources to use it. Further research will be needed after the actual implementation and operationalisation of the e-PROMs tool in PD clinical practice to conduct a more holistic evaluation and assessment.

Moving forward, some of the HCPs in this study emphasised the need to add a section related to PD medication, as some of the symptoms that most concern patients could be a result of their medication. Therefore, to have a full understanding of the requirements for the PD medications section and identify the necessary features that could help developers refine the design of the prototype iPad-based app, it seemed essential to explore the PwPs' perceptions regarding PD medication and usage of technology. For this reason, a mixed-methods study was designed and conducted to explore this issue, which is described in Chapter 6.

5.9 SUMMARY OF THIS CHAPTER

1. This mixed-method study (questionnaire and interview) explored the perceptions of PD HCPs regarding the use PROMs/e-PROMS intervention technology to support management of PD.

2. Potential advantages of and concerns to PROMs/e-PROMs use and adoption were identified.

3. The HCPs were receptive to using and integrating the e-PROMs tool into their clinical experience, and the e-PROMs tool may be useful in improving patients' health knowledge (patients' most concerning symptoms), the collection of PROMs, access to data, and improved communication with patients.

4. The HCPs were concerned about the impact of e-PROMs' use on clinic workflow, limited available time for consultation, and patient satisfaction.

5. Key considerations and recommendations for e-PROMs tool implementation in PD care settings were identified. All CFIR domains need consideration for the effective implementation and use of the mHealth intervention.

6. Several suggestions were reported that could help refine and redesign the prototype iPad-based app.

Chapter 6: Use of mHealth application to support medication taking and reporting in Parkinson's disease: A mixed-methods study of PwPs' perceptions

6.1 INTRODUCTION

In addition to the in-depth exploration of the potential benefits and concerns expressed by PwPs and their HCPs as the end users of the prototype iPad-based app (e-PROMs tool), it is important to gain an understanding of the context in which an mHealth app would be helpful in supporting PwPs to manage their medications and document side effects. Information obtained from this study will complement that obtained in earlier chapters. By understanding PwPs' perceptions of mHealth app use in relation to medication use, interventions to strengthen the collection of such medication-related data (medication taking and reporting medication-related issues) may be incorporated into the clinic-based tool to support patients and HCPs during clinical encounters.

As described previously, the participants in Chapter 4 (Section 4.4) suggested adding a section regarding medication to the prototype iPad-based app.

> *When I found out about dyskinesia, which is caused by the tablets, I thought that it was just part of the Parkinson's problem. Then I read that it is not Parkinson's, but it is a side effect of the medication. So, it would really help if I had space on there [iPad app] about medication, just to say, I am having problems with this and explain. G8, P2*

Additionally, some of the HCPs from Chapter 5 (Section 5.4.2) also emphasised the need to use technology in regard to PD medications.

> *I think it is helpful if you ask about medication, you know the psychiatric symptoms, depression, and if the patient is actually hallucinating or anything like that, is sometime linked to medication, and if you knew that upfront, then that might change your diagnosis [management]. C12 (Pharma)*

Indeed, using technology such as an mHealth app might be essential in a complex chronic disorder like PD, with its multifaceted symptoms requiring complex treatment regimes.

Chapter 6   PwP perceptions on digital management of PD medications via app.

As mentioned in Chapter 1, PD is controlled through pharmacological treatment for both motor and nonmotor symptoms to achieve good clinical outcomes and delay long-term complications. The treatment plan for PwPs is based on the stage of the disease (early or late) and the presence of NMS, which leads to a complex treatment regime. The aim of using a combination of anti-Parkinson's medications in several daily doses is most often to control the symptoms and improve patients' quality of life (NICE 2017). Usually, patients in the early stages take a single anti-Parkinson's medication, and then two or three medications at the advanced stages (Tan et al. 2005; Schapira et al. 2009; Schapira et al. 2009).

There is a risk of side effects from anti-PD medications (e.g., motor and nonmotor fluctuations, impulse control disorders, and dyskinesia are the most common side effects; see Table 6.1), which might require further treatment or gradual titration of medications. Treating the associated comorbidities might add further complexity to disease management. All of the aforementioned factors might affect PwPs' adherence to treatment.

Table 6.1: Adopted from NICE (2017). ↑ Evidence of increased motor complications/other side effects. ↓ Evidence of reduced motor complications/other side effects

Pharmacological Treatment	Motor Complications	Other Side Effects
Treatment for early PD		
Levodopa	↑	↑
Dopamine agonists	↓	↑
MAO-B inhibitors	↓	↑
β-adrenergic antagonists	Lack of evidence	Lack of evidence
Amantadine	Lack of evidence	Lack of evidence
Anticholinergics	Lack of evidence	Lack of evidence
Modified release levodopa	↑	↑
Treatment for late PD		
Dopamine agonists	↓	↑
MAO-B inhibitors	↓	↑
COMT inhibitors	↓	↑
Amantadine	↓	↑
Apo-morphine	↓	↑
Modified release levodopa	↓	↑

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Suboptimal adherence, where the patient is taking less medication than prescribed, was reported in a recent systematic review that assessed treatment adherence in PD (Straka et al. 2018). In contrast to suboptimal adherence, some PwPs might take several doses to control symptoms. Taking more than the prescribed doses was also reported in a systematic review (Shin et al. 2015). The rate of non-adherence to the prescribed medications among PwPs was reported previously by using different measurements, which showed great variation, ranging from 0% by using patient self-reporting in clinical trials to 60-70% by using pharmacy refill data and pill counts (Malek and Grosset 2015; Mendorf et al. 2020). The 0% rate of non-adherence in clinical trials might be unrealistic or not representative of what would happen in real life, where patients are not conscious of being assessed for adherence.

Additionally, several factors were identified that could affect medication non-adherence, such as complex PD regimens, stage of the disease, depression, cognitive impairment, lack of social support, low health literacy, and economic factors (Fleisher and Stern 2013; Shin et al. 2015). The cause of treatment non-adherence can be divided into unintentional causes, such as simple forgetfulness or carelessness, or intentional causes, where the patient decides not to take the medications as prescribed based on their beliefs or feelings (Wroe 2002). Recognising that poor adherence can be an issue for PwPs, these studies went on to suggest different strategies to improve adherence, such as educating patients and their carers, improving communication with HCPs, reminder systems, alarms, dosing devices, and utilising digital health technology to help PwPs improve their clinical outcomes, medication adherence, and quality of life (Wroe 2002; Fleisher and Stern 2013; Shin et al. 2015).

Digital health interventions, such as mHealth apps, may offer a new way to improve medication-taking behaviours, increase patients' knowledge of their medications, and provide a more robust mechanism for patients to provide feedback on side effects. Some of the main causes of unintentional non-adherence (e.g., forgetting to take medication) can be simply managed by using advanced technology (e.g., mHealth device with a reminder system) to improve adherence, clinical outcomes, and the patient's quality of life (Shin et al. 2015).

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A systematic review reported that there were currently more than 165,000 apps available on the market related to health (Pérez-Jover et al. 2019), and among these, numerous apps to help patients in the management of their condition, such as taking their medication and enhancing treatment adherence (Pérez-Jover et al. 2019). However, little is known about the efficacy and purpose of these apps, the level of acceptance among users, and their impact on safe medication use. In 2019, Park et al. identified 704 mobile phone medication adherence apps on both Apple and Android operating systems. The majority of them focused on behavioural strategies to enhance adherence. The quality of the availability of 12 features within each app was assessed for 20 selected apps (10 Apple and 10 Android) and showed that the alert (to take medications) and user friendliness (easy, moderate, and difficult) were the most common features reported by users. Even though features to enable users to export or print data from these apps were not available, the users appreciated that these apps could be used to support healthcare visits, as patients could use the data collected as a tool to aid discussions with their HCPs (Park et al. 2019).

A qualitative study by Morrissey et al. (2018) focused on exploring patients' perceptions regarding smartphone apps for antihypertensive medication adherence. This study reported that, while patients were willing and eager to use apps, there were concerns about the sustainability of these apps over time. This is because use of the app might cause health-related anxiety; in particular, the constant reminders from the app were perceived as potential barrier for long-term use. The reminder features in the app could be annoying for some patients and could lead to disengagement with the app over time. Engaging HCPs and providing assurance about the privacy standards used in the app to keep data safe were suggested to encourage the sustainability and long-term use of the app by the participants in this study (Morrissey et al. 2018).

The use of medication reminder mobile apps has been accepted by both younger and older patients with chronic disease (Fallah et al. 2017). This study reported that engaging target users and HCPs in the development process of the mHealth app was found to have better results in the usability of the app; however, the full text of this study was not found to allow a

full understanding (Fallah and Yasini 2017). Therefore, the findings of this study need to be interpreted with caution.

Furthermore, only one study evaluated the use of a smartphone app to promote adherence to PD medications (Lakshminarayana et al. 2017). Lakshminarayana et al. tested the feasibility and usability of the uMotif® app over 16 weeks at seven centres in England and Scotland, involving 158 PwPs in a randomised control study. Beside the reminder system (to help track PD medication), the PD tracker app (uMotif®) included several features, as shown in Table 6.2.

Table 6.2: Features of the uMotif® app

Features of the uMotif® app	
The app included features to record:	Sleep
	Exercise
	Mood
	Energy
	Movement
	Suppleness
Finger-tapping task	
Number-size Stroop test*	
An education section about PD from Parkinson's UK and the Cure Parkinson's Trust	
Feature to generate a report of the entered data to aid the clinical consultation	

* A widely used test to assess the selective attention that requires interference resolution, response inhibition, and response selection (David A. Rosenbaum 2010)

They demonstrated that the uMotif® app had the potential to enhance self-reported medication adherence. The participants in the app group reported better self-reported adherence to medication than the participants in the control group (score reduction difference 0.39, 95% CI 0.04 to 0.74; p = 0.0304). Furthermore, a significant improvement in the quality of the clinical consultation was reported based on the participants' perceptions (p = 0.011) after using the app. However, this app was tested for only 16 weeks, and while 29% of the participants kept using the app for over 6 months after the study, the long-term benefits and sustainability remain unclear. In addition, it was unclear from the paper whether this app is available and acceptable for use by the general public and PwPs, as the authors did not comment on this. The information related to the availability of this app for general use beyond this study could not be found.

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Long-term, sustained use of apps requires knowledge of how likely PwPs are to engage with these apps. Given the paucity of research into this, it would be useful to explore this subject with PwPs. The study presented in this chapter is intended to provide a general exploration and explanation of the opinions, beliefs, and concerns of PwPs regarding using mHealth apps to improve medication adherence and management, record medication side effects, and identify the necessary features that will allow to refine the iPad-based app and guide the development of an appropriate mHealth app for PwPs.

6.2 AIMS OF THIS STUDY

To date, no study has sought to explore the views and perceptions of PwPs regarding the use of mHealth apps that aim to improve medication management. This study was undertaken to address this gap. More specifically, it aims to explore responses to the following questions:

- Are there further information needs that PwPs have regarding their PD medications? What are they?
- How could the use of mHealth apps help PwPs manage their medications?
- What benefits could they see from the utilisation of mHealth technology?
- What factors may support the continued use of a mHealth app?
- What are the necessary requirements and needs regarding the design of the mHealth app (format and content)?

In addition, questions relating to adherence may provide further context in relation to whether PwPs have any concerns about the use of their PD medication and, if so, what they are

6.3 METHODOLOGY

6.3.1 STUDY DESIGN

In order to pragmatically and comprehensively investigate and explore the perceptions of PwPs regarding the use of digital technology and the value of using mHealth apps for the management of medications, an explanatory sequential mixed-methods design was chosen, as this involved the benefits from both the quantitative and qualitative methodological

approaches. The study was conducted in two phases. The schematic diagram in Figure 6.1 shows the method of this study. A broad overview of the methods is described in Chapter 5. The following sections provide specific details about the methods used for this stage of the study.

Mixed method study

Study was approved by Cardiff School of Pharmacy and Pharmaceutical Sciences Research Ethics Committee.

Phase I (Questionnaire)

- A short questionnaire was developed, piloted, and distributed to PwP across UK through the Parkinson's UK Organisation network with 1 reminder.

- The questionnaire was available for one month duration.

- Data was analysed using descriptive analysis and logistic regression.

Phase II (semi-structured interviews)

- PwP were recruited through convenience sampling from Phase I, Participants information sheet with invitation letter to the study were provided to each participant.

- Written informed consent obtained from all participants, face-face interview conducted using topic guide. Interviews were audio-recorded then transcribed verbatim.

- Data analysis conducted using thematic analysis.

Figure 6.1: Study design overview for mixed-methods exploration of perceptions of PwPs regarding the use of mHealth apps to aid in medicine taking and management

6.3.2 PHASE I QUESTIONNAIRE DESIGN AND PILOTING

A questionnaire was developed to explore PwPs' perceptions regarding the use of mHealth apps to aid medication adherence and to report its side effects. The questionnaire design was informed by current literature in the field of the mHealth app in relation to medication management and input from the research team (researcher and lead supervisors) and two HCPs (a PDNS and a neurologist). JISC online survey, a web-based survey tool in which documents and spreadsheets can be easily created, was used to develop the questionnaire. This tool allowed the questionnaire to be created, edited, and completed using a secure online platform that facilitated dissemination and data collection. The questionnaire mainly utilised quantitative questions to obtain valuable information from the respondents (Kumar 2014). To gather further information in a free text format, qualitative options were also included in the questionnaire.

To achieve a good response rate, the developed questionnaire was designed to be as short as possible without compromising the necessary data (Edwards et al. 2009). An approximate completion time of 10–15 minutes was determined following an initial pilot of the questionnaire (described below). An information page was presented at the start of the questionnaire, clarifying that all responses would be treated confidentially, and that any publication of the findings would not name any individual. The information page also provided instructions on how to complete the questionnaire.

The final questionnaire consisted of three sections (see Appendix 6.1). Section 1 sought to determine demographic information about the respondents, including age, gender, disease duration, year of first symptoms, current PD medications being taken and their frequency, and any medications taken for other conditions. These demographics might have an impact on the use of mHealth apps, as reported by a previous study (Mahmood et al. 2019). In Section 2, respondents were asked to indicate their perceptions about technology use, technology-based solutions for managing PD and PD medications, what devices they already used and what they used them for, and how interested they were in using technology for managing their PD medications and reporting side effects.

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In the third section, respondents were asked to assess their medication adherence by answering the Morisky four-item medication adherence scale (MMAS-4) (Morisky et al. 1983; Morisky et al. 1986). Permission to use the scale was obtained from the author before conducting the study. The scale has four items that have dichotomous responses (Yes/No) to each item. The rationale behind the scale is to understand the behaviour related to medication adherence where medication errors of omission could happen in several ways: forgetting, carelessness, stopping the medication when feeling better, or starting the medication when feeling worse (Chang et al. 2014).

The questionnaire predominantly utilised closed quantitative questions (a mixture of Yes/No and multiple choice). Some multiple-choice questions included an 'other: please specify' option to enable respondents to elaborate their answers and provide qualitative data.

Once the initial questionnaire was completed, it was shared with PPI representatives through the Brain Unit at Cardiff University, who were asked to review the design and contents of the questionnaire (Brain Unit, 2019). This unit included people with neurodegenerative disorders, such as PD. Their feedback suggested that it was acceptable and relevant to PwPs. The PPI were asked to complete and critique the questionnaire for general flow and face validity where applicable (Babbie 2015). They were also asked to indicate if they had any difficulty answering or understanding the questions and to provide further suggestions regarding the design of the questionnaire. Subsequently, some minor modifications to the wording of the questions and answer options were made (i.e., the term drug was changed to medicine, and both the generic and brand names of the medicines were added). The researcher acknowledges the importance of measuring the reliability of the questionnaire to enhance the accuracy of the developed tool. However, the questionnaire was reviewed by PPI representatives in terms of face validity, content validity, and flow, but it would not have been feasible to do a formal validation given the timescale available. Likewise, the reliability of the questionnaire was not measured for logistical reasons, but the PPI review was felt to provide sufficient reassurance about the ability of the survey to meet the needs of this small-scale survey.

6.3.2.1 SAMPLING CONSIDERATIONS, PARTICIPANTS, AND RECRUITMENT/DISSEMINATION

Even though convenience sampling does not ensure representativeness, it was the best sampling method for administering questionnaires to obtain a large and varied sample. Convenience sampling is a form of non-probability sampling and was used to identify participants who would be easily accessible to the researcher (see Chapter 4, Section 4.3). The study aimed to target only PwPs, so a participant requirement request application was sent to Parkinson's UK, who agreed to assist with the distribution of the questionnaire through their database of PwPs (5,500 members across the UK). A notification that included all the information about the study was made online on the Parkinson's UK website under the research support network section. Parkinson's UK is one of the largest PD charities in the UK; through its research support network, it offers help to researchers to advertise their research and recruit participants, and this network gives PwPs the opportunity to become involved in local research (Parkinson's UK 2019b).

To obtain thorough opinions of PwPs about the use of technology, an online (JISC online survey) version of the questionnaire was made available to the respondents, but there was also the option to complete a paper version in accordance with their preference. Both the announcement statement about the study that was published on the Parkinson's UK website and the cover letter included a statement about the availability of a paper version if required. Potential respondents were asked to contact the researcher via email if they preferred it, and a package that included a questionnaire, cover letter, and a free-post return envelope was then sent to respondents who requested the paper version.

By having the number of registered members within the Parkinson's UK database, the researcher was able to calculate the sample size and determine the number of the required responses. Calculating the sample size for the survey helped the researcher understand whether a large enough sample was achieved to generalise findings to a wider population, and have confidence that the findings were showing an accurate picture (Taherdoost 2017). There are several formulae and online websites that can facilitate the calculation of the necessary survey sample size, and for this study, it was calculated using the FluidSurveys calculator

(FluidSurveys 2016). This online calculator calculates the sample size based on population, confidence level, and margin of error. The number of registered members in the Parkinson's UK database was 5,500, with a confidence level of 95%, and margin of error of 5%. This indicated that the minimum sample size required for confidence in the findings was 360 respondents.

A cover letter was also attached to the questionnaire to provide further information, including the participant information sheet, the purpose of the questionnaire, and the targeted participants (see Appendix 6.1). Consent for participation was implied (Smith 1991) when the PwPs completed and submitted the questionnaire.

The questionnaire was short, and feedback from the research team and PPI indicated that it would take participants approximately 10–15 minutes to complete.

6.3.2.2 DATA HANDLING

The data were extracted from the JISC online survey into IBM SPSS® statistics data editor version 25 [SPSS] for Windows. To check the validity of the transferred data, 10% was taken randomly to check and validate the transferred data (this was repeated until no error was found) (Babbie 2015). All submitted questionnaires were included in the analysis. All questionnaires were anonymised through the allocation of a unique identifier that was automatically generated by the JISC online survey. In addition, a separate code was given for each response to questions that had multiple choices. In the case of no response to a particular question, a separate 'missing data' code ('99999') was used to indicate this.

The third section of the questionnaire and the written comments that were provided in the free text 'other-please specify' section of the questionnaire were input verbatim into Microsoft Excel 2013® version 15.0.5127.1000. Then, the questionnaire code and the number of questions were written next to each comment for qualitative analysis.

6.3.2.3 DATA ANALYSIS

The data were analysed using descriptive and inferential analysis. First, descriptive analyses were performed, including mean, median, standard deviation, percentage, and frequency of

response. As the data used were categorical ordinal (e.g., age group) and nominal (e.g., gender and Yes/No questions) and therefore non-parametric (data does not fit normal distribution), the assumptions of normality were made using scatter data (Pallant 2010). It was important to select and use appropriate statistical tests. The descriptive analyses, including mean (in the case of symmetrically distributed data), median (in the case of a skewed distribution), and standard deviation, were appropriate for the continuous data (i.e., disease duration) in Section 1 of the questionnaire (demographic dataset), while the percentage and frequency of responses were used for Sections 2 and 3 of the questionnaires.

Comparisons between the independent variables of interest were carried out using Fisher's exact test. A level of $p < 0.05$ was selected for statistical significance. Trends and differences in the data were observed and commented upon using the supporting written data. Items in the MMAS-4 scored one for every 'Yes' answer and zero for every 'No' answer. A total score of zero indicates high adherence, 1–2 indicates medium adherence, and > 2 indicates low adherence (Morisky et al. 1983; Morisky et al. 1986).

Logistic regression analysis was used to determine the association among the questionnaire variables (revised age, gender, disease duration, number of medications per day, previously owned and used smart devices, and adherence scores) and interest in using smart device apps.

A significant level of $p < 0.05$ was selected to determine potential factors that might affect the participant's interest in using technology. In addition, age was grouped into three categories (40–60, 60–80, and 80–100) to facilitate the analysis of logistic regression.

The qualitative data from the free text boxes were analysed using deductive thematic analysis to identify any comments that reflected the frequency of the respondent's perception of technology use (Braun and Clarke 2006).

6.3.3 PHASE II QUALITATIVE STUDY

Following the Phase I questionnaire, a qualitative approach was employed to explore PwPs' perceptions in greater depth, specifically to understand the factors of relevance to medications that most affect the patients, and how mHealth apps may help. This was accomplished through

semi-structured face-to-face interviews with PwPs. The interviews focused on a number of broad topic areas, including (i) identifying PwPs' knowledge of their condition, (ii) identifying PwPs' knowledge of their PD medications, any issues that arose, and the method by which they solved these issues, (iii) their perceptions of using technology such as mHealth apps, and (iv) the benefits of and concerns about using technology. This section describes the specific method for conducting these interviews, and a broad explanation of the qualitative methods used for these interviews can be found in Chapter 5.

6.3.3.1 DEVELOPMENT OF INTERVIEW TOPIC GUIDE

The interview topic guide (see Appendix 6.2) was developed based on the following:

(i)   Data gathered from the questionnaire in Phase I of this study; and

(ii)   Existing literature on the perceptions of patients with other chronic diseases of mHealth apps.

The interview topic guide was separated into two parts. In the first part, participants were asked about their knowledge of PD, its treatment, and the potential side effects of the medications. Participants were asked about their current and previous experience of using technology, any benefits they perceived, and any concerns they identified. In the second part, the researcher showed the participants pictures of the uMotif® app and its contents as an example of an app, used to provide an illustration of the concept of an mHealth app for the participants. The prototype iPad-based app does not currently contain a section about the medication, so the uMotif® app was used as an example. Using the uMotif® app as an example comprised a reflection on the aims of the study and helped immerse the participant in the interview. Then, participants were asked about their opinions of apps similar to uMotif® compared to their presently used method and were asked for suggestions for design improvements and concepts for an app that would meet their needs and requirements. They were also asked about the factors that might affect their continued use of the app.

The topic guide was reviewed by the researcher's lead supervisors, and the first two interviews were conducted to pilot the topic guide. The pilot interviews were successful, and no major

changes were required, so the results from these interviews were then included in the final analysis. As explained in Chapters 4 and 5, the purpose of the study was explained to the participants at the beginning of each interview.

6.3.3.2 SAMPLING CONSIDERATIONS, PARTICIPANTS, AND RECRUITMENT

Purposive convenience sampling was used to recruit PwPs across Wales. Recruitment continued until the data were saturated and strong repetition of data had been achieved (Corbin and Strauss 2008; see Chapters 4 and 5).

The participants were recruited from Phase I of this study (the questionnaire). Following the survey, the respondents were offered a separate link to input their contact details if they were from Wales and were interested in taking part in further interviews. In addition, a recruitment email was submitted to the staff organisers of the Parkinson's UK local café group (Local groups | Parkinson's UK) to recruit further participants. For logistical reasons (constraints regarding time, distance, and transportation), the recruitment of this phase was restricted to PwPs living in Wales.

Participant recruitment was conducted via email by contacting potential participants who provided their contact details. The email detailed the proposed interview time (typically prearranged by the participants) and provided a consent form (see Appendix 6.3) and a copy of the information sheet and cover letter (see Appendix 6.4). Written informed consent was obtained from each participant on the day of the interview.

6.3.3.3 DATA COLLECTION

As mentioned above, the data were collected by conducting face-to-face interviews. The interviews were conducted either at the participants' house, which was often a convenient place for them, or at the School of Pharmacy and Pharmaceutical Sciences, Cardiff University, upon the participant's request.

As explained in Chapter 5, at the time of the interview, the researcher introduced herself and gave the participants an opportunity to ask questions about the study. The participants were then provided with a consent form to sign and date. The researcher explained that the

interview was confidential and that only the research team would have access to the data. The researcher also explained how the collected data would be anonymised, stored securely, and retained for one year at Cardiff University. After permission was obtained, the interviews were started, and audio recorded.

A reputable, approved transcription company was used to help the researcher transcribe the interview audio files, which were sent electronically by uploading them to a secure server used by the transcription company. As described in Chapters 4 and 5, audio files were transcribed verbatim, and any information that could identify participants in the transcripts was anonymised (see example in Appendix 6.5). The researcher confirmed that the transcription company had a confidentiality agreement and was approved by Cardiff University to ensure that the participants' information and interview data were protected. Once they were complete, the transcripts were sent to the researcher, and to check the accuracy of the transcripts, the researcher listened to the audio recordings while reading the transcripts.

6.3.3.4 DATA ANALYSIS

The data were coded and analysed using thematic analysis via inductive and deductive approaches. The researcher is a pharmacist; however, she has no experience or background dealing with PD medications, and no experience working or living with a PwP, so may not fully understand the participants' experiences or the psychosocial context regarding their medications. This allowed for the use and conduction of the inductive analysis approach. According to Braun and Clarke (2006), both inductive and deductive approaches can be used to analyse the data. This is called 'hybrid' approach, where the researcher begins with a deductive or theory/question-driven coding system and then adds new codes inductively as they are discovered (Braun and Clarke 2006; Thomas 2006; Xu and Zammit 2020).

The transcripts were coded and analysed by the researcher and then reviewed by the researcher's lead supervisors. Further details on the general methodology of thematic analysis approaches can be found in Chapter 4. An example of the developed themes is shown in Table 6.3.

6.3.3.5 ETHICAL CONSIDERATIONS

This mixed-methods study was approved by the Cardiff University School of Pharmacy and Pharmaceutical Sciences Ethics Committee (see Appendix 6.6). The participants were invited to participate in Phase II by using the pre-approved invitation letter and participant information sheet, as discussed above (see Appendices 6.7 & 6.4).

Table 6.3: An example of thematic analysis leading to codes and themes

Codes	Themes	Quote
Neuro-degenerative, it is degenerative, dopamine cell shut down	Participant's knowledge of condition	*'There's no cure. It's degenerative, which means it'll just get worse.'*
Help me remember, personalised medications, generate report, alarm, and aid consultation	Perceived benefits of using smart device apps	*'It's getting it [medications] on time.'*

6.4 RESULTS

The results are presented in two phases: (i) Phase I–quantitative analysis (questionnaire) in 6.4.1, and (ii) Phase II–qualitative analysis (semi-structured interviews) in 6.4.2.

6.4.1 PHASE I – QUESTIONNAIRE DETERMINING THE PERCEPTIONS OF PWPS ON THE UTILITY OF TECHNOLOGY TO RECORD PD MEDICATION USE

The questionnaire remained open for one month, from September 16, 2019 to November 17, 2019. The respondents were asked to complete either the online survey or request a paper form of the questionnaire. All respondents completed and submitted the online version of the questionnaire; no requests for the paper version were received. Additionally, there was very little qualitative data (from the free text comments) analysis, although the researcher included it to provide some context to help understand participants' responses.

6.4.1.1 Response Rate

Of the 5,500 registered members of the network, 413 completed the online form of the questionnaire, providing an overall response rate of 7.5% and exceeding the calculated minimum sample size (360) required for validity. Considering the size of the sample is essential to have confidence in the findings and understand whether they can be generalised to a wider

population (achieving a proper estimation about the PwPs' perceptions who are registered in the Parkinson's UK database).

6.4.1.2 Demographic Characteristics

Section A of the questionnaire collected demographic data relating to the respondents. Each respondent was asked to indicate their age, gender, duration of disease, onset of symptoms before diagnosis, number of prescribed PD and non-PD medications, and frequency of PD medications per day. Table 6.4 shows the respondents' demographic characteristics.

Table 6.4: Summary of demographic characteristics (M = mean; SD = standard deviation)

Characteristics	N	%
Age		
30–40	2	0.5%
40–50	18	4.4%
50–60	74	17.9%
60–70	152	36.8%
70–80	145	35.1%
80–90	19	4.6%
90–100	3	0.7%
Gender		
Male	230	55.7%
Female	183	44.3%
Rather not say	-	-
Duration of disease (Year) M(SD)	6 (4.9)	(range 3–33 months)
Onset of symptoms before diagnosis (year) M(SD)	3.5 (3.6)	(range 0–29)
Number of prescribed PD medications (median)	2	(range 0–6)
Frequency of doses of PD medications per day (median)	5	-
Number of prescribed non-PD medications (median)	2	(range 0–14)

6.4.1.3 Perceptions of technology use

Section B of the questionnaire focused on exploring perceptions of technology, such as smart device apps, to aid in the management of PD medications. A total of 409/413 (99%) of the respondents owned some sort of digital technology (computer/smart device), and 407/413 (98.5%) had used a computer or smart device. The respondents were asked to specify the type of smart devices they owned and used (mobile phone, laptop or desktop computer, tablet or iPad, Kindle or e-reader, and smartwatches) and the health or game apps they used. The

mobile phone was the most frequently owned and used smart device, as indicated by respondents: 355/409 (87%) vs 318/407 (78%), respectively. Table 6.5 shows the frequency of respondents who owned or used a smart device, while Figures 6.2 and 6.3 show the types most used and owned by respondents. The study findings also showed that mobile phone (health and game) apps were owned and used by respondents: 118/409 (29%) and 128/407 (31%), respectively, as shown in Figure 6.4.

Table 6.5: The frequency of owned and used smart devices as reported by respondents

Number of smart devices	Number of respondents who owned	Number of respondents who used
No. of devices	4	6
1 device	26	29
2 devices	55	46
3 devices	66	72
4 or more devices	262	260
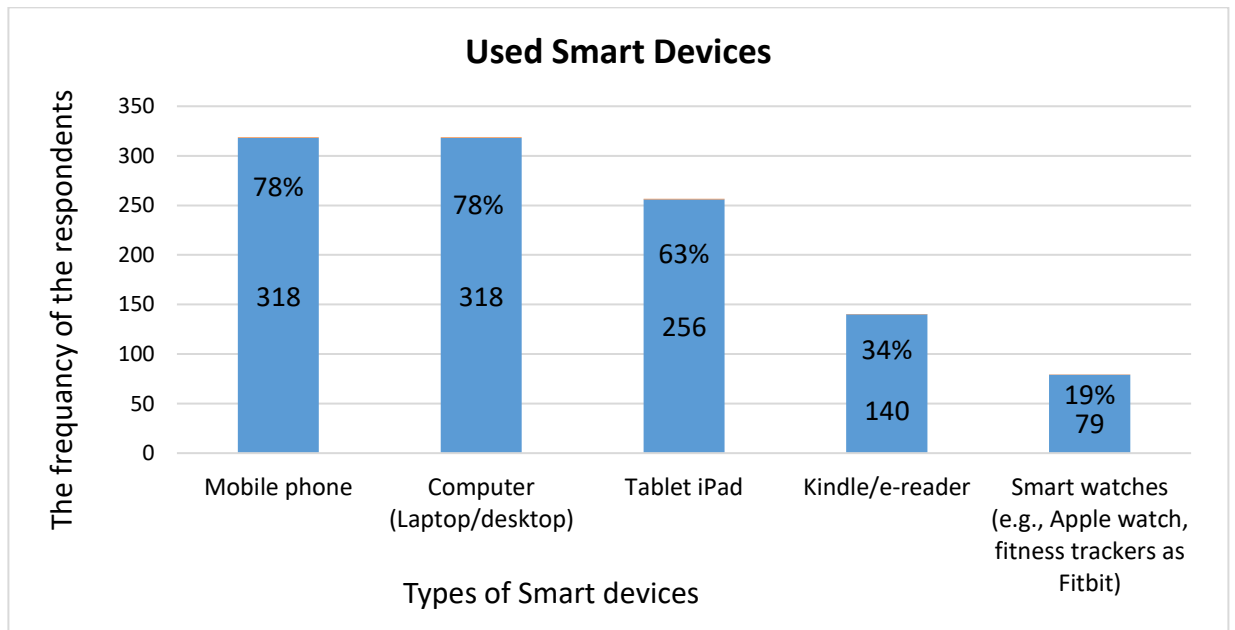
Figure 6.2: The types of smart devices most used by respondents (n=407)

Owned Smart Devices

The frequncy of the respondents

- Mobile phone: 87% / 355
- Computer (Laptop/desktop): 80% / 326
- Tablet iPad: 66% / 269
- Kindle/e-reader: 35% / 144
- Smart watches (e.g., Apple watch, fitness trackers as Fitbit): 23% / 94

Types of Smart Devies
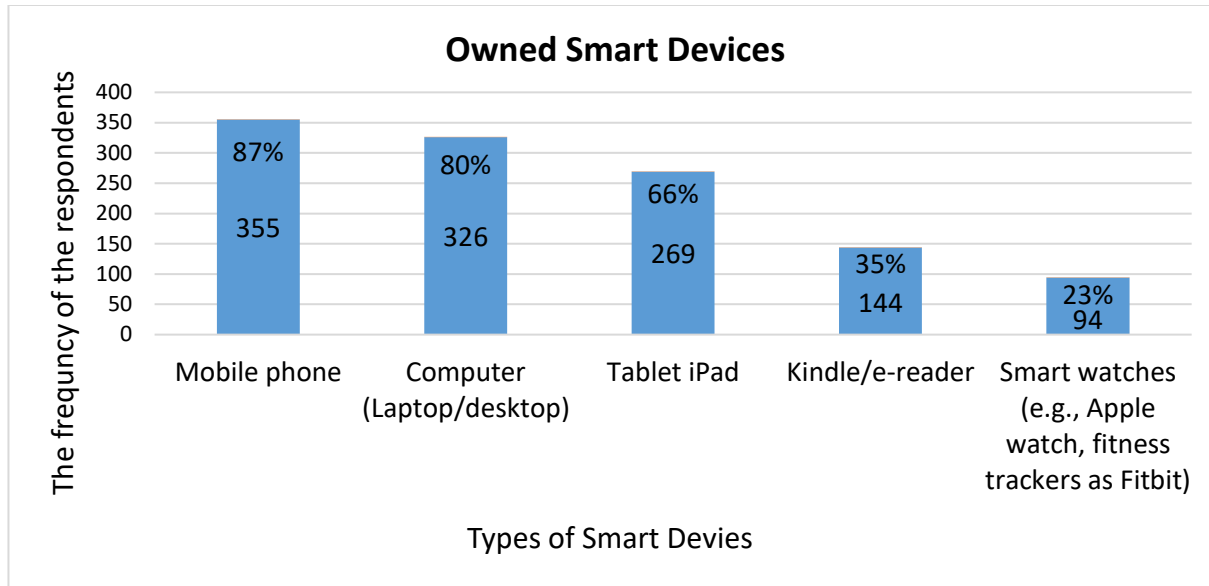
Figure 6.3: The types of smart devices owned by respondents (n=409)

Owned and Used Smart Device Applications

The frequancy of respondents

- Owned: 29% / 118
- Used: 31% / 128
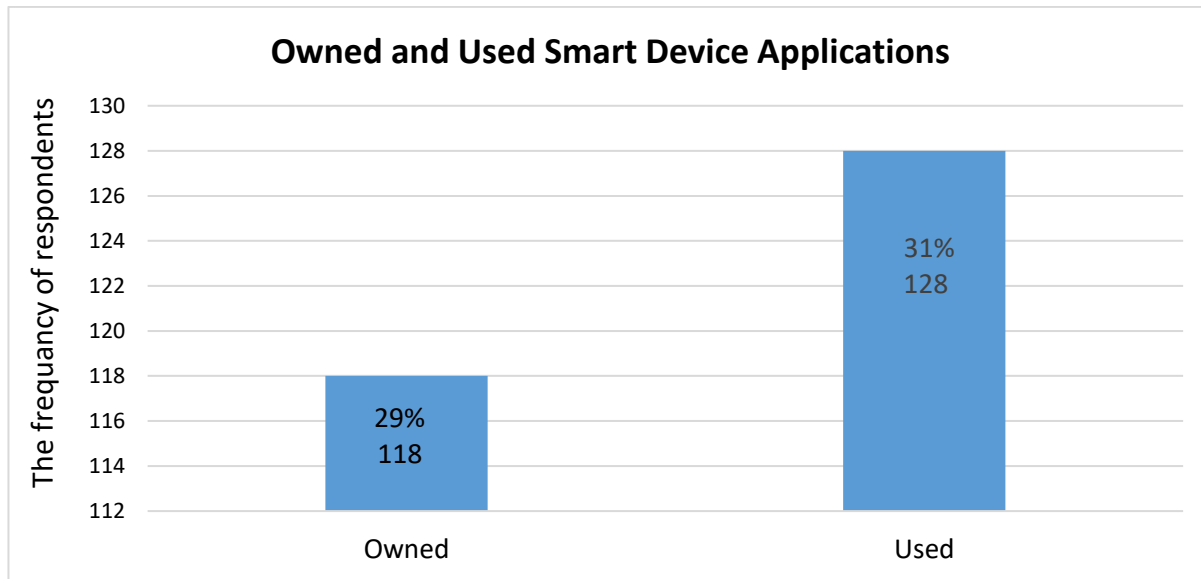
Figure 6.4: The frequency and percentage of smart device apps owned and used by respondents (n = 409, n = 407)

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To get a sense of how they were currently using their smart devices, respondents were asked about the activities for which they used their smart devices. Respondents reported a range of activities, which are shown in Figure 6.5.
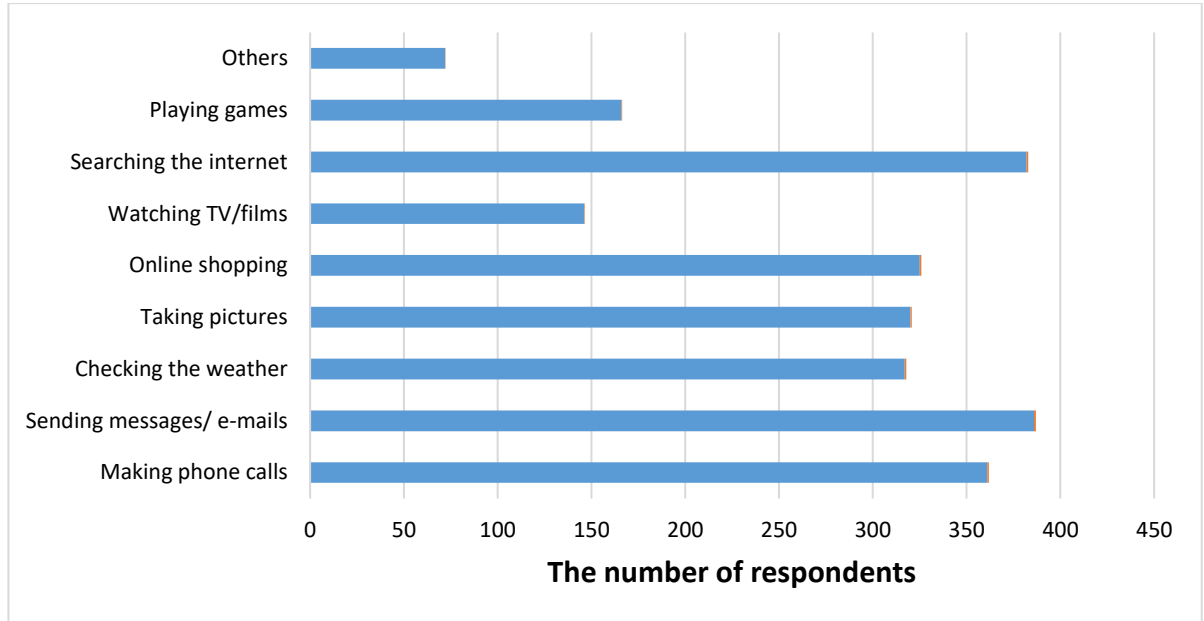
Figure 6.5: Activities for which respondents reported using their smart devices, shown as the number of respondents who selected each option. 'Others' included banking (n=5), Instagram (n=5), Facebook (n=2), writing documents (n=15), Microsoft office® (n=20), reading news (n=10), road maps (n=10), and fitness tracking apps (n=5)

In relation to the management of PD, the respondents indicated several activities for which they used their smart devices, as shown in Table 6.6. The majority (81%; n = 330) of respondents had used their smart devices to help them understand PD, and 3.4% (n = 14) indicated other activities, such as using the PD Warrior® app for exercise (n = 7) and using alarms to take tablets on time (n = 7).

Table 6.6: The number and percentage of activities used related to PD management and medication as reported by respondents (n=407)

Smart device activities related to PD		N	%
Information searching	To understand more about the disease	330	81%
	To look up ongoing research and potential treatments	318	78%
	To understand better the diagnosis of their health condition	277	68%
	To become involved as a participant in a clinical trial	275	67.6%
	To look up side effects of medications	236	58%
	To look for opportunities to become involved in research that is not a clinical trial	230	57%
	To look for treatment options	210	52%
Condition management	To manage symptoms	121	30%
	To manage medications	106	26%
	To record symptoms	57	14%
Communication and support	To communicate with others who have Parkinson's (e.g., forum websites)	151	37%
Others		14	3.4%

In total, 84% (n = 348/413) of the respondents were interested in using a smart device app that was specific for PD management in the future, while 16% (n = 65/413) were not interested. There was no significant relationship between respondents who were interested in using a smart device app and who had previously indicated that they *owned* a computer or smart device (phone/tablet/Apple watch) (84% vs 99%, **Fisher exact test**, p = 0.112). In contrast, there was a statistically significant positive relationship between respondents who were interested in using a smart device app and those who had *used* a computer or smart device (phone/tablet/Apple watch) previously. Respondents who had previously used a computer or device were more likely to report interest in using a smart device app than those who had not previously used a computer or other device (84% vs 98.5%, **Fisher exact test**, p = 0.006).

The respondents offered several reasons for their lack of interest in using a smart device app for PD, as shown in Figure 6.6. These included HCPs not recommending any app for them to use (37%; n = 24/65) while the same percentage of respondents mentioned other reasons

(37%; n = 24/65), such as memory loss (n = 1), tremors (n = 3), belief that there was no need to use an app (n = 15), and satisfaction with their current method (e.g., alarm and pill boxes; n = 5).
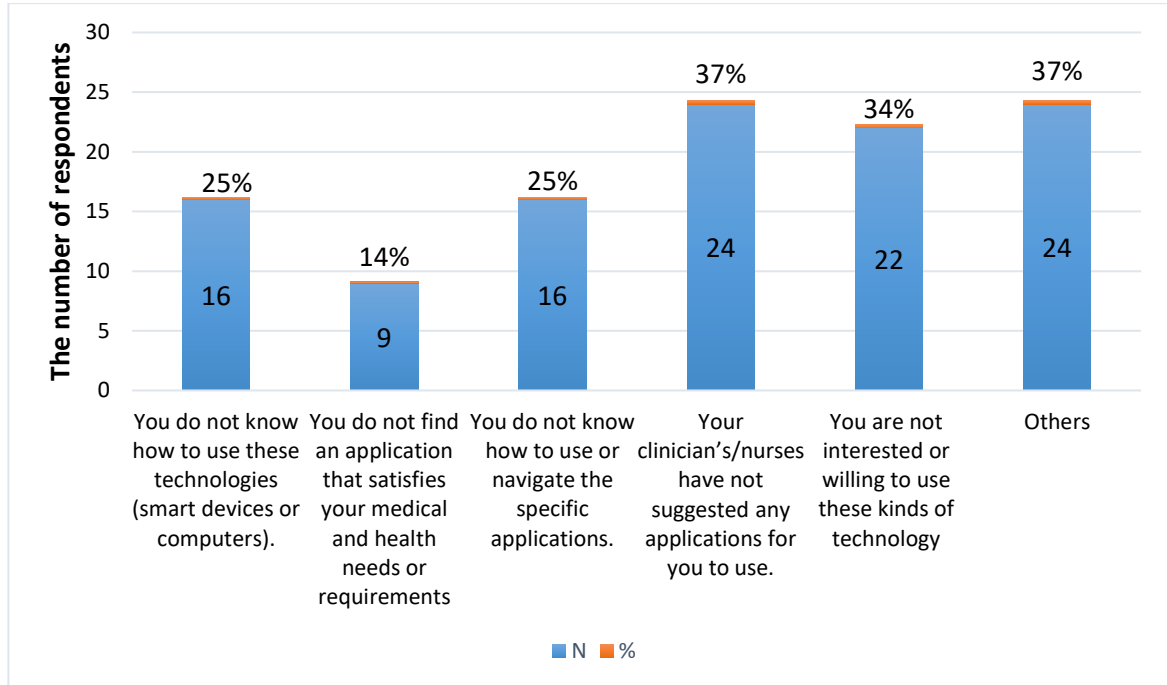
Figure 6.6: The number and percentage of different reasons for not using a smart device app, as reported by respondents (n=65)

Generally, apart from the respondent's interest in using a smart device app for PD, they identified the potential benefits of using such an intervention. The respondents thought that using a specific smart device app for PD could facilitate the recording and management of PD in different areas, such as taking medications on time and recording side effects (see Figure 6.7). A small proportion, 3% (n = 13/413) of the respondents, also mentioned other areas, such as reporting their conditions and medications to emergency services in the event of an accident (n = 3), recording the symptoms if they did not take their medication on time (n = 4), and tracking the progression of PD in more detail (n = 6).
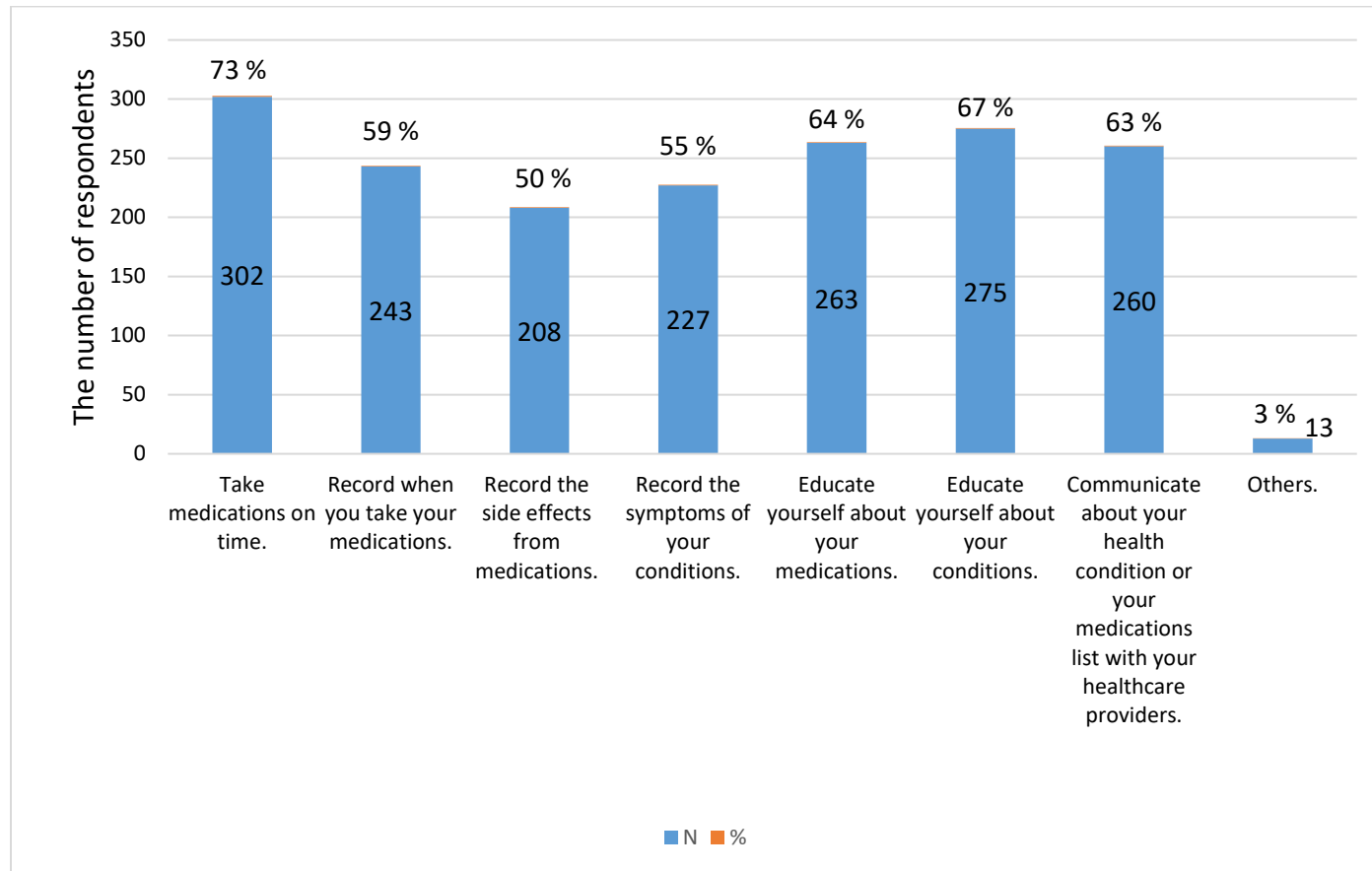
Figure 6.7: The number and percentage of the suggested areas in which using a smart device app could benefit the management of PD (n=413)

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To further explore the potential factors that might be associated with PwPs' interest in a smart device app, a binary logistic regression was used. A total of seven variables were included in the model, as shown in Table 6.7. These factors were included because they could impact the user's intention to use a smart device app (Davis 1993; Venkatesh et al. 2003). The findings show that only PwPs younger than 60 and who had previous use of a computer or smart device were significantly more likely to report interest in using a specific smart device app for PD (p = 0.034 and p = 0.040, respectively).

Table 6.7: Summary of logistic regression analysis; CI (confidence interval), OR (odds ratio), p<0.05

Factors	P-Value	OR	95% CI
Age, year (40–60)	0.034		
(60–80)	0.225	0.199	(0.015–2.694)
(80–100)	0.092	0.108	(0.008–1.437)
Disease duration	0.149	0.961	(0.910–1.1015)
Gender	0.270	0.729	(0.416–1.278)
Adherence score (MMAS-4)	0.179	0.819	(0.611–1.096)
Number of medications per person	0.672	1.057	(0.817–1.368)
Previously owned smart device	0.473	2.520	(0.202–31.47)
Previously used smart device	0.040	7.740	(1.095–54.71)

6.4.1.4 Adherence to PD medications

The final section of the questionnaire investigated the respondents' reported adherence to their PD medications using the MMAS-4. The number and percentage of respondents who responded, 'Yes' or 'No' to each item on the MMAS-4 are shown in Figure 6.8. The items with the highest percentages of PwPs responding affirmatively were 'Do you ever forget to take your medicine?' and 'Are you careless at times about taking your medicine?', at 63% (n = 260/413) and 53% (n = 220/413), respectively.
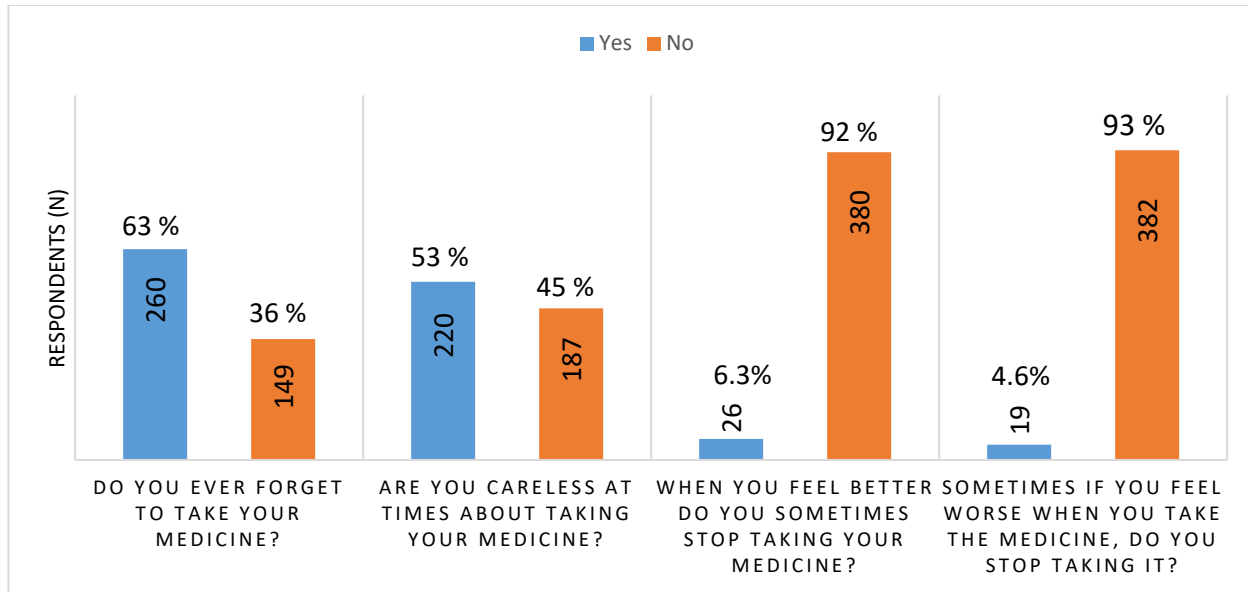
Figure 6.8: The number and percentage of respondents with 'Yes' responses by MMAS-4 items (n=413)

The percentages of respondents by MMAS-4 score (0, 1, 2, 3, or 4) are shown in Table 6.8. A score of 0 indicates high adherence, a score of 1 or 2 indicates intermediate adherence, and a score of 3 or 4 indicates low adherence (Morisky et al. 1983; Morisky et al. 1986). The majority of respondents reported intermediate (50%; n = 207/413) or low (49%; n = 203/413) adherence to PD medications.

Table 6.8: Number and percentage of respondents by MMAS-4 score (n=413)

MMAS-4 Score		%	N
0 score	(High)	0.73	3
1 score	(Intermediate)	6.5	27 ← **207**
2 score		43.6	180
3 score	(Low)	22	91 ← **203**
4 score		27	112

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6.4.2 PHASE II –SEMI-STRUCTURED INTERVIEWS

This section describes the results of the qualitative interviews with PwPs, which aimed to explore and better understand their perceptions regarding the use of technology to aid in the management of PD medications and related side effects.

6.4.2.1 Participants

In this study, nine PwPs were interviewed between October 2019 and November 2019, wherein data saturation was reached with a strong repetition of data and themes, and the study aims had been achieved. All PwPs were recruited via Phase I of this study, and the interviews were conducted either at the participant's house or in the School of Pharmacy and Pharmaceutical Sciences, Cardiff University. In order to maintain anonymity, the name of each participant was replaced by an abbreviation, such as P1 and P2. The mean duration of the interviews was 34 minutes (range: 27–45 minutes).

6.4.2.2 Interview findings

Building on previous studies conducted in this thesis, this phase aimed to delve deeper into the results from the questionnaire presented in Section 6.4.1 to gain additional understanding of the findings. Inevitably there is some overlap with discussions from the focus groups in Chapter 4, but the focus here is different. The researcher recognised this shared topic area with regard to mHealth technology use and acceptance by PwPs and tried to be more inductive during the analysis process to allow themes to develop from this new data, rather than deductively produced based on earlier phases of this PhD research. However, the similarity between some of the themes identified in this study and the previous work (Chapter 4) should be acknowledged, and the following findings should be read with consideration of these similarities.

Five key themes were identified: knowledge related to the condition, PD medications issues/solutions, attitude toward technology/use of a smart device app, motivators to use a smart device app, and a suggestion feature and design for a useful smart device app. Each

theme contained relevant subthemes, as shown in Figure 6.9. In addition, the themes captured the richness of the collected data, and theme development was driven by this data; therefore, unequal representation of the themes was apparent in this study.

As mentioned in Chapters 4 and 5, to gain a further understanding of the findings, some of the qualitative data were described and presented using quantitative inferences, such as 'the majority' and 'a few', and numerical indications (Maxwell 2010; Monrouxe and Rees 2020).

Knowledge related to condition

* PD

* PD medications

PD medications Issues/ used and suggested soluations.

* Unintentional non-adherence/used of personal method to resolve it.

*Experienced side-effects of medications/record it to PDNS.

* Lack of information regarding PD medications/the need to involve pharmacists to resolve issue.

Attitude toward technology/smart-device app use

* General attitude.

* Perceived advantages.

* Perceived concerns.

Motivators to use a smart-device app

* Perceived usefulness.

* Recommendations from HCPs

* Perceived ease of use

* Cost

Suggestion feature and design for a useful smart-device app

Figure 6.9: Identified themes and sub-themes

6.4.2.2.1   Knowledge related to condition

This theme reflects the views of PwPs regarding their level of understanding of PD and its medications. Two key subthemes were identified: knowledge about PD and knowledge about PD medications.

1. Knowledge of PD

The findings show that participants expressed varying levels of knowledge about PD; some of them demonstrated a basic level of knowledge as they defined the condition and described its main symptoms.

> *It is a neurodegenerative condition and, unless you come up with some new drugs, then I will deteriorate over time. The main facets of the disease are affecting my walking, also my voice. P2*

Four of the participants demonstrated a higher level of knowledge about PD, as they provided further explanations about the causes that might lead to PD (e.g., loss of dopamine in the brain).

> *I know the basic principles that certain neurons in the brain are dying away, and they are the ones that produce dopamine, which is a chemical that translates the thought process into action. I know that a protein called alpha-synuclein is triggering the death of the neurons, but nobody knows why that happening, why the protein is misfolding. P4*

The participants also explained how they gained knowledge about PD from different sources, for example, via HCPs, the Parkinson's UK website, and searching the internet. No single source was highlighted as the most frequently used source to gain information.

> *I do lots of work with Parkinson's UK, the Welsh team. I am one of those people that need to know about my condition. I am a bit of a Googler, and the work that I do in the charity brings me into contact with PDNSs and other medical people, so I am more than informed about my condition. P1*

2. Knowledge of PD medications

All participants showed a theoretical understanding of the importance of their PD medications and of taking them at the recommended time.

> *I tell people how important it is (a) to take your medication and (b) to take it on time, so I am fully aware of that, because the medication is actually a replacement for dopamine in the brain, and what you try to do is to take the medication in a way that actually keeps the dopamine levels at a certain amount within the brain. P1*

In the context of knowledge about the mechanism of action for PD medications, the participants demonstrated a basic level of understanding about such medications. They understood that PD medications were used to maintain the level of dopamine in the body and improve symptoms.

> *My medication replaces a chemical that is missing–dopamine. Seems that it hampers my ability to function. So, I get incredibly tired, stiff, and exhausted without it; it is very painful as well. P3*

6.4.2.2.2   PD medication related issues/used and suggested solutions

This theme explored the issues that PwPs had with regard to their PD medications and potential solutions for issues either identified by the participants or suggested by the researcher. Three key subthemes were identified and reported as issue/solution: unintentional non-adherence/use of personal methods, experience of side effects from medications/reporting to HCPs, and lack of medication-related information/subsequent need to involve pharmacists in patients' care.

1. Unintentional non-adherence/use of personal methods

There appeared to be a link between participants' daily routines and how well their medication doses fit with this routine, impacting levels of adherence. Six of the participants admitted that they occasionally forgot to take their medications. The explanations given were 'too busy with work'; 'change in routine', such as going out for shopping, to church, or meeting friends, or

'long-distance travelling', which might result in changing the time at which they took medications.

> *[I forget my medications] when I am travelling on holiday, particularly delayed flights; you have to think about how you manage your medication on that day... Otherwise, I just will not be able to function. P1*

Their awareness of symptoms not being controlled acted as a reminder that they may not have taken their medication at the right time, although they might not recognise this until considerably later.

> *I tend to forget [medications] when it is working well. Normally, every three hours, I can feel it wearing off, so you know you have to take it, but sometimes you can go as much as six hours, and you feel quite normal. P3*

Three of the participants reported that they never forgot to take their medications. The reason given was that the medication regimen was simple (e.g., just one or two PD medications) or that the frequency of administered medications was very straightforward (e.g., once or twice daily).

> *At the moment, I'm in a fairly simple situation that the drugs I'm taking, both for Parkinson's and for other conditions, are normally taken first thing in the morning, which is easy. So, I do not think I have ever forgotten to do that. P2*

> *It is very easy because I have only got two drugs. P6*

However, seven of the participants had solutions and systems in place to help minimise the impact of changes in their daily routines or forgetfulness regarding adherence. The participants reported having a personal system in place to remind them to take their PD medications. Several systems were described by the participants, which included using some sort of digital devices (e.g., pill boxes, phone alarms, smartwatches with multiple alarms, and mobile phone apps like MediSafe®), taking medications first thing on the morning, and use of a diary. One of the participants described how using his alarm watch helped him remember his medications.

I discovered through Parkinson's UK that there are watches with multiple alarms. I have invested in two of those. I bought a bigger watch, and it has eight alarms on it, and that reminds me, because it is a vibrate alarm as well as a sound alarm, if I want. I set it on vibrate, and that reminds me at the appropriate times to take my medication. P8

Two of the participants mentioned how using a mobile phone app helped them organise and remember their medications during different situations.

I use a dosette box, but more recently, I have started using an app called Medisafe… which allows you to set up your times and gives you a reminder. So, it reminds me to take my medication. Once you have taken your medication, you can go in and indicate you have taken it, or in fact, you can delay it as well if you want. So, you can actually say, 'I am putting it back half an hour because I am on a flight', in the airport, or maybe not take the medication, or you take it early. P1

One of the participants explained how having a routine in place helped her remember to take medication. This routine negated the need for any external device prompts.

When I wake up...I take everything [medication] because they say you should not take them with a full meal. P6

Another strategy reported by one of the participants was using a diary.

Simply, I diarise taking my medication every day at the time I wake up. I am quite keen on keeping my diary up to date, so I always look at my diary for the coming day, and the first thing I'll see is 'Take your medication'. P2

In contrast, two of the participants preferred to rely on their memory for taking medications, as they believed that they were at a stage of their disease where they did not need assistance, and because they were on simple regimens with no need for any device at that time.

I may need help at some stage in the future. I do not know yet, but at the moment, I am just relying on my memory. I think I am quite good at remembering to do it [take medication on time]. P9

At the moment, I am managing, so this is a way of keeping myself mentally active. P3

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2. Side effects from PD medications/reported to HCPs

In the context of PD medication side effects, there was agreement among all participants on the lack of awareness about the potential side effects, and many of the participants explained that they only became aware of potential side effects when they became reality as they experienced them. The most prominent side effect reported by four of the participants was dyskinesia.

> *I learned about dyskinesia by myself. It was never explained to me that I might get dyskinesia from taking Sinemet. P4*

Another participant also explained how difficult it was for him to identify or differentiate the side effects from the actual symptoms of PD.

> *I was very aware from the beginning that there is a long list of potential side effects, but the basic things, I found it hard to identify any side effects of the medications as opposed to symptoms of the disease. I have quite a few symptoms, but I do not put them down as side effects of the medications, just because I do not know what a side effect of the medication is. P9*

Almost all participants reported that they had direct contact with their HCPs (PDNSs and consultants) to report medication-related issues or other issues.

> *I have a Parkinson's nurse, so I can ring her up, or even the consultant, and report it to them. P3*

3. Lack of medication-related information/need to involve pharmacists in patient care

All participants consistently reported insufficient practical information with regard to PD medications. They reported a lack of information related to medication administration instructions, potential side effects, contraindications, and possible drug-drug interactions. For example, one of the participants described how he had been taking his medication without any instructions provided by HCPs.

> *I take Rasagiline first thing in the morning. I have been doing that now for four or five years. Nobody has ever said to me, 'Take it first thing in the morning'. So, I do not know*

whether that is the right time to take it or not. It may be better for me to take it last thing at night or midday, but nobody has ever explained that to me. P4

Another participant added:

I was going on a boat, and I usually get sick, and my husband said, 'Do you want to take this [travel sickness tablet]?' Then he said, 'Oh, hang on a sec. I have got to check it is not going to interact with anything.' I said, 'No, I'll be fine. I am just on Levodopa.' He looked it up, and it said I was not supposed to take it with Levodopa. P5

I learned not to take it [PD medication] at lunch time because the protein can affect the efficiency, but all of that I have just got from websites and [a] Facebook group. So, that kind of just basic information, 'Okay, this is Parkinson's medication, here are a few things you should be aware of' [is missing]. P5

The researcher asked about the participants' views on involving pharmacists to minimise the issue of insufficient medication-related information. Participants' opinions varied from 'totally agree' to 'totally disagree'. All participants consistently reported that pharmacists were not engaged in their healthcare in any aspect, and the only role they had was dispensing and preparing their medications.

I have very little communication with the pharmacist. The doctor sends my prescription to them, and they prepare it. With regard to Parkinson's, I have had no conversation with them. P8

Another participant added:

The pharmacist sees his role really to provide the medication that has been prescribed. P1

Only two of the participants were not opposed to involving pharmacists in their healthcare, but they believed that pharmacists would need training to be capable of doing that.

I do not think that is an overnight solution, educating pharmacists to understand Parkinson's. They sometimes say to me, 'Are you sure you need this medication?' I do

not think that is a question that you should be asking somebody with Parkinson's at all, honestly, because you need it. P7

Although one advantage relating to the accessibility of pharmacists was noted, participants explained how it would be easy for them to contact pharmacists for information about their medications.

I think the pharmacist is easier to contact than the specialist. If they could play a role in that, that would be important. P4

The remaining participants were opposed to the suggestion of involving pharmacists in their care. The explanation was that pharmacists are not specialised in PD, and the PwPs would therefore not trust them in regard to PD-related information.

I do not think I would trust them. There are so many illnesses out there that a doctor has been trained in for years and years and knows all the disease and the medications. A pharmacist has not had that amount of training and can dispense the pills, but does not see the results of the medication, and I do not think I would trust a pharmacist to have that information. P6

6.4.2.2.3   Attitude toward technology/smart device app use

Although some of the participants said they had used some sort of digital device to help them with medication taking, this theme reflects the views of PwPs on using a specific smart device app to aid in the management of PD medications and report side effects. Three key subthemes were identified: general attitude, perceived advantages, and perceived concerns.

1. General attitude

All the participants described their interest in using technology, such as a smart device app, to help them with their PD medications and report any side effects from it. Some of the participants demonstrated the importance of using a smart device app to help them with their medication, especially in the advanced or later stages of PD, as some PwPs might develop dementia.

> *I think it is useful, and it would be useful in the future when I probably become more forgetful and because it's important and the condition has progressed. P3*

Another participant described his interest, even though he thought there was no need for him to use it at that moment, as he was on a simple medication regimen.

> *I think that is the best way because, in the future, when I am supposed to be taking drugs, say eight in the morning and two in the afternoon, when it gets to three or four o'clock, and suddenly remember that I should have taken my drugs two hours ago. So, you need all the help you can get, and a smart device app, I think, is the best way you have got. P2*

As mentioned in 6.4.2.2.2 (1), two of the participants were already using a mobile phone app to assist in their own medicine management. They also described how their personal positive experiences with technology had led them to encourage and advise other PwPs to start using these kinds of technologies.

> *I always mention the technology, and some of the older people, who are sort of longer into their Parkinson's diagnosis, have taken up using Medisafe®, and that is benefitting them as well because they were using things such as alarms on their phone or just having trained [to take medication on time], some people are forgetting it. So, it is something that I have really tried to get others to embrace as well. P7*

As described in Section 6.3.3.1, the uMotif® app was used as a case example to illustrate what a specific app for PD might look like. When shown this exemplar, all the participants reported positive impressions, even expressing an interest in using it over their current personal methods.

> *I think it is a good idea. I think that would be even more helpful; certainly, yes, I could use something like that. P5*

One of the participants who used the MediSafe® app, which is a general app for chronic disease, said:

> *It is designed more for Parkinson's [uMotif® app]; this is more specific to my requirements, then I would use it obviously. P1*

2. Perceived advantages

Four main advantages were identified by the participants in regard to the use of a smart device app for medication management: taking medication on time, a reminder system, empowering patients, and aiding consultation with HCPs.

2.1 Taking medication on time: Almost all participants described how a smart device app could help them take their medication on time, but when they were asked about the potential benefits, only two of them described that clearly.

> *It is getting it on time, and I cannot emphasise enough how my consultant has told me. 'You have got to take your medication on time!' P7*

2.2 Reminder system: There was agreement among all the participants that the main advantage of using a smart device app was having a reminder system, such as a notification with an alarm. PwPs can set reminders on the app, and then an app can remind them about their medications**.**

> *This is my phone—much better to nag, to remind you to do it, than just relying on your pill box. P4*

Another participant explained how using an app could help him, even though he did not have any memory issues:

> *I normally remember, but there are days when the app rings, and I think. 'Oh, time to take my medication!' If I am sort of occupied in the garage or in the garden, and I forget, it will just remind me. P1*

2.3 Empowering patients: Three of the participants described how a smart device app could be used to enhance self-monitoring and support self-management, especially for PwPs who are either on a complex medication regimen or at an advanced stage of PD.

> *I went to a course on self-management, and there were about ten Parkinson's sufferers there, and one of them was on a sort of pump that pumped something into his body. I mean, there were advanced stages, and some of them were on several lots of medication in a day. They, I think, would benefit greatly from that [app]. P6*

Another participant explained how using a smart device app would help him keep track of his medications and progress.

> *Simply just to note what medication you are on, any changes, and, when they do have little problems, what triggers those problems. Personally, I think that would be helpful. P8*

2.4 Aiding consultation with HCPs: There was agreement among all participants on the importance of having feedback from smart device apps, and they explained how they could use this feedback to enrich and support their consultation with their HCPs:

> *My doctor showed me this wavy diagram, and he said, 'I want you to be in the middle of this'. He drew a line through. 'So, we want to smooth out those curves and make your medication work as long as we can, and if we could take that [feedback from app] to your consultant, he can then see how things are working.' P7*

3. Perceived concerns

The participants expressed several concerns with regard to the use of a smart device app to help them with their PD medication, which included age, disease status, security, and behaviours.

3.1 Age: Almost all participants expressed their concerns regarding the age of PwPs and their ability to use a smart device app, even though they tried to avoid generalising and seemed to be very comfortable themselves with using technology. The participants explained their concerns by referring to the fact that PD predominantly affects older people and that they may be less familiar with technology.

> *I can say it is older people where technology is a bit of a barrier. Certainly, my mother and father, they're 80 years of age, they haven't got an app on their phone at all; they would struggle to use that. I am a bit more of a generation where we use technology day in, day out. So, I think it could be an age barrier thing. P7*

A number of participants commented that age would be a temporary barrier for PwPs, as future sufferers would be more familiar with using technology:

> *I think as time goes past and people in their 70s and 80s have grown up using smartphones and technology, then it will be a lot easier for that sort of app to [gain] acceptance, but now, people in their 70s and 80s aren't necessarily that familiar with the technology. P2*

3.2 Disease status: Tremors and shaky hands are key symptoms of the disease, and this was highlighted by five participants as a potential barrier to using a smart device app. These symptoms may lead to a lack of easy manipulation of the screen, and the swiping motion and typing could be problematic.

> *Touch technology is not really the best thing in the world for sufferers with PD with tremors, because your finger goes all over the place sometimes. P9*

3.3 Security and privacy: The participants expressed vastly different opinions regarding the security and privacy of app-held data. Only two of the participants expressed concerns about the security and privacy of their data, as they explained how the stored data might be vulnerable to hacking and accessible to other people.

> *I think I am a little cautious about new technology; I try not to avoid the internet. Some of [the] older people are not afraid of [it] but concerned about where the information is going, how it is being stored, whether it can be hacked, or if it is being read by somebody else. P8*

The remaining participants expressed no concerns about the security and privacy of their data, as they reported that they were very open to sharing their data with people and that they were not concerned about who would have access to it.

> *These days, nothing is private and that's information which is worth giving. So even if there's risk, it is a risk I would be prepared to take. I do not mind so much about my privacy if I know that information is going to be useful and valuable. P5*

Additionally, two of the participants, among those who expressed no concerns about privacy and security, emphasised the importance of developing an app in accordance with the laws.

> *I will accept the fact there are GDPRs out there, and people should be comfortable that it protects their data. So, I think, as long as the app is properly developed and the data that people contribute is properly protected, then I'd be happy for my data to be used. P2*

3.4 Behaviours: Five participants reported that their general behaviours towards using a smart device might be a temporary barrier to their future use of an app related to the management of medications. They explained how they kept forgetting to carry their phones with them all the time, and that using such an app would mean they would need to establish effective discipline.

> *The problem is that I have got an iPhone, but I tend not to carry my iPhone with me, or my iPad. I keep forgetting to put the iPhone into my bag when I am going out. It is just getting into the discipline of doing that. P4*

6.4.2.2.4   Motivators to use a smart device app

This theme reflects PwPs' views on the factors that might affect their decision to use and continue using a smart device app to aid in the management of PD medications. Four key subthemes were identified: perceived usefulness, recommendations from HCPs, perceived ease of use, and cost.

1. Perceived usefulness: In addition to the previously mentioned potential advantages, five of the participants felt that demonstrating how the information from the app would be informative, meaningful, helpful, and relevant to their needs and requirements, and empower them by tracking their conditions, would encourage them to continue using the app.

> *I think if the information they get, they find are useful. If the information is good, beneficial, I would continue to use it. So, it has to be not just observant information; it must be meaningful, and if I see benefits to me as well as to my professionals, then I'd continue using it. I think the important thing is to emphasise at the beginning to patients is the importance of keeping [using app] and continuing because you have taken the 12 months [with] no change: 'Oh I'll stop doing it' and then the next 12 months, you get a*

deterioration, or you wished you had kept that information. The medication I was on, so I think if this 'sold' in the way it says you will see benefits in due course. In the long term, people, I think, would continue, but you have got to sell the idea to them. P8

2. Recommendation from HCPs: The role of HCPs in making recommendations was discussed in different contexts. The majority of participants reported that if their HCPs (either their consultants or PDNSs) promoted an app for them to use, that would affect their decision to use it. There was significant commentary on being guided by their knowledge and specialist expertise in the field, as well as a sense of 'obeying'.

> *I usually try to do what I am told by the consultant or advised by a consultant, because they are the ones who know. I would rather try it [app]. P6*

Not only would patients be more inclined to follow guidance if it came from an HCP, but there was an active desire to see advice in this area coming from specialist clinicians and going beyond a recommendation to actually guide the patients on how to use it:

> *If it is recommended by the medical community, if they can support it, they should say, you know, at the consultation stage, 'Oh by the way, did you know that we have this app?' A little conversation with the nurse, possibly, rather than the consultant, because they have not got time, about how the app works. How they can download it and any questions you have got about the app would be quite good, and the nurse could bring that into their consultations they have first time around with somebody who's been diagnosed with Parkinson's. So, if they could introduce it [app] at that stage and brief [the patients] on how it all works. P1*

Only two participants reported that they would not value a recommendation from their HCPs to either use an app or not, as they would make that decision by themselves if they perceived it to be useful. Beyond that, they perceived a potential bias in the information based on the HCPs' own preferences.

> *The bottom line is that there will be some PD nurses and some consultants that are into technology, and they see the benefit, and there will be those that do not. So, I think if there is an app that is available now, I would like to try it to see if there's benefit. I will make the decision as to whether it is giving me benefit. Rather than merely relying on someone who does not suffer, fortunate for them who do not suffer with PD. So, it is individual again. P2*

3. Perceived ease of use: The importance of user friendliness was commented on in the context of the motivation to use the app.

> *I can use it [app], but the important thing is that it is simple, just simple and clear. P3*

Supporting this, concern about low digital literacy skills among PwPs was raised as an argument for ensuring a simple interface.

> *Thirty percent, forty percent of the Parkinson's population, they are not computer literate, so they will not be able to use [the app] if it is too complicated to use. P1*

3. **Cost:** While most participants had no issue regarding the price of an app if they found it useful, one of the participants considered the (low) price of the app to be an incentive for him

to start and continue using an app. They would be more willing to use it if it were free to download.

> *It depends on the cost, but if it were more informative, personally I would be happy to pay towards something. P7*

> *If it is not free, I think it is a consideration because there are apps out there which are on the market free which do the basic job. People are going to compare this app if they are being charged for it. P1*

6.4.2.2.5   Suggestions for features and design of a useful smart device app

This theme reflects PwPs' views on a smart device app that aims to help them with their PD medication management. The participants reported that an ideal app for them would include features for medication adherence, measurement of disease progression, physical activities, and information about PD and its medications.

> *Covered those medication timings and maybe sleep patterns, side effects, and things to talk to at the next clinic. P9*

In addition, suggestions for the ideal smart device app design, according to the participants, were divided into features related to the contents of the app and its functionality. Table 6.9 shows the main suggestions mentioned by the participants.

Table 6.9: Main suggestions for smart device app highlighted by the participants

Features	Suggestions	Descriptions	Quotations
Contents	Information section	An information section regarding both PD and its medications was seen as important by most of the participants. Four of the participants suggested a section detailing basic information on the **disease itself**, although this was contradicted by others who felt it unnecessary, as that kind of information can be found on websites such as Parkinson's UK in more detail. Six of the participants thought adding information related to **PD medications** into an app that included different drug names, dosage strength, shape of drugs, side effects, contraindications, and potential drug-drug interaction would be useful for them.	*'Newly diagnosed with Parkinson's handed leaflets about how to cope with Parkinson's and tips and hints, just general information about Parkinson's, and they are useful, but I know that most people look at them once and then put them aside and don't look at them again. Whereas if it is on an iPhone, it's easier to go back and look at it again.'* P4 *'I think there's a lot of information about Parkinson's. It could be signposted to the Parkinson's UK website, it's very good website in my opinion, and I don't think you are going to cover everything in an app.'* P1 *'There's an array of, say, seven pills, shapes and colours to choose from, so you pick the one that most resembles your pill, and recognised every medication that's there and probably different dosages as well. So, it needs to be robust.'* P7 *'I think in terms of the design, just that key side effects are listed.'* P5
	General activities section	A 'general activities' section in the app was popular, **to support recording activities**, such as **exercise, sleep patterns, and diet.**	*'It would be quite good to [have] a little remember and say, "Oh time to have a little walk, time for a little movement, to go up the stairs".'* P3 *'If you could incorporate things like tips on diet, another thing which is dear to my heart is exercise. I think it's vital for people with Parkinson's.'* P4
Functionality	Simple and easy to use	Almost all participants asked for **a user-friendly app** with simple instructions for use as the app tends to be used by older people.	*'Very simple for my age, it would have to be pretty simple instructions I think for a lot of us.'* P6 *'If you make it user-friendly, once it's set up it's probably straightforward and easy to use.'* P7
	Practicality for reporting side effects	The participants liked the idea of the app enabling them to report any side effects of their PD medications within the smart device app, but **adding a list of the common side effects** of each medication with a dropdown menu next to each one was preferred over free text, as writing it was a concern.	*'I think recording the actual symptoms, I had a bout of tremors or a bout of dyskinesia, where I could tap in information, like causes of dyskinesia, would be helpful; I think the disadvantage for me would be having to write in or type into a tablet, onto a smartphone. There could be a dropdown box for any side effects I've had.'* P8 *'If they are saying something like, are you having side effects? Yes, and then something simple, so I do not have to type too much, but if there*

Functionality			*are common side effects and they're listed, and you just tick what you're having, probably that's easier.'* P5
	Accessible through different devices/ platforms	Five of the participants suggested making the app **accessible to download and use through different smart devices**, such as mobile phones, tablets, and digital watches, and to be available to download through both Apple and Google stores. Two of the participants suggested **connecting the app with the patient's database** at their clinics to benefit from its advantages during consultations.	*'So, if they can be read across devices, if the app can be pretty much standard whether it's Android or an Apple and also between two different Apple devices, that would be helpful.'* P2 *'It would be easier to use an iPad or get the app on watches. Maybe I ought to invest in one of those.'* P6 *'If I was uploading the app on my phone, there needs to be a way of that information getting exported and accessible by your PD nurse, so they can pull down data before your meeting, so they're aware of what your experience has been over the previous six months since the last meeting. That might make the meeting a little bit more productive.'* P2
	Reminder strategies	The participants also liked the idea of having a reminder system within the app to improve medication adherence and suggested different strategies. Seven of the participants liked the idea of having **an alarm feature within the app**, and they suggested including both **sound and vibration** options, as some PwPs may prefer one or both of these options. They also suggested that the alarm should continue ringing until physical action has been taken.	*'The time reminder would be helpful. With the alarm I prefer vibrate rather than sound.'* P8 *'It's got the alarm and it's got the functionality to let you accept the alarm. I think the alarm has to continue to go off until there's a positive action to say that I have taken my drugs. Otherwise, you'll continue to miss them.'* P2
	Reminder strategies	Five of the participants suggested including **a notification option** to notify their carers and enable them to track and remind them if they forget to take their medications. Three of the participants thought that adding a notification option to the app might be better as an optional selection, as some PwPs might find that annoying.	*'One of the other applications that I can think is missing is say I missed a medication. I have not ticked it or acknowledged taking it within two hours, to have a secondary person, for example, to notify her, it would be my wife, and it would say, "He has missed his medication." So, it will flash up on her phone. I think that would be really good.'* P7 *'Having some technology that allows you to know that someone has taken their drugs, ticked the box for that, so you don't have to nag them [if they don't want], because people don't like being nagged.'* P2

6.5 DISCUSSION

In this study, the focus remained on the use of technology but specifically looked at this in relation to supporting medication management. The motivators and concerns about the use of the mHealth app to support PD medication management from the perspective of PwPs were identified. Not surprisingly, most of the identified themes and subthemes in this study were similar to the previous study in Chapter 4. Since both studies' objectives looked at aspects of mHealth app use, the views and expectations of PwPs were similar. Despite this, the intention behind the use of mHealth apps in each study was a little different. In this study, the focus was more on understanding the need for such an app to support PD medication management and record side effects from medications, whereas in Chapter 4, the focus was on supporting data collection (PROMs) in clinical settings. In particular, the views and expectations of PwPs were found to be similar in regard to app design, potential motivators, and concerns about mHealth app use for PD. These confirmatory findings can be accounted for to further understand PwPs' perceptions of the mHealth app for PD.

In this study, a mixed-methods approach was used to understand the perceptions of PwPs and identify the key factors that might affect the future use of an app to support PD medication management, including recording side effects. Previous studies have highlighted the importance of understanding patients' perceptions to ensure better engagement with the use of a smart device app, where factors such as system usability, health literacy, and socioeconomic status might influence the patient's decisions to use an electronic system or app (Kelders et al. 2012; Irizarry et al. 2015; Alkhaldi et al. 2016; Almarashdeh and Alsmadi 2017).

The results of the questionnaire showed that 99% of respondents owned a smart device, and 98.5% had used some kind of smart device before. This result was similar to a previous study conducted with PwPs (Mathur et al. 2017), which evaluated the factors that might affect patients' quality of life and improve self-monitoring. In this study, 94% of participants reported using some sort of digital device. While this does not necessarily suggest engagement with technology for health purposes, it does show that PwPs aged 60 and above are becoming more

engaged with technology use, and this could be a good indication to support the future uptake of mHealth technology for health-related purposes. The qualitative studies that looked at users' adoption and use of mHealth have shown the importance of factors such as previous experience or use of technology as a facilitator of mHealth use (Cajita et al. 2018; Spann and Stewart 2018).

In the present study, 14% (n = 57) of the respondents reported using their smart devices to record their PD symptoms, and 26% (n = 106) reported using their smart devices to help them with the management of PD (Table 6.6). The previous study found that 37% were using a drug diary tool to record their PD symptoms, and 27% of those were using a written diary, while 20% were relying on their caregiver to record symptoms (Mathur et al. 2017). These slight discrepancies in the reported percentages shown above may be because the focus of the present study was exploring the perceptions of PwPs on the technology, and the previous study did not specify the type of reported tool, whether it was digital or not.

In Mathur et al.'s study, 88% of the PwPs were interested in using technology, and similarly, 84.9% of respondents in the present study reported their interest in using technology, such as a smart device app. Factors including the effect of PD symptoms, such as tremors and cognitive impairment, a lack of recommendation from HCPs to use a specific kind of app, perceptions of no apparent need to use technology, and satisfaction with current methods were highlighted by the respondents as reasons for not being interested. These findings were consistent with those of Nguyen and colleagues (2017), who found that some of the older patients with heart failure did not find technology to be useful or relevant to aid in the management of their symptoms for several reasons. These reasons included that they were already comfortable with their routines, they suffered from cognitive impairment, or they lacked confidence in their knowledge of heart failure and relied on their caregivers for guidance. This indicates that introducing an mHealth app to older people with chronic disease may be more challenging and needs further investigation.

As no direct connection has been explored previously, the MMAS-4 was used to assess adherence levels among PwPs. A moderate (50.1%) to low (49%) level of adherence was

observed. After an extensive literature search, only one study was found that used MMAS-4 to assess adherence to PD medications. It was cited within a systematic review (Straka et al. 2018), but unfortunately, the original study could not be found (Cibulčík et al. 2012). However, in contrast to our findings, this study reported a higher adherence rate among patients (52%), which may at least be partly accounted for by the fact that, in this study, the PwPs were mainly taking medication just once a day (Cibulčík et al. 2012).

An individual's medication-taking behaviour could be a factor that affects patients' perceptions of the utility of an mHealth app. The current study found that the issues that most impacted adherence to PD medication were forgetting (64%) and carelessness (54%), which could be tackled by using the mHealth app. PwPs can have support from the mHealth app as a reminder to take medication. In line with this finding, a recent study by Orcioni et al. (2021) showed that several smartphone apps are commercially available and have been proposed to address medication adherence (e.g., MediSafe®, Pill Reminder®, and Pharm NFC®). The findings from this study reported that mHealth apps may have great potential to support medication adherence and encourage patients to take medication as prescribed (Orcioni et al. 2021). However, this study had a small sample size (n = 4) and no statistical relevance, so further research is required to provide evidence of the efficacy of mHealth apps for medication adherence.

Findings from Straka et al.'s (2018) systematic review showed that forgetting to take medication was more common among PwPs than taking extra medication. A previous study in the mHealth app for PD reported promising findings on the potential of the mHealth app (uMotif®) for tackling and improving medication non-adherence in PwPs (Lakshminarayana et al. 2017). However, the authors of the study did not investigate the reason for non-adherence. Further investigations are still needed to explore multiple aspects of medication-taking behaviour after developing the mHealth app, such as preference, satisfaction, and continuity.

An interesting finding of our study was that no significant association was found among respondents who were interested in using technology and factors like age, number of prescribed medications, and adherence level. In contrast to our findings, previous studies that

assessed the adoption of adherence apps within patients with cancer and serious mental disease showed that patient age was strongly correlated with the patients' interest in using technology (p = 0.034 and p = 0.001, respectively) (Ben-Zeev et al. 2013; Carroll et al. 2017; Ali et al. 2019). This contrasted finding might be because previous studies included larger sample sizes: n = 3677 in the Carroll et al. (2017) study and n = 1592 in the Ben-Zeev et al. (2013) study, compared to the present study (n = 413), which could facilitate the identification of associations between variables.

Less surprisingly, a significant association was found between respondents who reported using some kind of technology and their interest in using a smart device app. This finding is in line with Ali et al. (2019), who assessed the acceptance of using an adherence app among older cancer patients (aged 54 years old and above) and reported a significant association between the current use of mHealth technology and interest in using the adherence app. Knowing the previous experiences (owning or using technology) is useful and could help the researcher and app developers apply effective strategies to improve engagement with mHealth apps for PD support.

In the current study, both quantitative and qualitative findings showed that the use of a smart device app by PwPs to aid in the management of PD medications and record their side effects could be a useful and acceptable approach. Even though few PwPs (n = 9) were included in Phase II, the findings of this study may provide valuable insights into PwPs' perspectives on using a smart device app to manage and record medications. However, these findings need to be interpreted with caution, considering this small sample size. Five themes with several subthemes were identified: knowledge about PD, PD medication-related issues, attitude towards using technology, motivators to use a smart device app, and suggestions to make the app useful.

The respondents in this study expressed adequate knowledge about the aetiology of PD, which is in line with previous studies that have assessed the level of knowledge among PwPs and their caregivers (Yadav et al. 2012; Riggare et al. 2019). Riggare et al. (2019) found that PwPs mainly acquired PD-related knowledge from online sources, which is similar to the findings of

the current study. The respondents reported that websites, such as Parkinson's UK, were their main sources of PD-related knowledge. In addition, the respondents expressed adequate levels of knowledge regarding the importance of taking PD medication on time to maintain functionality.

This finding is in line with a previous study (Hermanowicz et al. 2019) conducted with patients and physicians to explore their perceptions about PD management. The study reported that the patients expressed a moderate level of satisfaction with PD medication. These findings can partly be attributed to future interest in using an mHealth app for symptom recording and medication management. The advent of technology may enhance the accuracy and ease of identifying access to PD-related information, provide feedback on symptom recording, and provide a tool for medication management and adherence. This concept corresponds with Ali et al. (2019), who reported that cancer patients accessed and identified medication-related and health-related information from the internet. In addition, they used digital devices, such as notebooks, MS Excel® spreadsheets, and smartphone apps to record their symptoms and medication side effects (Ali et al. 2019).

Furthermore, the findings from the Parkinson's UK surveys of 700 PwPs regarding the administration of PD medications while they were hospitalised indicated that PwPs were knowledgeable about the importance of taking their medicines on time (Parkinson's UK 2019a). In this survey, 78% of the respondents highlighted that their health had worsened due to not taking their PD medication on time while they were in the hospital. The Got It On Time campaign across all UK hospitals and care homes was launched by Parkinson's UK, which targeted hospital staff to ensure that every PwP received their medication on time (Parkinson's UK 2019a). Future mHealth apps for PD must support both PwPs and HCPs.

The participants in this study reported several PD medication-related issues, such as unintentional non-adherence, the experience of medication side effects, and lack of information. Although participants had already used different methods to overcome these issues, the current situation indicated that the methods mentioned by participants were

insufficient, and there was still a need to discover further solutions to improve PD medication management.

As previously mentioned, forgetting to take medications on time was the most frequently reported issue by the participants in this study and also one of the most frequently reported causes of medication non-adherence among older people and PwPs in previous studies (Fleisher and Stern 2013a; O'Quin et al. 2015; Shin et al. 2015). Forgetfulness was reported by the participants in this study, even though they acknowledged the importance of taking their PD medication on time. This suggests that adherence to PD medications is a complex issue that is not affected only by the patient's knowledge, side effects, and motivation to take medication. Use of a more advanced tool and strategies to support that are necessary, and the mHealth app could play an essential role.

A notable finding was that most of the participants were unable to recognise specific side effects of the PD medications, even though they mentioned having direct contact with PDNSs to report any issues. There was confusion between the main PD symptoms and side effects from the medications, with participants unlikely to attribute new symptoms to their medication. This might be because the focus of the consultation was on the beneficial effects of the medicines. Some of the participants in this study explained how their HCPs emphasised the importance of taking PD medications on time to maintain dopamine levels in the body to improve motor symptoms.

Consistent with the present's findings, the perceived lack of knowledge about medications was reported by older people in a previous study (Belcher et al. 2006). The study was conducted with older people to explore their views of involving patients in medication-related decision making. The participants in this study acknowledged the restricted time for consultations, so they did not expect to discuss everything with their HCPs during their visit. Hence, involving pharmacists was suggested as a solution to provide information related to PD medications, such as contraindications, side effects, and instructions for administration.

In contrast, the present study's participants were not convinced about involving pharmacists in their care, as many of them reported pharmacists' lack of knowledge regarding PD medications and preferred to restrict their role to dispensing services. A similar finding was reported in a previous study that investigated the perceptions of patients with type 2 diabetes, where the participants felt that the role of the pharmacist should be restricted to supplying medicines and providing advice regarding over-the-counter medications (Twigg et al. 2013). These findings indicate the need to educate PwPs on the knowledge, skills, and other services that pharmacists can provide to support their involvement in patient care.

In addition, there is a need to inform, train, and encourage pharmacists to become more involved with PwPs. A study conducted in Germany demonstrated how community pharmacists have the potential to improve pharmaceutical care services for PwPs (Schröder et al. 2011). This study reported that 32 community pharmacists were able to provide 474 service interventions over an eight-month period across 113 outpatient pharmacies. This included 26.3% for PD drug-related problems (e.g., not receiving medication, unsuitable time of intake, symptoms, underdosage, and drug interactions); 19.6% of the interventions were about providing patients with PD treatment advice; 11.6% were regarding PD adverse drug reactions; and 43.6% were for adjusting PD medication regimens (Schröder et al. 2011). However, this study's findings should be interpreted with caution, as the included pharmacists were also responsible for recruiting PwPs, so they could have recruited PwPs who were more prone to drug-related problems (selection bias). The pharmacists involved in this study were more clued up about PD than 'regular community pharmacists', as they received an advanced training course on pharmaceutical care services for PD before this study begun. They were therefore more likely to be able to make helpful interventions than regular pharmacists who were not in the study.

In 2014, a PD-specific 'medicines use review' service was piloted in England across eight different pharmacies to encourage and train community pharmacists to support PwPs with their PD medications. A total of 96% of PwPs found this service useful, and 86% reported an improvement in understanding their medicines (Bancroft 2016). Further, the pharmacists who

participated in the Bancroft study stated that their knowledge, competence, and confidence improved after piloting the PD medicine use review service and taking the related training courses to deliver this service. However, they emphasised the need for additional training on how to communicate with PwPs to take this service forward.

Currently, Parkinson's UK offers the training necessary to deliver this service, so any community pharmacists with an interest in Parkinson's could be trained to provide and become more involved in the care of PwPs (Parkinson's UK 2018), but the level of uptake is not known. Given the potential benefits, wider promotion of this opportunity may help to improve community pharmacy services for PwPs, and piloting and rolling out such a service in Wales could also contribute to improving the somewhat negative perceptions of PwPs in Wales (as demonstrated in the present study) about pharmacists' roles.

Many of the participants in this study showed their interest in using the mHealth app over their currently used methods. According to the TAM, the perception of usefulness is one of the two factors directly influencing the intention and actual use of technology (Davis 1993), and previous studies have reported that the perceived usefulness of the mHealth device would significantly influence uptake and engagement with mHealth technology (Cajita et al. 2017; Spann and Stewart 2018; Alsswey and Al-Samarraie 2020). Indeed, several of the perceived advantages highlighted by PwPs in the current study included taking medications on time, using reminder systems, empowering patients, and aiding consultations. These positive perceptions of the potential usefulness, therefore, could potentially lead to future uptake of technology to support medicine taking for PwPs, in line with the TAM (Davis 1993).

Many PwPs in this study reported that using an mHealth app has the potential to track medication taking, support the self-management process, and improve the patient's consultation with HCPs. A similar qualitative study (Morrissey et al. 2018) on a smartphone app to improve medication management in hypertension found that some of the participants identified how using the app would empower them to have more control over their health, and also how the data from the app could be used to enhance communication with their HCPs.

Chapter 6   PwP perceptions on digital management of PD medications via app.

The findings of this study contradict previous studies that reported that older people are unwilling to use new technologies, due to old age and privacy and security concerns. A meta-ethnographic review study that explored the perceptions of mHealth apps in patients with chronic diseases found that privacy and security were highlighted as the main issues in the effective use of apps (Vo et al. 2019). In addition, the findings from a mixed-methods study (questionnaire/interview) showed that despite willingness to use mHealth apps, the healthy people in the age group between 51 and 65 years expressed the strongest concerns regarding the privacy and security of mHealth apps when compared with the younger age group (18–50 years) (Zhou et al. 2019). Meanwhile, in the current study, older age and security and privacy were not reported as concerns by some participants with regard to future use of an mHealth app. However, the participants in this study acknowledged that these factors might affect the ability and decisions of some other PwPs to use such an app. It seems that PwPs are willing to use an intervention that could help them better manage their condition, and this might outweigh any concerns over security.

The PD symptoms, tremors in particular, were also reported as a concern that might affect the ability of some PwPs to use an app. This is in line with the previous findings presented in Chapters 4 and 5 and the previous studies that health-related limitations in physical and cognitive functioning can make using technology challenging (Patel et al. 2015; Cajita et al. 2017; Spann and Stewart 2018). Considering the user's ability and capability seemed important, continued research and development efforts are needed to ensure that the new mHealth app is accessible and usable by PwPs, despite physical and cognitive limitations. In addition, app designers should consider user-centred approaches in designing an mHealth app for PwPs that is user-friendly and more sensitive to their physical ability. This could include, for example, a simple interface, clear instructions, and short content (not too many tasks to perform to minimise cognitive load).

This study's findings showed that PwPs do not base their intention to use the mHealth app solely on perceived usefulness and ease of use, as mentioned in the TAM (Davis 1993). Another social context mentioned in the UTAUT (Venkatesh et al. 2003) may also influence PwPs'

intention to use the mHealth app, such as a recommendation from HCPs (to promote mHealth adoption and use), and cost was identified by the participants of this study a factor that might affect their decision to use an app.

This is in line with previous studies that explored patients' perceptions of mHealth app use for hypertension and medication management among older people (Morrissey et al. 2018). Morrissey et al.'s study emphasised that the participants recommended the involvement of their HCPs for them to use the smartphone app.

A few participants in the present study reported the cost as a minor reason not to use an app, while cost was reported as a strong reason for not using an app in Morrissey et al.'s study (2018). However, all of these factors might be associated with PwPs' interest in using an mHealth app for PD. App developers must place great emphasis on these factors to enhance the acceptance and use of an mHealth app.

Finally, a future mHealth app should be designed with consideration for PwPs' needs and requirements to improve its acceptability. There are similarities between what has been suggested as useful app features in this and previous studies, such as a medication reminder system, medication information, accessibility, and availability of data for HCPs (Dayer et al. 2013; Grindrod et al. 2014). Even though the feature requirements for condition-specific mHealth apps may be different, the findings of the present study suggest that older peoples' general attitudes towards mHealth apps are similar, and the perceived facilitators and barriers to technology use, regardless of the conditions, can be used to assist the development of an mHealth app for older people by giving further consideration to unique features for each condition.

6.6 STRENGTHS AND LIMITATIONS

The use of a mixed-methods study design provided an in-depth understanding of PwPs' perspectives on using a smart device app to support PD medication management and record side effects. However, the findings of this study should be interpreted with caution, as a number of limitations exist.

Chapter 6   PwP perceptions on digital management of PD medications via app.

Within Phase I (questionnaire), a response rate of 7.5% of the 5,500 Parkinson's UK members was achieved. Despite this relatively small response rate, the number who responded (413) was sufficient to obtain reliable results. As mentioned in Section 6.3, a sample size calculation was conducted to evaluate the number of responses required to have confidence in the results. This was calculated as 360, which was exceeded. A greater response rate would have been beneficial in supporting the generalisability of the findings, although efforts were made to maximise the response rate by, for example, offering a paper-based questionnaire. Even though the paper form of the questionnaire was offered to the PwPs, all respondents completed and returned the online form of the questionnaire. For this reason, generalisation of these findings to a wider population is limited.

While enough responses were obtained, the findings from the perception questionnaire may not be representative of the whole population of PwPs, as all responses were collected online and from one particular subgroup (technology users). Thus, the perceptions of people who did not own or use a smart device were not captured, which may have resulted in a possible response bias arising from self-selected participation. For this reason, the findings cannot be generalised to the whole PwP population. In addition, apart from generalisability and due to logistic reasons (limited time scale available), the Cronbach's alpha reliability test was not undertaken for the questionnaire either. Therefore, the findings of the questionnaire should be interpreted with caution.

A limitation of the Phase II (semi-structured interviews) study was also related to the recruitment method, as all participants were recruited through the Phase I study, which may be why all participants showed a favourable opinion towards using an mHealth app. Nevertheless, effort was made to expand the recruitment beyond the collected data from Phase I. A recruitment email was also submitted to the staff organisers of the Parkinson's UK local café group (Local groups | Parkinson's UK) to recruit further participants (Parkinson's UK 2017). However, no interest in taking part in the study was obtained through these groups. This might be because the study was conducted at a time close to the holiday season.

Chapter 6   PwP perceptions on digital management of PD medications via app.

Even though data saturation from the interviews was reached, the sample of nine participants was relatively small and from one geographical area (South Wales), so the findings may not encapsulate the perspectives of all PwPs. A case example (uMotif®) app was used during the interview discussion to provide a deeper understanding of the study aims, so the findings of this study were based on the participants' expressed intention to use an mHealth app and not on actual usage. However, previous studies have shown that behavioural intention may predict the actual usage of an intervention, so the impact of this limitation may not be that significant (Davis 1989; Holden and Karsh 2010).

6.7 IMPLICATIONS

The findings of this study have several implications for the future development and acceptability of a smart device app that aims to aid PwPs with their PD medication management and report side effects, which would be a valuable addition to the evidence base (see Chapter 6, section 6.4). Several of the study participants used some methods (diary, alarm, or app) to manage their PD medications. This means that a smart device app should be designed that has relative advantages over the currently used methods based on PwPs' needs and suggestions. Participants generally wanted features that offer accessibility across different platforms and devices, PD-focused information, tracking capabilities, and two-way communication with HCPs to enable management of medication, side effects, and adherence issues. Currently, most of the available adherence apps focus on chronic disease and medication reminder features (Dayer et al. 2013). It is important to highlight that designing an inclusive smart device app with multiple features that include both an educational section (disease knowledge, medication knowledge) and a practical section (reminder systems, activities related to the disease conditions, and recording side effects/symptoms and offering feedback) would facilitate user acceptance and sustainability. Furthermore, it is important for app developers to involve HCPs in promoting the smart device app and increasing its uptake by PwPs. Finally, app developers should consider users with low digital literacy levels when designing a highly user-friendly smart device app.

6.8 CONCLUSION

This was an exploratory study intended to understand the perceptions of PwPs towards using a smart device app for the management of PD medication and to recording side effects. Potential motivators of and concerns about mHealth app adoption and use were identified that could help guide the development of future mHealth apps for PD.

The participants were potentially willing and interested to use an mHealth app to help them manage and take their medications on time. An mHealth app that provides high-quality information on PD medication, including potential side effects and drug interactions, in addition to the reminder features, is desirable. Although mHealth apps were considered a useful tool by many of the PwPs who participated in this study, some concerns emerged that might influence the adoption and use of mHealth apps, such as the need for user-friendly designs, cost, and privacy and security. The researchers and mHealth developers can address these concerns to help facilitate the development of an appropriate mHealth app based on the PwPs' needs and functional abilities.

While acknowledging the possibility of responder bias, this study has nevertheless offered a snapshot of PwPs' perceptions of PD medication management. Understanding PwPs' opinions and experiences would contribute to the design of a successful app. This study's findings have implications for researchers and developers in advancing the quality of PD-specific mHealth apps. In addition, it provides a starting point for further investigation into the use of mHealth for PD medication management. Finally, the app developers will benefit from involving PwPs early in the design process and HCPs later during the promotion process. This study suggests that there is potential in the growing trend of using digital technology, such as an mHealth app, to track, prompt, and encourage adherence and management of medications in chronic diseases.

6.9 SUMMARY OF THIS CHAPTER

1. This was a mixed-method exploratory study (questionnaire/semi-structured interviews) intended to explore the perceptions of PwPs towards using an mHealth app for the management of PD medication and to record side effects.

Chapter 6   PwP perceptions on digital management of PD medications via app.

2. A total of 413 PwPs completed the Phase I questionnaire study, of whom 409 reported having owned a smart device before, and 407 having used one. In addition, 384 PwPs who participated in this study reported interest in using an mHealth app for PD medication management and recording the side effects of medications.

3. As the prototype iPad-based app did not include a section about medication, the uMotif® app was used to aid the Phase II study's conduction.

4. The PwPs in the Phase II study were highly amenable to the concept of using an mHealth app to support the management of PD medications, as it may be useful in improving medication adherence and patients' health knowledge about both the condition and medication.

5. The PwPs who participated in this study also reported concerns that researchers and mHealth app developers could address to improve the app for PD. Future researchers seeking to develop an mHealth app for PwPs should address health-related (e.g., physical impairment) and technology-related (e.g., user-friendly and privacy and security concerns) issues. In addition, they should take advantage of potential facilitating influence, such as HCPs' recommendations, to promote mHealth app adoption and use.

6. Finally, a comprehensive mHealth app that provides easy access to disease-health-related information, feedback on symptom recording, and medication management and adherence was suggested by the PwPs who participated in this study.

Chapter 7: General discussion

7.1 CHAPTER OVERVIEW

This chapter presents a brief overview of this PhD project and discusses how the findings from each study could be used to facilitate the development of an mHealth app for PD. This PhD aimed to: (1) identify factors that might influence users' acceptance of mHealth app use for PD, (2) explore and understand the needs and preferences of PwPs regarding the use of an mHealth app to support data collection (PROMs) in clinical settings and help them manage their PD medications, and (3) explore and understand the needs and preferences of PD HCPs regarding the use of an mHealth app to support data (PROMs) collection in clinical settings.

To understand the background and critical features of a mHealth app and the feasibility of its utilisation in PD clinical settings, this PhD project was conducted in three different stages. In Stage 1, the perceptions of PwPs and their carers about using the prototype iPad-based app while they were waiting for their consultations were explored using a qualitative method (focus group) study design. The original plan was to then redesign the prototype iPad-based app based on the recommendations from the Stage 1 study (see Appendix 4.9) and then pilot it at two clinics in South Wales, but for the following reasons, that was not possible.

- As described in Chapter 1, the prototype iPad-based app includes three sections: NMSQuest, EQ-5D, and the two fingers test. However, one of the clinics that had intended to pilot the app had begun using a different PROMs scale (MDS-UPDRS). They suggested changing the app's format to be more compatible with their EHR. Hence, it became evident that understanding the perceptions and needs of HCPs who are dealing with PwPs in PROMs content and use that aimed to collect patients' data in PD clinics was necessary.
- Additionally, piloting the app was not possible because it took longer than anticipated to develop a mock version of the prototype iPad-based app, and this PhD project was restricted to a fixed time. This would be important follow-up work.

The second stage of this project then explored the perceptions of HCPs towards using an app to collect patients' information before their consultation, utilising a mixed-method

explanatory sequential study design to facilitate the identification of the perceptions of HCPs. As described in Sections 4.4 and 5.4.2, the findings suggested that incorporating a PD medication section into the prototype iPad-based app was essential for both PwPs and HCPs. The HCPs thought that some of the NMS of PD might be linked to the PD medications. That led to the third stage of this PhD project, which explored the perceptions of the PwPs regarding the use of an mHealth app to help with PD medication management and report side effects. Another mixed-method explanatory sequential study design was utilised to identify PwPs' views and opinions.

7.2 RAPID REVIEW OF FACTORS THAT INFLUENCE THE ACCEPTANCE OF EXISTING MHEALTH INTERVENTIONS FOR PD

Previous reviews have been conducted to explore the use of mHealth interventions for PD, including supporting disease self-management and the general use of the mHealth app (Linares-del Rey et al. 2019; Majhi et al. 2019; Grosjean et al. 2020; Zhang et al. 2021). This thesis's rapid review focused on identifying users' perceptions of mHealth intervention use for PD.

This review made several contributions to the wider PD intervention field. First, it was found that mHealth technology appeared to be an acceptable platform to deliver interventions for PD. Second, the potential advantages of this type of intervention were highlighted, including improving symptom identification and management, patient empowerment and involvement in the decision-making process, improving communication with HCPs, and supporting medication adherence and management. Third, the potential concerns about the effective adoption and use of an mHealth intervention were also highlighted, including potential lack of privacy, health-related issues, workload, and the intervention-associated cost.

The fourth finding of this review was that the factors that might influence the acceptance of the mHealth app for PD were identified. Based on the findings, mHealth app designers and developers are recommended to incorporate technological, organisational, and social factors at the early development stage to improve the adoption and use of the mHealth app intervention.

A final finding of this review is that it identified how, so far, the majority of mHealth interventions have been designed and focused on assessing the motor aspects of PD in the form of symptom-monitoring interventions. This type of intervention has sought only to support the diagnosis and management of PD; however, its actual impact and use are not known, and no published data were found. This highlighted a gap for an app intervention that facilitates the collection of patients' data to aid both PwPs and HCPs during clinical encounters. Also, an app enables patients to meet their full range of information needs (e.g., PD-related information and patients' knowledge of their medication side effects).

The majority of mHealth intervention studies have placed greater emphasis on assessing quantitative outcomes (i.e., usability and feasibility), with little attention paid to the user experience during the evaluation process of mHealth technology. Therefore, the review identified the need to reflect on all stakeholders' (PwPs and HCPs) needs and requirements throughout the design process of the mHealth app for PD. The early involvement of stakeholders might lead to a more accurate understanding of needs and requirements when designing an mHealth intervention for PD, and ultimately influence the acceptability and uptake of the mHealth intervention by end users.

7.3 ESSENTIAL CONSIDERATIONS FOR DEVELOPMENT AND IMPLEMENTATION OF DIGITAL TECHNOLOGY WITHIN PD CLINICAL PRACTICE

The development and implementation of a digital health technology intervention is at the forefront of the Welsh Government's agenda to improve the quality, safety, and efficiency of care (Welsh Government, 2015). However, such interventions are often far from straightforward to implement within clinical practice and may require complex strategic planning alongside design and evaluation. The development of a digital intervention for use in a clinical setting, such as the prototype iPad-based app, is a complex and lengthy process that might include several stages. It might also be necessary to utilise an interdisciplinary team-based approach. An interdisciplinary team that consists of technology experts, HCPs, and PwPs is essential in designing a function-appropriate mHealth intervention that is of value to end users.

In addition, the implementation of digital health technology interventions (e.g., the prototype iPad-based app) within clinical practice may require systemic organisational changes related to the available resources and infrastructure. In order for these technologies to fit the usual workflows of the clinic and achieve the anticipated individual and organisational benefits, many considerations need to materialise. The findings and novel contributions of this thesis highlight some of these considerations, as discussed below.

7.3.1 Clarify the gap for which digital intervention is needed

A thorough understanding of the findings from Chapters 4, 5, and 6 presented the views of PwPs, their carers, and HCPs on the current information used during consultations. The poor communication regarding treatment options and NMS between the PwPs and their HCPs was found in these studies, echoing those in previous research (Mathur et al. 2017; Damman et al. 2019). Reasons for this included limited consultation time, forgetting, and lack of awareness of NMS and their relationship to PD. Even though the HCPs acknowledged the importance of the NMS of PD and its impact on the patient's quality of life, it was not their focus during consultations; instead, they focused on the motor aspects of PD.

Mathur et al. (2017) also reported a lack of interest in discussing the NMS of PD during consultations. The HCPs mentioned that some PwPs relied on them to start the conversation during consultations, which was consistent with what the PwPs and their carers described in the Stage 1 study (Chapter 4). They discussed how their HCPs usually led the discussions during their clinical encounters and focused on the motor aspects of their condition. These findings imply that current patient-clinician communication is a unidirectional approach. Patients need to be more involved in discussions with their clinicians to receive care that is more patient centred. A core aspect of patient-centred communication is achieving a shared understanding of the issues of concern to the PwP and treating them in accordance with their values and preferences (McCabe and Healey 2018). Once again, the findings from this thesis suggest the presence of a gap in communication between PwPs and their HCPs.

As a result of the communication issues in PD consultations and moving towards patient-centred care, there seems to be a clear need for an electronic tool with features to support

PwPs in order to recall the main issues related to their condition, facilitate communication in consultations with HCPs, and support management of medications. Using an mHealth app that includes features to support the collection of PROMs for NMS and facilitates medication management was found to be a potential solution to improve communication issues during consultations. Collecting PD-specific PROMs electronically via an mHealth app before consultations was found to have the potential to empower PwPs to be more engaged during the consultation and focus the consultation on the issues of concern. For these reasons, it is anticipated that this type of app will be useful.

Even though the findings from Chapter 5 showed that the paper forms of the PD-specific PROMs were currently used occasionally during consultations, the development and use of an electronic tool to collect PD-specific PROMs would potentially allow for a more efficient, easier, and faster method of data collection, analysis, and onwards transmission. A major challenge in developing the mHealth app was identified: Which PROMs scale should be incorporated into the mHealth app? The HCPs expressed different views on the PROMs needed, and different PROMs scales were suggested; however, there was a consensus on using the NMS related scales (e.g., NMSS and NMSQuest). As mentioned in Chapter 1, the NMSS (that assesses the severity and frequency of nonmotor symptoms) and the NMSQuest (that identifies the presence of nonmotor symptoms) are both 30-item screening tools for patients and clinicians that could aid further management of PD during clinical encounters. Even though the NMSQuest scale does not evaluate the severity of NMS or the effect of treatment, it is a simple and easy screening scale for PwPs to complete to provide a comprehensive evaluation of NMS (Martinez-Martin et al. 2014). This scale could be used as an initial assessment for further investigation (using more specific PROMs scales) and management (either through pharmacological treatment or allied health therapists).

In comparison, the MDS-UPDRS, which is an updated version of the original UPDRS scale, has comprehensive coverage of motor symptoms, but some of the NMS are not covered. These include hypersexuality, sleep disorders, and anxiety, which could be important clinically (Gupta 2008). In addition, the MDS-UPDRS was considered too long to be completed routinely before

the clinical consultation. According to Goetz et al. (2008), the estimated time to complete the scale is more than 30 minutes, which may vary from patient to patient. Therefore, an app including a short PROMs scale to complete before clinical consultation with a focus on the NMS seems to be more acceptable and adoptable.

Developing a fixed format of an iPad-based app with a specific PROMs scale might not be acceptable to all HCPs and all health boards within Wales, as each health board has a different EHR system, and concern regarding the incompatibility of the app format with the current systems may be raised. One of the main problems that faced the PROMs and PREMs Effectiveness Programme in Wales was that the EHRs between different clinics were not standardised, which could limit the linking of any future interventions with the existing EHR systems (O'Connell et al. 2018). Developing a more flexible app with features to enable HCPs to select from a range of validated PROMs scales would be more acceptable and usable.

7.3.2 Enhancing data collection and medication management via a smart device app through stakeholder engagement with the tool

As mentioned in Chapter 1 (Section 1.7) and Chapter 3, different types of mHealth interventions have been developed, especially to help in the diagnosis and management of PD. However, the actual acceptance and usability of these interventions in PD clinical settings or by PwPs is either not known or limited. This is mainly due to the fact that these apps were not available to the public beyond the pilot studies, or to the lack of involvement of target users during the early phases of mHealth app development (Linares-del Rey et al. 2019; Majhi et al. 2019). This is an important consideration because understanding the factors that influence the target users' acceptance would allow researchers and developers to address these requirements and promote the use of these interventions.

 According to TAM and UTAUT, success in designing and implementing a new electronic intervention is dependent on the target user's perceptions of usefulness and ease of use. Therefore, appreciating the preferences of all stakeholders within PD clinical settings (including PwPs, HCPs, IT departments, and clinic administrative staff) is essential, as this could contribute to understanding the requirements of acceptable and usable interventions (apps)

that are of more value to them. This is preferable to interventions designed using a theory-driven approach, without the direct engagement of its target users. Involving all stakeholders could facilitate the creation of a common strategic plan and shared roadmap to facilitate the uptake of digital interventions into clinical settings.

This thesis employed a multistage, mixed-methods study design to explore the needs and preferences of PwPs, their carers, and HCPs for an mHealth app in a PD clinical setting. Further projects should aim to investigate feasibility and readiness after finalising and developing a mock version of the prototype iPad-based app and exploring the perceptions of other stakeholders on the health board, including the IT department and PD clinic administrative staff.

The participants in this thesis provided positive feedback regarding the use of digital interventions within PD clinical settings. PwPs anticipated that the smart device app would be an acceptable tool through which to collect patients' data via PROMs and manage and report PD medications, which could provide a preliminary indication for the potential uptake of an app in clinics. Additionally, HCPs were not hesitant regarding the development and adoption of an mHealth app to collect PD-specific PROMs in their clinical setting. The PwPs, their carers, and the HCPs provided valuable information regarding the essential features to aid in the development and design of a smart device app, which are discussed in more detail in Section 7.5. Exploring the perceptions of the target users was useful in identifying refinements to improve the design of an intervention based on their feedback, to enhance its value and future usability.

Even though PD is a deteriorating condition and observing positive outcomes from using PROMs in routine practice may be difficult, the participants in this thesis anticipated that using a digital intervention such as the e-PROMs app would have a positive influence on the overall process of consultations for both HCPs and PwPs. It could help to focus consultations on the patients' needs and support initial assessment, and deliver healthcare services, such as dividing clinics based on patient cohorts (e.g., complex PD clinics, dementia clinics, and newly diagnosed clinics), and audit services. Interestingly all of these were observed as an early

benefit in the ICHOM PD study, and that encouraged the ABUHB to expand the use of e-PROMs into other clinical settings, both for PD and other health conditions (Arora et al. 2017).

The findings of Chapter 5 (Section 5.4.2) highlighted that HCPs might find PwPs' use of an e-PROMs app before consultations to be an acceptable approach, as it aims to facilitate patient-centred care by empowering the patient and engaging them in clinical decision making. In addition, an e-PROMs app may play a key role in referring PwPs to other supportive care services, such as physiotherapy and occupational therapy, and formalised supportive care sessions on the patients' needs. However, additional research is needed to examine how the actual use and implementation of e-PROMs and decision aids delivered by an mHealth app might affect patient care and patient-HCP interactions.

Importantly, exploring the perceptions of target users also facilitates the identification of possible barriers to the uptake of an app intervention, such as age, lack of experience with smart technology, increased anxiety for patients with low digital literacy skills, the impact on face-to-face time with HCPs in consultations, the perceived lack of security of information, and the lack of privacy of patients within the clinic waiting area. Similar concerns about using digital health interventions have previously been reported across different health conditions (Pinnock et al. 2006; Bostock et al. 2009; Morrissey et al. 2018; Slevin et al. 2019). These seemed to be general concerns for older people, which can be considered and addressed during the early stages of mHealth app development and implementation process to improve the uptake and adoption of such interventions.

While several PwPs in this thesis were very comfortable using technology, the age of PwPs may influence their future acceptance of such an app. This data reflected the findings of previous literature (Durso et al. 2003; Grindrod et al. 2014; Hamine et al. 2015; Duroseau et al. 2017). The age of patients might be considered a temporary barrier to the use of technology, as the participants in this thesis acknowledged the importance of using it. Also, the most recent data from the Statista website indicate that the smartphone penetration rate in 2019 was over 73% for the 55–64-year-old age group in the UK, compared to 19% in 2012, and was 40% for people over 65 years old in 2019 compared to 5% in 2012 (Statista 2021). This indicates that older

people are becoming more familiar with technology and engaging with it more. However, a core consideration regarding the adoption of new technology interventions is that there will always be late adopters of technology, especially among older people. The reason for this could be age-associated psychomotor and cognitive challenges and the associated costs of learning such technology (Charness and Boot 2009; Ali et al. 2018). Nevertheless, this lag in adoption will diminish with time as the current younger users grow older. The participants in this thesis also acknowledged that new PD sufferers would be more familiar with technology and using an app would not be an obstacle for them.

In addition, the findings from Chapter 6 highlighted that mHealth technologies are indeed adopted by PwPs, with 409/413 owning a smart device and 407/413 having used one. They adopted and used smart device technology for a variety of activities, including shopping, working, learning, and searching for health information. Although these findings are promising, there are still some PwPs who feel intimidated by the technology used, as the findings from Chapter 4 highlighted. In addition, the findings from the rapid review (Chapter 3) highlighted that the majority of mHealth interventions for PD excluded PwPs with severe physical and cognitive impairment. The reason for this could be that these interventions were not initially designed to suit their abilities. However, mHealth technology classes designed specifically for older people or PwPs are a great start to improving acceptance and usability.

Many of the participants in this thesis expressed the need for mHealth technologies to take physical and cognitive impairments into account when designing an intervention for PwPs. Eventually, when there is a good fit between users' needs and mHealth interventions, intention and actual use are likely to occur. According to the TAM's perceived ease of use and the UTAUT's effort expectancy, the perception of physical and cognitive abilities required to use technology influences the perception of usefulness and subsequently the use of technology (Davis 1993; Venkatesh et al. 2003). Thus, continued research and development efforts are required to ensure that the mHealth app intervention is accessible and usable by PwPs, despite physical and cognitive limitations.

Cautions about privacy and confidentiality issues when using an mHealth app to collect patient data and aid PD medication management were identified by participants, including opinions on the types of inputted data that would worry them the most and might hold potential risks. The findings highlighted that participants had more concerns about the privacy of personal information like online banking and finances than about personal health information (e.g., symptoms, diagnoses, and treatment) that is stored electronically. Some PwPs seemed to be comfortable sacrificing their privacy rights in terms of electronically held data, for the overall benefit of their PD management (e.g., *'These days nothing is private and that is information which is worth giving'* P5, Chapter 6).

Similarly, previous studies also reported that people (especially those over the age of 65) would be more cautious about their nonmedical information (e.g., home address) being shared with other groups beyond HCPs (Whitehead S. 2010; Papoutsi et al. 2015). In contrast, Tang et al. (2017) and Ware et al. (2017) reported that people who were 50 years or older expressed concern about the privacy and security of their medical information when using the eHealth system. However, the older people might need assurances that their electronic information would remain protected and confidential to encourage their uptake and use of eHealth (Ware et al. 2017; Frik et al. 2019).

Concerns about online banking are common among older people, as reported by Knowles et al. (2018), and such concerns related to the confidentiality of online banking are one of the contributing factors to older people's general lack of acceptance of digital technologies (Knowles et al. 2018). A lack of confidence and previous knowledge of how to use online tools could be the reason for this. In 2012, a study by Asmi and Ishaya also showed that older people in the UK preferred traditional banking to online banking because of the complexity of online transactions (50%), privacy concerns (85%), and security concerns (35%). Therefore, researchers need to better understand the type of data that most concern older people to improve their acceptance and use of a new intervention.

Although this thesis found that concerns about the privacy and confidentiality of electronically held health data seemed to be minor, these concerns still need to be addressed and

considered. Insufficient data protection may negatively impact users' acceptance and adoption and pose a risk to the success of mHealth app use. Technical standards and regulations should be applied to ensure high levels of trust and the success of the intervention. Furthermore, explaining the type of data collected via an mHealth app is a key element in overcoming any potential concerns that may influence trust, adoption, and implementation of such an intervention in clinical settings.

A noteworthy finding of this thesis is that some of the potential concerns (e.g., concern about losing face-to-face consultation time) regarding the successful use of the app could be considered, managed, and reduced if the HCPs introduced and presented the mHealth app to PwPs at the earliest opportunity following diagnosis, in order for them to maximise the benefits of the app. This finding is supported by Cajita et al. (2018), who found that HCPs' recommendations influenced older people's intentions to use mHealth interventions for heart failure.

Although the provision of information or training was not provided or tested in the current research, based on the findings, PwPs may find it useful to be provided with information leaflets or websites by HCPs when diagnosed in a consultation. These could explain how the app works, the type of data required, and how it is going to be stored. Providers could also offer instructions and training on use to maximise the usability and acceptability of a future mHealth app. Additionally, information should be provided on how the security of the collected data will be maintained. Reassuring target users that app developers follow the guidance of the Data Protection Act 1998 and the General Data Protection Regulations (Information Commissioner's Office 2020) during the development process of an app to protect privacy and security could improve users' confidence and likelihood of using an app.

Further concerns were also highlighted by HCPs regarding the use of mHealth app intervention. Some HCPs were concerned that an app used in consultations could affect the clinic workflow, increase the workload on the clinical staff, and annoy patients, as it might hinder direct communication and distract from face-to-face communication. Meanwhile,

others anticipated that some PwPs might not like the use of the mHealth app because of its negative impact on the quality of HCP-patient communication.

> *I think anything that detracts you from face-to-face contact, anything that changes the conversation away from what the patient wants to talk about, you have to be a bit careful about. But I think the more we look at computers and bits of paper on our desk, the less happy the patients are likely to be with their 20 minutes of time. (C8 (Neuro), Chapter 5, Section 5.4.2)*

The perceptions of the PwPs were inconsistent with these findings, as one of the potential advantages of app use identified by PwPs in this thesis was improving and enriching communication with HCPs.

The mHealth app might not be perceived as useful by some PwPs who adopt a paternalistic approach. The findings from Chapters 4 and 6 supported the concept of medical paternalism (Häyry 1991), which implies a 'doctor knows best' attitude, as several PwPs indicated that they would use the mHealth app if their HCPs were to recommend it to them. It is important that HCPs engage during the early phases of the development and implementation of new interventions. The HCPs' recommendations could facilitate and encourage mHealth adoption and use.

Finally, these findings demonstrate the usefulness of obtaining the different perspectives of the target users, included PwPs, their carers, and HCPs, as different groups of participants may anticipate potential outcomes that others may not have considered. Even though there was a general acknowledgement that there was potential for mHealth technology to be useful and serve a beneficial and practical purpose, app developers and designers need to understand target users' perceptions of potential benefits, concerns, or needs that an mHealth intervention could address for it to be perceived as useful and acceptable.

7.3.3 Consider resources and infrastructures within the health board

After understanding the need for mHealth technology and the perceptions of target users regarding the acceptance and usability of the prototype iPad-based app within routine practice, it is essential to understand the variables that might influence future implementation.

Adequate time to use apps and available resources within health boards might influence the successful implementation and use of mHealth interventions in clinical practice. It is important to be aware of when and where new interventions could be used, whether clinical staff can deliver the new intervention, or if there is a need for additional staff (and therefore higher costs). As the implementation of new digital interventions might change the way clinics usually work, it is important to consider gradual implementation of new technology. This could minimise the possibility of disrupting the clinics, as well as enabling incremental learning at every stage of the process (from individual to health board organisation).

The use of the CIFR framework in Chapter 5 helped to facilitate the assessment and understanding of potential factors that might affect the use and implementation of the app in PD clinics. Many of the findings in this study were described and presented as articulated by Damschroder et al. (2017). Even though no scores about the readiness to use and implement an mHealth app were generated from this study, this framework was used to facilitate the understanding of the variables that might influence (positively or negatively) future development and implementation. Nevertheless, it is not yet clear whether clinics in South Wales (particularly the Cardiff and Vale Health Board) would be ready to implement digital tools to collect patients' data, so a future project will be needed to investigate that.

The interviewees in this thesis expressed some concerns about the feasibility of using the mHealth app in the clinic. Concerns about additional workload for the HCPs, disturbing clinic workflow, and having appropriate infrastructure (equipment, wi-fi, and waiting area) were highlighted. Involving non-clinical staff was highlighted in Chapter 5 to facilitate the implementation and use of the mHealth app. In order for the mHealth intervention to be successful in a clinical setting, appropriate representation from the IT department and administrative staff is required. They may be required to deal with technical and practical matters of the intervention, reduce pressure on HCPs, and enable HCPs to run their clinics seamlessly.

This could be potentially problematic in some health boards, as it might be associated with high-cost implications. Although a formal economic evaluation was beyond the remit of this

thesis, financial considerations are inevitably of importance in any healthcare setting, and the HCPs in Chapter 5 expressed the need to have enough finances to adopt and use any kind of mHealth technology in the clinic. This could be associated with the development of IT infrastructure, hiring additional staff, or setting up an appropriate place for a new intervention to be used. Considering the financial resources in the early stages and supporting the funding of these activities is essential.

The implementation of the ICHOM PD standard set in ABUHB revealed the investment in essential resources and infrastructure, such as hiring a healthcare assistant to support PDNSs with the new system, changing the chairs in the waiting room so PwPs can use the system better, and allocating a dedicated IT team to solve and deal with IT and informatics problems and assess security measures (Arora et al. 2017). It is noteworthy that other e-PROMs scales also implemented similar measures to make the intervention more broadly implementable across the health board, overcome any issues, and address correction where appropriate.

Previous studies anticipated that the associated costs would be reduced once interventions were implemented and run-in clinics (Arora et al. 2017; O'Connell et al. 2018). Additionally, concerns related to resources and infrastructure can be managed once a decision on the basic type of digital technology has been made and the affordability of running the intervention in the clinic is assessed. Even though assessing the financial considerations of the prototype iPad app is inevitably important in a healthcare setting, this was beyond the remit of the project. Therefore, further studies are needed to investigate the costs associated with implementation after finalising the intervention design.

As previously mentioned, providing, and having the proper infrastructure (e.g., wireless networks, enough computers, and EHR systems) is an essential consideration for the successful use and integration of a new intervention (iPad-based app) in clinical practice. Some of the participants in this thesis highlighted concerns about the lack of necessary infrastructure within their health boards, which could negatively shape their attitudes towards using the proposed iPad-based app and hinder its adoption. In Arora et al.'s (2017) study, the ABUHB developed a new EHR system to have the appropriate infrastructure and facilitate the

implementation and integration of the ICHOM PD standard set system, as well as improve its usability and performance. Inappropriate or insufficient infrastructure (e.g., a slow wireless connection or not having an EHR system in practice) can negatively impact the acceptance and usability of an intervention. This could compromise the benefits and maximise risks associated with the implementation of digital technology within clinical practice (Sheikh et al. 2011). Infrastructure and resources are a major consideration when introducing a new digital intervention into clinical practice.

7.3.4 Introduce technology and train people

Once a decision on the format and content of a digital intervention (prototype iPad-based app) has been made, it is important to provide training to the target users during the implementation phase. Providing adequate training and instructional support in mHealth use could address the PwPs' lack of knowledge or lack of technology experience. Adequate training and support were found to be facilitators of mHealth use by the participants in this thesis. Similar findings were also reported by Patel et al. (2015). This study found that for successful implementation of the mHealth system in the waiting area of a primary clinic in the USA, it was essential to educate and train staff and providers on the benefits of the intervention system and how to use it (Patel et al. 2015).

In the ABUHB study, general instructions about how to use the ICHOM PD standard set system and leaflets explaining the changes in the process of the clinical consultations were provided to PwPs during the implementation stage of the system. This was done to engage and inform PwPs about the expected changes in the clinic and to enhance the usability of the system. The ABUHB also provided clinicians with essential training to better use the extracted data from the new system to provide high value for PwPs and for optimal use of the system (Arora et al. 2017).

Yusof et al. (2008) showed that users who had not been adequately trained tended to be less satisfied with the new health information technology system than trained users. The reason for this may be the lack of understanding of the new system's capabilities, which could influence the system's usability (Yusof et al. 2008). Providing adequate training, clear

instructions, and support is essential to allow target users to accept, understand, and trust new health technologies.

Providing training to both HCPs and PwPs, as well as assistance for PwPs on an ad hoc basis, was seen to be a necessity for the successful use of digital intervention. Providing assistance and guidance to PwPs during the initial phases of implementation in the clinic seemed vital to the successful uptake of the app. Support and assistance from either the patients' carers or clinical staff is needed. Perhaps for that reason, the ICHOM PD standard set tool study showed that the ABUHB assigned a dedicated healthcare assistant to help the PwPs use and complete the PROMs scales with the tool (Arora et al. 2017).

Designing an adequate training programme based on target users' capabilities is also essential for the digital intervention's successful use. Special consideration in developing an appropriate training programme is needed to meet target users' knowledge, roles, skills, and abilities. Training needs to allow target users to practice the use of technology (app) and interact with it (Dagroso et al. 2007). This thesis concludes that the best training programme would provide face-to-face training and a detailed leaflet with basic instructions explaining the purpose of the development, and how to use and navigate the app.

7.3.5 Set up a plan for the final development and implementation of intervention

This thesis has considered the initial design of the app; the next stages would be to further develop and refine the app with regard to the selection and development of app features and the content and design of the interface. After this, it is important for app developers and designers to conduct a user testing discussion group with a sample of PwPs and their HCPs to inform the final version. Finally, conducting real-life setting testing (i.e., in clinical settings) to assess the feasibility and validate this thesis's anticipated findings is essential to understand whether there are benefits and value in using the app in the real world.

In parallel, it is important for researchers and health board organisations to set up a plan for the implementation strategy of an mHealth intervention. This might include assessing the existing resources and infrastructure to ensure the app is coherent with EHR systems, evaluating the need for extra clinical support staff, providing adequate IT support; anticipating

the positive and negative impacts on clinic and individual workflows; and tracking desirable and undesirable consequences of the intervention. It is also essential to understand and expect that it might take years for the potential benefits and consequences of such an intervention to emerge, which could be associated with ongoing costs for maintenance and upgrades (Cresswell et al. 2013). Therefore, providing an implementation plan of expectations is essential, as it could influence the decisions and capabilities of the health board and HCPs to adopt the system in their clinical practice (Arora et al. 2017; Sheikh et al. 2011).

7.4 STUDY METHODOLOGY STRENGTHS AND LIMITATIONS

7.4.1 Rapid review

A rapid review method was used in this thesis to identify studies of existing mHealth interventions for PD that had features to support PwPs in clinical settings. Rapid review is a type of knowledge synthesis and is considered a component of the systematic review process. This type of review offers a high level of evidence because of the efforts taken to minimise potential bias and the transparency of the methods. Some reviews extended the search to involve grey literature to be as inclusive as possible. However, this review aimed to identify the factors that might influence users' acceptance and usability of an mHealth intervention for PD (provided by empirical studies), understand the gap in the literature, and conduct a formal assessment of the quality of the methodologies used. Therefore, it was decided that not all grey literature would be searched, as some of these sources are not peer-reviewed and are unlikely to include empirical data.

The findings of this rapid review must be interpreted with caution, as it was conducted by a single researcher. However, the researcher's supervisors verified all the data included in the analyses presented in the review. A meta-analysis was not conducted for this review because of the small number of identified studies, lack of appropriate data, and heterogeneity across the studies.

7.4.2 Exploratory Studies

Multistage, mixed-methods studies were selected for this thesis to enable an in-depth exploration of the psychosocial context of PwPs' and their carers' needs and preferences

regarding an mHealth app intervention to collect their information before a clinical appointment, as well as HCPs' opinions on the value of such an app. The use of a multistage mixed-methods design allows an open approach towards this research field and focuses the research on subjective aspects of end users of the intended app.

A qualitative method included focus group discussion, and face-to-face interviews were used to facilitate exploration of personal responses to these topics to provide a deep understanding of each individuals' experiences and opinions. These methods are considered suitable for exploring a sensitive subject, such as PD. Furthermore, focus group discussions enabled the researcher to interact with participants, ask follow-up questions to profoundly investigate the topic, and get information from non-verbal responses (such as facial expressions, body language, and interactions between group members) to provide additional contextualisation to the findings. The researcher used non-verbal communication during the transcribing process of the recording (e.g., facial expressions and body language to report positive or negative agreement) and during data presentation by reflecting on the consensus of findings when interpreting the data. The researcher concluded and assumed the positive or negative findings in the thesis by looking at and capturing ideas or patterns beyond what the participant said (latent theme, e.g., some of the barriers were identified as minor concerns).

Similarly, semi-structured interviews enabled the exploration of pre-determined questions and gave the researcher the freedom to deviate from the topic guide to explore any interesting issues raised by the participants. The questionnaire enabled the researcher to obtain primary and quantitative data about people's attitudes, values, and experiences towards the use of technology.

Although mixed-method studies were the most suitable for these studies, there are limitations to consider. First, the lack of generalisability is usually a criticism for qualitative methodology. While qualitative methods provide an in-depth understanding of people on a case-by-case basis, results may not be generalisable to the wider study population. Participants included in the studies in this thesis were recruited from local Parkinson's UK groups. There were high numbers of smart technology owners (smartphone, iPad, smartwatch, and e-reader), and the

majority seemed to have higher levels of digital literacy skills, which meant that the positive findings on the potential usefulness and acceptance of a mHealth app have to be interpreted with caution. As the sample used in these studies was not representative of the general PwP population, the perceptions of many subgroups of PwPs are still unknown, and they may therefore have different needs and preferences for an app compared to those included in this thesis. Qualitative studies usually seek to explore perceptions rather than generalise findings.

Another criticism of qualitative methods is the potential influence of researcher bias on the analysis and interpretation of findings. It is claimed that qualitative research is so sensitive to the researcher's epistemology, values, and experiences that they may analyse and interpret data in ways that favour their own view. The lack of reproducibility is another criticism of qualitative methods, as one study might produce different findings to another. Nevertheless, the researcher used reflexivity throughout the data collection, analysis, and interpretation of this thesis. The researcher's lead supervisors also reviewed and checked the findings of this thesis to reduce potential bias.

Several measures were considered and taken to prevent any social desirability bias that might have influenced the findings.

1. Prior to the interviews, the researcher clarified to participants that there were no 'right' or 'wrong' answers to questions and that both positive and negative views were useful in informing the development of an mHealth app for PD.

2. The researcher clarified the purpose of developing an mHealth app for PD, which would support PwPs and their HCPs during the clinical encounter.

3. The researcher assured the participants that all the collected data would be anonymised and could not be linked back to them in any way.

The researcher was also aware of how she may be perceived by participants (particularly PwPs and their carers) as a pharmacist doctoral researcher from a reputable university (Cardiff University) and familiar with the technology use. To minimise any potential influences of her own social standing during discussions, the following steps were undertaken.

1. The researcher made efforts to build a relationship with the participants and dressed appropriately to make them feel comfortable during the discussion.

2. The researcher has never received a diagnosis of PD, lived with a PwP, or worked with PwPs, which means that the researcher may never fully understand the impact of this disease and the needs and views of PwPs and their carers and HCPs who participated in the studies. Their experience and relationship with PD are a unique and new experience for the researcher.

3. Even though the researcher is very comfortable with technology use, she has no prior knowledge about the participants' experiences with technology and understands that her experiences and beliefs may be very different from anything the PwPs and their carers have experienced or believed. This allows the researcher to therefore assume, without having preconceptions about data, that the participant may find the technology use either useful, intimidating, or stressful, and to report any positive/negative findings.

Finally, a questionnaire was used to gather the participants' self-reported views and technology use experiences. This may have resulted in possible self-selection bias; thus, the participants who chose to participate may not sufficiently represent the target population. Similarly, participants in Chapter 6 had returned and completed only the online version of the study questionnaire, which indicates that PwPs with no access to technology or with no previous experience with technology use were not included in this thesis. In addition, the findings from the questionnaire need to be interpreted with caution, as the Cronbach's alpha reliability of the questionnaires was not assessed. PDNSs only completed the Phase I questionnaire in Chapter 5, so the findings from this questionnaire need to be interpreted with caution, and generalisation of these findings to all HCPs working with PwPs should be avoided.

The different age groups and disease stages of PwPs were not highlighted in these studies due to their potentially different needs and preferences regarding an app. Future research will be required to explore the perceptions of subgroups of the PD population (different area, range

of age groups, level of education, PD stages) to provide a more realistic indicator of the uptake of an mHealth app intervention in PD clinics.

7.5 MODEL OF FACILITATORS AND CONCERNS ABOUT MHEALTH APP USE FOR PD

Based on this thesis's findings, the researcher proposes a model of PwP and HCP facilitators and concerns for using the prototype iPad-based mHealth app in PD clinical settings and recommends possible strategies to manage the concerns. Figure 7.1 shows this model schematically.

The prototype iPad-based app was developed for use within clinical settings and to be integrated with EHRs. However, the suggestion to enable remote access to the app for home use was highlighted in this thesis.

During the recent COVID-19 pandemic, the health landscape has been changed with much greater use of technology focusing on access to services, change in healthcare settings and promote remote healthcare technologies. The NHS Wales added features to the Welsh Clinical Portal to support virtual outpatient clinics and rolled out Microsoft Teams for free use for HCPs (NHS digital 2020; Shanthanna et al. 2020). This electronic platform includes chats, video conferences, document storage, and app integration to facilitate communication between HCPs and patients. This could be a great opportunity for app designers to consider remote access to apps to facilitate the acceptance and uptake of an intervention. Therefore, enabling remote access to the mHealth e-PROMs app could provide a promising tool for assessing the health of PwPs during and post the COVID-19. Remote access to the app could be considered; however, going into details of what its features require to enable this goes beyond the scope of this thesis. Further studies are needed to assess users' acceptance of remote access for the mHealth app after finalising the development or improvements of the app, as well as the legal considerations to integrate an app intervention with the current system.

The influence of PD symptoms (e.g., motor and cognitive decline) on the usability and acceptance of an mHealth-based PD intervention is also highlighted. The technical details involved in ensuring that the new mHealth app is accessible and usable by PwPs, despite physical and cognitive limitations, are beyond the scope of this thesis. This might require

cooperation with engineering professionals when developing mHealth-based PD interventions (Denno et al. 1992).

The data published by Parkinson's UK (Parkinson's UK 2020) suggest that the PD could cover a wide age range (from 20-to-90+ years), and prevalence increases with age. Therefore, it is expected that the level of digital literacy among PwPs might be variable, and they may have varying degrees of experience with mHealth apps due to a reported age-based 'digital divide' (Choi and Dinitto 2013; Fox and Connolly 2018). Therefore, it is essential to consider recommendations for the design of mHealth for older people when designing an app for PD (Lewis and Neider 2017). For example, large surface area and well-spaced apart between button options (to account for motor and dexterity issues), adjustable font size (to account for visual issues), and minimizing the numbers and steps required to complete tasks and enable a pause and return function (to account for cognitive impairment and fatigue).

PWP/HCPs

Facilitators

1. Participatory design (engaging PwPs/HCPs during development process.
2. Perceived usefulness: Improve communication, empower PwPs, identify complications or symptoms early, and track progress.
3. Provision of training /support to use app and instructions to navigate and learn how to use app.
4. Perceived ease of use and user-friendly interface (easy to operate).
5. Performance summary or feedback for PwPs and provision of actionable data to HCPs.
6. Compatibility of the content of app with the current system in the clinic.
7. Preservation of privacy: Develop app based on the regulation standards.

Possible Strategies

-Provide education and training on app use.

-Seek support from carers/clinical staff with app use.

-Ensure appropriate encryption and app security.

-Consider remote access for app use.

-Consider engaging non-clinician staff (e.g., IT people, clinic secretary, or healthcare assistant).

-Consider engaging HCPs to promote the mHealth app.

Concerns

1. Concerns around workload/ clinic workflow.
2. Concerns around infrastructure of clinics (not enough equipment/wifi).
3. Concerns about lack of knowledge on technology use.
4. Concerns about losing face-to-face contact with HCPs.
5. Concerns about ability to use app and suitable time and place to use app.
6. Concerns regarding privacy/confidentiality of the collected data.
7. Concerns about PD-health status (tremors and cognitive symptoms).

-Minimise number of tasks in the app to reduce cognitive load and consider the physical impact of PD (motor symptoms and touch interface and using Stylus pen if that could improve usability).

Figure 7.1: The model of PwP and HCP facilitators and concerns about the use of an mHealth app and possible strategies to manage concerns

7.6 RECOMMENDATIONS FOR APP DEVELOPERS AND IT COMPANIES (USEFUL APP DESIGN

FOR PWP/CO-DESIGN APPROACH)

Following the findings from Chapters 4 (Section 4.3), 5 (Section 5.4.2.2.1), and 6 (Section 6.4.2.2.5), there are a number of suggestions for the general development of an mHealth app that aims to facilitate data collection in the hospital setting and enhance management of PD medications. These suggestions would be of value for IT designers and developers of apps and may enhance its future acceptability. Listed below are six recommendations that may aid future mHealth app development.

1. Findings from Chapters 4, 5, and 6 highlighted the need for an mHealth app intervention that enables PwPs and their carers to understand their full range of symptoms and highlights the main issues prior to their consultation in PD clinical settings. It could also help them with the management of their PD medications. The researcher recommends that app designers understand the target users' needs early in development to enable them to focus on the features and components that matter most to ensure the successful development and use of an mHealth app.

2. The findings presented in Table 7.1 provide information that can guide the process of development and implementation of an app and identify the features to consider in selecting and shaping the app intervention within PD clinical practice. These findings highlight the most appropriate mHealth app intervention design for PwPs and their HCPs. Understanding the circumstances within which mHealth app interventions are to be used and delivered is key to their successful delivery. Prior to developing an mHealth app intervention for PD, the researcher recommends a co-design approach, engaging the intervention's end users during the development process (Bjerkan et al. 2015; Revenäs et al. 2018). This is done to determine which app features, policy categories, techniques for users' behaviour change, and methods of delivery are most applicable for such an app intervention to ensure successful implementation and have an impact in routine practice. These recommendations echo the calls to adopt participatory design or co-design approaches in previous research when designing an mHealth intervention (Vaghefi and Tulu 2019; Grosjean et al. 2020).

3. This PhD thesis used 'the person-based approach'. The person-based approach for the development of digital health interventions implies that determining the purpose, acceptability, feasibility, and key characteristics required to achieve each purpose are important for developing a successful mHealth intervention to help manage chronic diseases (Yardley et al. 2015). As a result, this framework facilitates the exploration and identification of the main characteristics of the intervention app, as presented in Chapters 4, 5, and 6, which will help app designers design a more meaningful and useful intervention for PwPs and their HCPs. The researcher recommends that app designers consider this approach during the creation and development of a digital intervention.

4. The participants in this PhD thesis highlighted several potential advantages of using an mHealth intervention app, as presented in Chapters 4, 5, and 6, which could contribute to their future intention to adopt and use this intervention. According to the TAM, perceived usefulness and perceived ease of use are the determinant concepts of an individual's intention to use a new intervention (Davis 1989). For this reason, the researcher recommended that app designers prioritise these two concepts during the design and testing of an mHealth app.

5. As highlighted in Chapter 5, the adoption of these types of technologies would also be easier if supported by the eHealth infrastructure at the health board, where it could be integrated into existing EHR systems; however, this is yet to be achieved in most of the available apps for PD. The researcher recommends that app designers evaluate and assess the infrastructure within health boards where the developed app is intended to be used.

6. Finally, the findings from Chapter 5 emphasised the need to test the final version of the mHealth app in clinical settings to recognise the actual advantages of and barriers to implementing and using such an intervention. The guidelines also emphasise the need to test the prototype of the app with a sample of PwPs and HCPs to evoke their perceptions of and reactions to the app features, including the content and design (Brown et al. 2013; Yardley et al. 2015), as user testing provides an opportunity to enhance the usability and acceptability of the app by future users prior to final

implementation within clinics (Yardley et al. 2015). The researcher recommends that app designers conduct a field test study with the app's target users prior to its implementation in clinical practice.

7.6.1 Recommendations for app design

The findings from Chapters 4 (Section 4.3), 5 (Section 5.4.2.2.1), and 6 (Section 6.4.2.2.5) provide app developers with suggestions to design an mHealth app that could facilitate future implementation and enhance the usability of such an intervention for PwPs and HCPs. The instructions were determined from the synthesis of users' and key stakeholders' perceptions to inform the future development of the app, including the interface and selection of features and content. Generally, app designers must consider the following instructions to design a successful smart device app:

1. The smart device app must be user-friendly.

2. The navigation of the app has to be clear and easy for users who lack previous experience using smart technology.

3. The app has to be developed with functionality that enables the PwPs to use it on any smart device, such as a smartphones, tablets or iPads (as they have a larger screen for users with poorer physical health), and smartwatches, and it should be available for download across different platforms (Apple or Android).

4. Each feature within the app needs to have a separate tab on the home screen as well as an icon for further information or instruction for the purpose of each feature.

7.6.2 Recommendations for app feature selection and content

The suggested features and content for the mHealth app were identified based on the input of PwPs, their carers, and HCPs. They desired the inclusion of four types of features, as described below (see **Table 7.1**). The information in Table 7.1 represents the final recommendations for the design of the app, based on the participants' suggestions from Chapters 4, 5, and 6.

Support for each of these features is anticipated to be useful for patients at different stages of PD, according to the views of PwPs, carers, and HCPs. Following a diagnosis of PD, it is likely

that most PwPs will have to self-manage their symptoms, overcome barriers to obtaining additional information about their condition and PD medications, and face challenges to understanding during consultations, as described by PwPs, carers, and HCPs in qualitative interviews in Chapters 4 (Section 4.3), 5 (Section 5.4.2.2.1), and 6 (Section 6.4.2.2.5). A need to develop a specific PD app that could help PwPs overcome these issues (remembering their main symptoms of concerns prior to consultation and aiding PD medication management) was highlighted. An app should contain the following:

1. Features that support data collection and facilitate discussion during consultations and that can be facilitated by PD-specific PROMs (It is suggested to start with NMSQuest initially and add features to adopt further individual PROMs).
2. Features that support management of PD medications and reporting of side effects.
3. Features that increase access to support (information about PD as well as recommendations of HCPs).

Features for carers of PwPs to provide feedback on the patient's health status and wellbeing. Carers often know patients they care for better than anyone else, and this knowledge can be useful in planning care for patients and identifying issues that may require intervention.

Table 7.1: Final summary of mHealth app features suggested by PwPs, their carers, and HCPs

Suggested App Features	Feedback
Features that support data collection within PD clinics	
Features that facilitate discussion during the consultation and enhance PwP understanding about their conditions	
Both PwPs and HCPs anticipated that using PD-specific PROMs would be a useful feature to help patients understand and remember their main issues and enhance communication during consultations.	As there are several types of available PROMs, it was suggested to include NMSQuest initially. An app could consist of a feature to enable further addition of any other types of PROMs requested by HCPs.
Features to record patients' activities/symptoms such as walking and sleeping	
PwPs suggested adding features that motivate them to exercise and record any other issues that they might have.	These are possible features that app designers can consider.
Features that support PD medication management and reporting of side effects	
PD medications diary	
PwPs found adding a list of different PD medications, including brand and generic names, and the shape, colour, potential side effects, interactions, and contraindications of medications would be a useful feature. HCPs also suggested adding a marker about medication taking across the NMSQuest questions to understand whether the reported issue is related to PD medication (a side effect) or not.	Building an in-app feature that contains all of this information will not be practical due to the huge amount of information available. Alternatively, it was suggested a Dropbox icon could be added beside each medication, which patients can press to record any side effects they experience. Also, an app could include a feature that contains links to additional information that already exists on reputable PD information websites.
Reminder function for medication	
PwPs suggested adding different types of reminders (sound/vibration) to enhance adherence to PD medication.	Enabling patients to programme reminders and alerts using the 'Reminders' feature on their smart device would be convenient for them.
Features that increase access for support.	
Information needs (signposting)	
For additional information about PD and medications, PwPs suggested linking the app to reputable PD information websites such as Parkinson's UK.	This is a possible feature that app designers can consider.
Increasing access to HCPs	
A feature to link the app with patients' database (EHR) at the clinics and provide	App designers would need to treat this suggested feature with caution, as existing EHR systems may differ from

printed feedback to the patients was suggested.	clinic to clinic, which might affect the compatibility of the app format.
Features that highlight the views of PwPs' carers	
A section for carers to input their feedback regarding the patient's health status and wellbeing was suggested.	The app could include a general section for carers to comment on the patient's status. However, further study is needed to explore this section's content.
A feature to connect patients' app devices with their carers' devices would be helpful.	This feature will need further research to ensure practicality and safety.

7.7 GENERALISED LOGISTICS AND CONSIDERATIONS TO ENCOURAGE DEVELOPMENT AND IMPLEMENTATION OF A SMART DEVICE APP

The development of an app that aims to improve data collection and enhance communication during consultation in PD clinics can be supported by the principles of prudent healthcare published by the Welsh Minister for Health and Social Services, which emphasises the importance of the co-production concept (Aylward et al. 2013). Co-production supports collaboration between patients and HCPs during clinical consultations via the exchange of information and shared decision making. The development and implementation of a smart device app within PD clinical practice follows the strategy set out by the Welsh Government (2015), which encourages the use of digital smart devices within health clinical practice to engage patients with their health and improve the services provided. As a result, in 2016, a national programme was launched across NHS Wales to promote the collection and use of PROMs electronically across several health conditions, including orthopaedic conditions, lung cancer, asthma, and cataracts, with the potential to expand it to other conditions (NHS Wales, 2016). Hence, a future smart device app within PD clinical practice can be supported by this programme.

In 2017, the NHS launched the NHS digital apps library platform with a set of guidelines and questionnaires for health app developers to follow to ensure an app's safety and effectiveness

(NHS 2017). Researchers and app developers may draw the best evidence or use a systematic approach to develop and create a smart device app that aims to support data collection and enhance the management of PD medications by considering these policies.

7.8 CONCLUSION AND FUTURE WORK

Advances in mHealth interventions offer the potential to support management, documentation, and symptom tracking of PD, and provide information that could be shared with HCPs to help better manage treatment. However, these mHealth interventions will not be valuable unless target users adopt and use them, and there are several ways in which mHealth interventions can fail to obtain acceptance. Users are less likely to adopt and use an intervention if they perceive it as disadvantageous (i.e., not useful, or difficult to use) or incompatible with their needs, values, or experiences.

The findings of this thesis help to understand different stakeholders' (PwPs, their carers, and HCPs) perceptions of values and concerns about the use of mHealth intervention for PD, as well as suggestions for improvement. PwPs and HCPs were receptive to the idea of using the mHealth app (prototype iPad-based) for PD and they anticipated it to be a useful intervention in the clinical settings. Barriers expressed by both PwPs and HCPs were concerns regarding the privacy and confidentiality of information collected using the proposed app, losing face-to-face contact with HCPs, and PD health status.

Some of the reported concerns could be minimised if HCPs supported the use of apps and standards established by the Data Protection Act 1998 and the General Data Protection Regulations were used and implemented to address security and privacy issues that some of the participants were concerned about. Also, the symptoms associated with PD that could affect PwPs' use of mHealth app, such as decreased dexterity, motor symptoms, and cognitive changes, were considered during the design process.

The time that a PwP spends in the clinic's waiting area is an opportunity for app developers and researchers to use the proposed iPad-based app to collect patient data that may support their clinical encounter with HCPs. However, due to the limited waiting time, and to reduce the negative impact on the clinic workflow, suggestions to use the mHealth app outside of the

clinic time were reported in this thesis. Future research should consider and evaluate different settings to use the mHealth app for PD (clinical settings vs. home settings) and determine the most appropriate settings based on responses.

Using a co-design approach when designing the mHealth-based PD intervention may have the potential to improve the intervention's acceptance and usability. It was noticed that the majority of mHealth intervention studies for PD reported their findings in terms of the intervention evaluation rather than how and to what extent the users were involved in the development. User involvement in mHealth development is most common in the evaluation phase of the intervention development lifecycle, and the most common methods of user involvement include usability tests and questionnaires, while other methods, such as interviews, design workshop sessions, or focus groups, are less common.

As such, this thesis employed a variety of methods (focus groups, questionnaires, and interviews) to identify and explore the suitable mHealth-based PD app design from the end users' point of view. This thesis reports the features (functionality and content) of mHealth-based design suggestions that could be implemented and would likely be feasible and acceptable for PwPs and HCPs. App designers should also consider the wide range of progression stages of PD and design apps with features to enable personalised and customised options that accommodate users' specific needs and allow better engagement.

To enhance the adoption and acceptance of the mHealth app, the usability needs of the target users should be addressed during app design to further optimise the user friendliness of the app. Findings indicated that an inclusive mHealth app would obtain a good level of acceptance. Therefore, a future app should have a feature to collect patients' information (PROMs), PD medication lists, medication information, multiplatform functionality to motivate PwPs to be more physically active, and interoperability with existing EHR systems in PD clinical practice. Also, the app should be designed to enable PwPs to prioritise their most bothersome symptoms and encourage HCPs to view the outcomes in an actionable manner for this app to be useful in improving quality of care within a short consultation time.

Moving towards the NHS approach of 'patient-centred care', the use of an mHealth app intervention would support a change from 'clinician-focused' to 'patient-focused' care. PwPs will need confirmation and reassurance regarding the main aims of such an intervention, which is not intended to negatively impact the patient-HCP relationship during consultations. Also, findings demonstrated that this type of mHealth app intervention has the potential to provide a range of advantages to both PwPs and HCPs.

This thesis considered general acceptability to be a primary factor in evaluating the intention to use an mHealth app intervention within PD clinics. It is too early to conclude whether the use of such interventions within PD clinics would be adequate and acceptable or not. Future research is needed to move beyond this exploratory thesis's findings to understand the specific features and functionality that PwPs and HCPs would like to see in an mHealth app intervention. This could include several stages. First, additional research is needed to collect data on these features from a more diverse sample of PwPs, HCPs, and non-clinician staff in PD clinics. Other factors, such as the level of knowledge, age group, disease status, and socioeconomic status, could affect perceptions towards app use. The preliminary findings from this thesis show that the successful implementation of an mHealth app within PD clinical practice is possible by considering factors such as involvement and collaboration with HCPs, IT departments, manager services, and other clinical staff.

Second, after finalising the key features and developing a mock version of the app, it is essential to evaluate its acceptability and feasibility with small samples of target users (PwPs and HCPs). It would be beneficial to use a mixed-methods study design that includes semi-structured interviews or focus groups for detailed assessment, then a questionnaire to confirm and validate breadth of information and app activity, as well as provide further insight into app use and compare this data to the findings of this thesis (participants' potential perceptions). A feasibility study should also consider evaluating the best time and place to use an app intervention, the time taken to recruit participants, and the time required for PwPs/clinical staff to learn how to use the app to estimate the time scale needed for a larger pilot study.

Concerns that are identified during the feasibility study should be considered, and ways to manage or minimise these concerns should be recognised and implemented.

Obtaining further evidence for the perceived usefulness of the app features (content and functionality) will enable a more refined version of the app and an iterative modification of the app design to be optimised. Finally, upon completion of the small-scale feasibility testing and if the mHealth app is found to be successful and acceptable for target users, a larger pilot study to evaluate the effectiveness of the app can be conducted to provide both PwPs and HCPs with safe and reliable interventions for the care and management of PD.

In summary, this multistage study explored the perceptions of PwPs and their carers and HCPs regarding the use of an mHealth app for PD. Potential facilitators of and concerns about mHealth acceptance and uptake were identified that could guide the development and implementation of future mHealth applications for PD. These findings indicate that participants are interested in using mHealth technology for PD. Future researchers seeking to develop and implement mHealth-based interventions for PD should understand users' needs, preferences, and concerns in ways that encourage acceptance and uptake of the intervention.

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Appendices

Appendix 3.1 Search strategy

Databases: EMBASE, Google scholar, Scopus, and MEDLINE

All terms were entered with .mp

'Smart devices' terms

Smart device* OR Smart-devic* OR Cell* phon* OR handheld computer* OR handheld devic* OR mobile phon* OR smartphon* OR smart-phon* OR smart phone* OR iPhone* OR text messag* OR short messag* OR multimedia messag* OR multi-media messag* OR ((smartphone or smart-phone or smart phone or mobile) adj10 app*) OR iPad* OR tablet devic* OR tablet computer* OR personal digital assistant* OR mHealth* OR m-Health* OR m Health OR mobile health*

'Parkinson's disease' terms

Parkinson's disease* OR Parkinson's* OR Parkinson* OR PD*

'Acceptability' terms

Acceptability* OR Patients' feedback* OR Patients' satisfaction* OR Users' Satisfaction* OR Users' feedback* OR People perception* OR patients' perception* OR Users' experience OR Perspectives* OR users' view* OR views* OR Evaluation*

Google Scholar:

1. Place quotation marks around key words: "Smart-device", "mHealth", "tablet", "iPad", "Parkinson's disease", "Parkinson's", "PD".

2. Google Scholar automatically places AND between words.

3. Search for alternate terms using OR, with the terms enclosed in parentheses: ("Parkinson's disease" OR "Parkinson's").

Limits:

Language – English

Publication Year: 2010-2020

Appendix 3.2   **EPHPP Quality Assessment Tool for Quantitative Studies**

Paper Title: Feasibility and utility of a clinician dashboard from mobile application PD data.

Year: 2019

First Author: Elm et al.,

Component Rating:

A)   SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?

1. Very likely
2. Somewhat likely
3. Not likely ✓ (excluded PwP with cognitive and included only patient having WiFi access only)
4. Cannot tell.

(Q2) What percentage of selected individuals agreed to participate?

1. 80 -100% agreement
2. 60 -79%   agreement ✓
3. Less than 60% agreement
4. Not applicable
5. Cannot tell.

Rate this section	Strong	Moderate	weak
See dictionary	1	2	3 ✓

B) STUDY DESIGN

        Indicate the study design!

1. Randomised controlled trial.
2. Controlled clinical trial.
3. Cohort analytic (two group pre + post)
4. Case control
5. Cohort (one group pre + post (before and after))
6. Interrupted time series
7. Other specify ✓ ……… (Feasibility and observational study) ………………………
8. Cannot tell.

Was the study described as randomized? If NO, go to Component C.

            No ✓   Yes

If Yes, was the method of randomization described? (See dictionary)

No   Yes

If Yes, was the method appropriate? (See dictionary)

No   Yes

Rate this section	Strong	Moderate	weak
See dictionary	1	2	3 ✓

C) CONFOUNDERS

(Q1) Were there important differences between groups prior to the intervention?

1. Yes
2. No
3. Cannot tell ✓

The following are examples of confounders:

1. Race
2. Sex
3. Marital status/family
4. Age
5. SES (income or class)
6. Education
7. Health status
8. Pre-intervention score on outcome measure

(2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g., stratification, matching) or analysis)?

1. 80 -100 % (most).
2. 60 -79 % (some)
3. less than 60% (few or none)
4. Cannot tell.

Rate this section	Strong	Moderate	weak
See dictionary	1	2	3 ✓

D) BLINDING

 (Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?

1. Yes ✓
2. No
3. Cannot tell.

(02) Were the study participants aware of the research question?

1. Yes ✓
2. No
3. Cannot tell.

Rate this section	Strong	Moderate	weak
See dictionary	1	2	3 ✓

E) DATA COLLECTION METHODS

(Q1) Were data collection tools shown to be valid?

1. Yes ✓
2. No
3. Cannot tell.

(Q2) Were data collection tools shown to be reliable?

1. Yes ✓
2. No
3. Cannot tell.

Rate this section	Strong	Moderate	weak
See dictionary	1 ✓	2	3

F) WITHDRAWALS AND DROP-OUTS

(QI) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?

1. Yes ✓
2. No
3. Cannot tell.
4. Not Applicable (i.e., one-time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).

1. 80 -100 %
2. 60 – 79 % ✓
3. Less than 60 %
4. Cannot tell.
5. Not Applicable (i.e., Retrospective case-control)

Rate this section	Strong	Moderate	weak	
See dictionary	1 ✓	2	3	Not Applicable

F)   INTERVENTION INTEGRITY

(QI) What percentage of participants received the allocated intervention or exposure at interest?

1.   80 -100 %
2.   60 -79 %
3.   Less than 60 %
4.   Cannot tell.   ✓

(Q2) Was the consistency of the intervention measured?

1.   Yes
2.   No
3.   Cannot tell.   ✓

(Q3) Is it likely that subject received an unintended intervention (contamination or co-intervention) that may influence the results?

1.   Yes
2.   No   ✓
3.   Cannot tell.

H)   ANALYSES

(QI) Indicate the unit of allocation (circle one)

Community   Organisation/institution   Practice/office   Individual ✓

(02)   Indicate the unit of analysis (circle one)

Community   Organisation/institution   Practice/office   Individual ✓

(03)   Are the statistical methods appropriate for the study design?

1.   Yes ✓
2.   NO
3.   Cannot tell.

(Q4) Is the analysis performed by intervention allocation status (i.e., intention to treat) rather than the actual intervention received?

1. Yes   ✓
2. No
3. Cannot tell.

GLOBAL RATING COMPONENT RATINGS:

Please transcribe the information from the above boxes on pages onto this page. See dictionary on how to rate this section.

A SELECTION BIAS	Strong 1	Moderate 2	Weak 3✔
STUDY DESIGN	Strong 1	Moderate 2	Weak 3✔
CONFOUNDERS	Strong 1	Moderate 2	Weak 3✔
BLINDING	Strong 1	Moderate 2	Weak 3✔
DATA COLLECTION METHOD	Strong 1✔	Moderate 2	Weak 3
WITHDRAWALS AND DROPOUTS	Strong 1✔	Moderate 2	Weak 3

GLOBAL RATING FOR THIS PAPER (circle one):

1. Strong (no weak ratings)
2. Moderate (one weak rating)
3. Weak (two or more weak ratings) ✓

With both reviewers discussing the ratings: (this work was conducted by single researcher)

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

    No   Yes

If yes, indicate the reason for the discrepancy.

        1. Oversight
        2. Differences in interpretation of criteria
        3. Differences in interpretation of study.

RATING FOR THIS PAPER based on reviewers' judgment (circle one):

1. Strong ✓ (Involved both quantitative and qualitative approaches in design of the study, the blinding was not applicable for this study due to the nature of study intervention).
2. Moderate
3. Poor

CASP Qualitative Research Checklist

Paper Title: How PwP and HCPs wish to partner in care using eHealth: Co-design study.

 Year: 2020

 First Author: Carolina Wannheden.

Questions	Consideration	Study
1. Was there a clear statement of the aims of research?	• What was the goal of the research? • Why was it thought important? • Its relevance	Yes
2. Is a qualitative methodology appropriate?	• If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants • Is qualitative research the right methodology for addressing the research goal?	Yes
3. Was the research design appropriate to address the aims of the research?	• If the researcher has justified the research design (e.g., have they discussed how they decided which method to use)?	Yes
4. Was the recruitment strategy appropriate to the aims of the research?	• If the researcher has explained how the participants were selected • If they explained why the participants, they selected were the most appropriate to provide access to the type of knowledge sought by the study • If there are any discussions around recruitment (e.g., why some people chose not to take part)	No
5. Were the data collected in a way that addressed the research issue?	• If the setting for data collection was justified • If it is clear how data were collected (e.g., focus group, semi-structured interview etc.) • If the researcher has justified the methods chosen • If the researcher has made the methods explicit (e.g., for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)? • If methods were modified during the study. If so, has the researcher explained how and why? • If the form of data is clear (e.g., tape recordings, video material, notes etc) • If the researcher has discussed saturation of data	Yes (No discussion about saturation)
6. Has the relationship between researcher and participants been adequately considered?	• If the researcher critically examined their own role, potential bias, and influence during (a) Formulation of the research questions (b) Data collection, including sample recruitment and choice of location. • How the researcher responded to events during the study and whether they considered the implications of any changes in the research design.	No (based on the judgment of the researcher)

7. Have ethical issues been taken into consideration?	• If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained • If the researcher has discussed issues raised by the study (e.g., issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) • If approval has been sought from the ethics committee	No
8. Was the data analysis sufficiently rigorous?	• If there is an in-depth description of the analysis process. • If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? • Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process. • If sufficient data are presented to support the findings. • To what extent contradictory data are taken into account. • Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation.	Yes (No explanation About reflexivity or potential bias were discussed)
9. Is there a clear statement of findings?	• If the findings are explicit. • If there is adequate discussion of the evidence both for and against the researchers' arguments • If the researcher has discussed the credibility of their findings (e.g., triangulation, respondent validation, more than one analyst) • If the findings are discussed in relation to the original research question	Yes
10. How valuable is the research?	If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g., do they consider the findings in relation to current practice or policy? Or relevant research-based literature? • If they identify new areas where research is necessary • If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used.	Yes

Comment: Moderate quality (**limitations:** small and bias sample size (4 FG), participant have technology experience).

Appendix 4.1- Research Project Topic Guide

Introduction

Introduce ourselves. "Hello. We are three pharmacy undergraduate students from Cardiff University, here today to ask you a few questions to help us with our research project which surrounds Parkinson's disease. We would like to find out your thoughts and opinions on the use of technology to gather information at Parkinson's clinics. Today's session will be structured as an informal chat and all information collected will be kept confidential."

- Fill out consent form before information gathering begins.
- Rapport building could be an option if they do not know each other.

"For the tape, please could you introduce yourself and something about yourself, for example something you get up to into in your spare time or hobby?"

Opening questions (general technology)

- Electronic data collection.

"How do you feel about the use of technology to record data in Parkinson's clinics?"

 Use of technology.

"How comfortable/capable are you in using a computer or tablet?"

- Initial thoughts, before seeing the app.

"What would you think of using a tablet, such as an iPad, to collect your own data in a Parkinson's clinic?"

iPad App Introduce app and explain need for app.

- Explain use so far and future- how info held, who sees.

"So, at the moment, when you go into a Parkinson's clinic your information is stored as an electronic health record on the computer. However, every time you visit the clinic, the clinician needs to ask you the same set of questions, which can be a lengthy process. The aim of this iPad app is to speed up the process of the visit to the Parkinson's clinic, whilst giving clinicians more time to spend focusing on the important issues that have been identified by the iPad app."

 Get them to try.

If they have questions about.

Further Questions (specific to the app)

- How did they find app- layout, activities, dexterity issues?

"How did you find using the iPad?"

- Need for training!

"Would you need assistance in using the app?"

- Information- worries about sharing, who sees, confidentiality.

"Do you have concerns about using technology with regards to personal information?"

- Clinic appointments- waiting times, waiting room environment (privacy)

"Would you feel comfortable using this app in a clinic waiting room?"

"How long do you usually wait before your clinic appointment?"

- Need for app.

"Do you feel that there is a need for this app?"

- Content of app – any questions that could be added or removed.

"What do you think of the questions asked in the app?"

"Are there any questions or parts to the app that you think are unnecessary?" Are there any questions or parts to the app that you think could be added?"

- Improvements- things missing, general improvements, formatting etc.

"Any general comments about the app?" "Or using the iPad?"

Feedback

Our session- form?

Anything we have missed that you think is important.

Closure

Opportunity for further questions Explain again what will happen to the data.

Points of contact (follow up?)

- **Thanks for attending.**

"Thank you for attending and being a part of today's focus group and thank you for providing your thoughts and opinions. **Before we end the session, are there any further questions you would like to ask?** As I have stated before, the information that you have provided today will be kept confidential. If you do think of anything that you wanted to ask or any future points of contact, my supervisors email addresses are provided on the information sheet. Once again, thank you very much for your participation!"

Appendix 4.2- Research Project Topic Guide

Introduction

Introduce myself.

"Hello. I am a PhD student from Cardiff University, here today to ask you a few questions to help me with my research project which surround using electronic device in Parkinson's disease clinic. I would like to find out your thoughts and opinions on the use of technology to gather information at your clinics. Today's session will be structured as an informal chat and all information collected will be kept confidential."

- Fill out consent form before information gathering begins.
- Rapport building could be an option if they do not know each other.

"For the tape, please could you introduce yourself and something about yourself, for example something you get up to into in your spare time or hobby?"

Opening questions (general technology)

- Electronic data collection.

"How do you feel about the use of technology to record data in your clinics?"

- Use of technology.

"How comfortable/capable are you in using a computer or tablet?"

- Initial thoughts, before seeing the app.

"What would you think of using a tablet, such as an iPad, to collect your own data in the clinic you visit?"

iPad App

Introduce app and explain need for app.

- Explain use so far and future- how info held, who sees.

"So, at the moment, when you visit any clinic, your information is stored as an electronic health record on the computer. However, every time you visit the clinic, the clinician needs to ask you the same set of questions, which can be a lengthy process. The aim of this iPad app is to speed up the process of the clinic visit, whilst giving clinicians more time to spend focusing on the important issues that have been identified by the iPad app."

Show them the iPad app.

If they have questions about.

Further Questions (specific to the app)

- How did they find app- layout, activities, dexterity issues?

"How did you find using the iPad?"

- Need for training!

"Would you need assistance in using the app?"

- Information- worries about sharing, who sees, confidentiality.

"Do you have concerns about using technology with regards to personal information?"

- Clinic appointments- waiting times, waiting room environment **(privacy)**

"Would you feel comfortable using this app in a clinic waiting room?"

"How long do you usually wait before your clinic appointment?"

- Need for app.

"Do you feel that there is a need for this app?"

- Content of app – any questions that could be added or removed.

"What do you think of the questions asked in the app?"

"Are there any questions or parts to the app that you think are unnecessary?"

"Are there any questions or parts to the app that you think could be added?"

- Improvements- things missing, general improvements, formatting etc.

"Any general comments about the app?" "Or using the iPad?"

- Usefulness of electronic informed consent.

"Would you feel comfortable giving the informed consent by using the iPad device instead of the paper-based informed consent?"

Feedback

Our session- form?

Anything we have missed that you think is important.

Closure

Opportunity for further questions.

Explain again what will happen to the data.

Points of contact (follow up?)

- Thanks for attending.

"Thank you for attending and being a part of today's focus group and thank you for providing your thoughts and opinions. **Before I end the session, are there any further questions you would like to ask?** As I have stated before, the information that you have provided today will be kept confidential. If you do think of anything that you wanted to ask or any future points of contact, my supervisors email addresses are provided on the information sheet. Once again, thank you very much for your participation!"

Appendix 4.3 Invitiation letter

Cardiff School of Pharmacy and Pharmaceutical Sciences
Cardiff University
Redwood Building
King Edward VII Ave
CF10 3NB

Dear Sir/Madam,

I am undertaking a research project at Cardiff University into 'Perceptions of the utility of iPad based apps to collect data in a hospital clinic' which is part of a larger study looking at the use of iPad based apps in Parkinson's disease clinics supervised by Dr Emma Lane (Laneel@cf.ac.uk) or Dr Louise Hughes (HughesML@cf.ac.uk). We are also interested in the views of older people without Parkinson's disease, which is why you have been asked to take part.

I would like to invite you to take part in a focus group on:

Date:

Time:

Location:

The focus group is expected to take around 45 minutes and will take no longer than one hour and a half.

The focus group will provide an opportunity for you give us your opinion on the use of an iPad device to input patient information when you attend a hospital appointment. We want to ensure that is a suitable method to be used for older people and make any changes if they are relevant.

Your views will be used to help us develop this new method for collecting patient information; we will not be collecting any of your personal information during this focus group.

More background information can be found on the attached information sheet.

If you would like to take part in the focus group on (*insert date*), please let me know by contacting (*name and contact number*) or e-mailing (*e-mail address*) by (*date*) at the latest so that arrangements can be finalized.

Yours faithfully

Amani Khardali (PhD. researcher)

Tel: 07474911856

Email: KhardaliA@cardiff.ac.uk

(In association with Dr. Emma Lane and Dr. Louise Hughes

Appendix 4.4 Participant Information Sheet

Perceptions of the utility of iPad-based apps to collect data in a hospital clinic.

What is the purpose of the study?

The purpose of this study is to find out your opinions on gathering patient information in medical appointments using an iPad device. Currently, patient information is often collected using paper-based questionnaires (examples might include patients' health questionnaires or satisfaction surveys). We are trying to develop a new method to improve collecting information in hospital clinics using new technology (iPads). This study is part of a larger study into the use of iPads for patients with Parkinson's disease, but we are also interested in the views of other groups of people without Parkinson's disease. The information we gather from this study will be used to help develop this new method to collect patient information, ensuring that it is suitable for use in clinics, including people with Parkinson's disease.

Why have I been invited?

You have been invited to participate as a member of the general public. In particular, we are seeking the views of members of the public aged 60 years and over. We are recruiting people through local groups such as the one you are a part of. We hope you will be able to share your thoughts and experiences of using a new type of technology.

Do I have to take part?

No, it is up to you to decide. Choosing to take part will have no direct effect on you or any medical treatment you may have. This information sheet, which is yours to keep, provides the main information about the study but you are welcome to ask any questions you might have. If you decide to take part, we will ask you to sign a consent form to show that you have agreed to take part. You are free to withdraw at any time without giving a reason.

What will happen to me if I take part?

If you agree to take part, we will contact you to confirm attendance. At the beginning of the focus group, we will ask you to complete a brief confidential form with your gender and age. We will not collect any other personal information during this focus group; we just want to hear your opinions about using our iPad application to collect patient information in hospital clinics. A focus group is a discussion involving people with something in common, in this case, all the people in the group will be from the same background, such as the same social club. The group will be informal, with participants talking to each other and the researcher about the study topic. There are no right or wrong answers – we are just interested in your opinions. Please be aware that the discussion will be audio recorded for our research and you may be quoted, although this will be anonymised. The focus group will typically last around 45 minutes and may last for up to 1 hour and a half, but you are free to leave at any time. The original recording will be kept for no longer than one year after the study ends then it will be deleted.

Expenses and payments

We will reimburse any reasonable additional travel expenses you incur as a result of attending the focus group.

What are the possible advantages and disadvantages of taking part?

Taking part in this study will not alter your usual care or any clinic appointments in any way. It has been found that some people find being part of a focus group a positive experience as it allows them to share their views with other people. A potential issue with focus groups is that participants may choose to reveal sensitive information; while we ask all participants not to tell others about what people said in the discussions, we cannot guarantee absolute confidentiality from other members of the group.

Will my taking part in the study be kept confidential?

Yes. The study has been granted ethical approval from the Cardiff School of Pharmacy and Pharmaceutical Sciences Research Ethics Committee, and we will follow the ethical and legal practice and ensure all information about you will be handled in confidence. Your name and personal details will not be included in any publications, and any data which is used will be anonymised (this means it will not be possible to identify any individual and your name will not be associated with anything you say).

What will happen if I don't want to carry on with the study?

Your participation is voluntary, and you are free to withdraw from the study at any time without giving a reason. This will have no impact on your clinical care.

What do I do if I have a problem or complaint?

If you have any questions or concerns about the study, please contact the study supervisors at Cardiff University, Dr. Emma Lane (Laneel@cf.ac.uk, 02920874989) or Dr. Louise Hughes (HughesML@cf.ac.uk, 02920876432). If you wish to make a formal complaint, you can contact the Director of Research at Cardiff School of Pharmacy and Pharmaceutical Sciences, Prof Andrew Westwell (WestwellA@cardiff.ac.uk).

If you have any further questions, please get in touch using the details on the enclosed letter.

If you have read this information and wish to participate, please get in touch so we can make arrangements.

Appendix 4.5 Ethical Approval

SPPS Ethics Approval Notification (EAN)   8/9/14 v12

Cardiff School of Pharmacy and Pharmaceutical Sciences, Research Ethics Approval

This form has been signed by the School Research Ethics Officer as evidence that approval has been granted by the Cardiff School of Pharmacy and Pharmaceutical Sciences Research Ethics Committee for the following study:

Project title:	1617-12 Electronic data collection in a Parkinson's clinic – Patient perspectives

This is a/an:	Undergraduate project	X
	ERASMUS project	
	Postgraduate project	
	Staff project	

Name of researcher: (PG/Staff projects only)	
Name of supervisor(s):	Emma Lane, Louise Hughes

STATEMENT OF ETHICS APPROVAL
This project has been considered and has been approved by the Cardiff School of Pharmacy and Pharmaceutical Sciences Research Ethics Committee
Signed ▮▮▮▮▮▮▮   Name R Price-Davies   Date _13/10/16__ (Chair, School Research Ethics Committee)

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Appendix 4.6 Amendment ethical approval

SPPS Amendment Approval Notification (AAN)   11/10/14 v1

Cardiff School of Pharmacy and Pharmaceutical Sciences, Research Ethics Approval

AMENDMENT APPROVAL

This form has been signed by the School Research Ethics Officer as evidence that approval has been granted by the Cardiff School of Pharmacy and Pharmaceutical Sciences Research Ethics Committee for amendment(s) to the following study:

Project ref and title:	1617-12 Electronic data collection in a Parkinson's clinic - Patient perspectives

Name of researcher: (PG/Staff projects only)	Amani Khardali
Name of supervisor(s):	Emma Lane, Louise Hughes

The amendment(s) dated 30 Aug 2017 have been reviewed and approved.

Any further amendments will require approval.

STATEMENT OF ETHICS APPROVAL
The proposed amendment(s) have been considered and approved by the Cardiff School of Pharmacy and Pharmaceutical Sciences Research Ethics Committee Signed ████████ Name R Price-Davies   Date _16/09/17__ (Chair, School Research Ethics Committee)

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Appendix 4.7 Consent form

Project: Perceptions of the utility of iPad-based apps to collect data in a hospital clinic.

Please initial Box

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason.

I agree to take part in the above study.

I agree to the focus group being audio recorded.

I agree to the use of anonymized quotes in publications.

I understand that all of my information will be held confidentially.

_____   _____   _____

Name of Participant   Date   Signature

_____   _____   _____

Name of Researcher   Date   Signature

• Age……………………….

• Gender (please tick):   ☐Male   ☐ Female

Please tick the relevant box below if you:

☐ Is a person with Parkinson's disease   OR   ☐ care for someone with Parkinson's disease?

☐ Is a person without Parkinson's Disease?

• If applicable, how long have you had Parkinson's disease (years)……………………………………

Appendix 4.8 Example Transcript (Monmouth Support Group)

Amani: Hello, my name is Amani, and this is Luke. We are a researcher from Cardiff University, and we are here today to ask you a few questions to help us with our project, which is surrounding using technology to collect your information at the Parkinson's clinic. Today's session will be structured as informal chat, there is no right or wrong answer and anything you will say will be kept totally confidential. So just for tape can we go around, and everyone tell me your name and anything you would like to do in your spare time.

TT: Right yes, my names T T. With regards to what I like to do in my spare time, we enjoy going on holiday, although I'm retired, I retired 15 years ago I still just do one day a week at a garage down in Raglan, it's basically, I enjoy gardening as well. And that's basically it.

MJ: My names M J. In my spare time I like socialising with friends, I like reading, I like going to the theatre and I just generally like enjoying myself.

E: I'm E, I haven't got Parkinson's, David's got Parkinson's he's, my husband. I read, do crosswords, go to exercise classes, things like that.

AH: My names A H I've been retired 12 years. I like DIY, I just reconverted my double garage into a workshop, and I like reading but I vary rarely get the chance and that's about it

DR: I'm D R and I'm married to E, I've had Parkinson's now for 10 years, I'm 75 and I am a keen gardener, a keen sportsman and I volunteer. Currently I'm a driver, I've got a bad knee and I'm a little bad on my feet at the moment I'm waiting for an operation but I'm able to drive so I bring old people, mainly to this place from outlying areas as a sort of community taxi service, that's basically it

JM: My name is JM, I'm 74, I'm an ex-marathon runner I've had Parkinson's and celiac for 3 years. That's about it.

JM: I'm JM, I'm his wife and I think my hobby in my spare time and every minute I have is running the group (laughter)

Amani: So, thank you for that, just to begin, right now currently when you go to your clinic appointment are you aware how they store your information in the clinic? Like on the paper or on the computer?

MJ: Computer

DR: It is all on computers yes

J: Well, he's sitting looking at a screen all the time; I don't know what he's looking at

TT: A computer

Amani: Okay great so how do you feel about using technology in the clinic?

MJ: Pardon?

Amani: How do you feel about using technology to collect your information in the clinic, in the Parkinson's clinic?

TT: It's more vulnerable than paper, with people hacking in, into various databases, whereas with paper you've got it in your draw and that's it

DR: Personally, I'm happy with it and I don't see how you can manage without it nowadays, it wouldn't be possible what they do on the computer in the medical business, because it's not just Parkinson's it's when you go to the surgery because you've got something else, they all look at the computer and also, we can do the same, we can Google whatever. I think patients are probably more knowledgeable now because of the Internet than they ever used to be and probably doctors are more knowledgeable because they can get the information themselves and that is what most of them do.

Amani: So, what do you think?

MJ: I think as long as it's, confidentiality is properly protected, I think that's important, for any medical information. That it's not shared with other people without your permission and I also based upon my service in the national health service feel there's a great need for improving communication between the various department treating people, because there's a tendency for everyone to see their little bit of the person and no one to put the person together as a whole person, in relation to the treatment and the diagnosis.

Amani: Good great, so Mary said she has a concern about confidentiality, like if we protect the confidentiality, so does anyone have any other concern or fear of using technology in clinic?

TT: No, I've got no problems with it.

DR: I cannot say it worries me; I don't think there's any information about me that I would be terrified if anybody else got a hold of it. My bank account number would worry me greatly, but health information does not really concern me too much. I do not know that is probably me being naïve but perhaps you could explain it, is there any reason we should be worried about it...You don't know?

Amani: No

DR: I cannot say it's something I worry about, I worry about security in terms of banking, and I don't bank with the computer, I don't do computer banking for that reason, the finance would worry but knowledge about medical matters wouldn't worry me too much.

MJ: I think it's unlikely that anything could go wrong but all kinds of organisations that could benefit from knowing about your medical condition, insurance, and that sort of thing, I do not particularly lie in bed worrying about it but it's something I feel needs to be…

J: When you say technology do you mean us using the technology? Or the medical profession…

Amani: You are using the technology.

J: In what respect?

Amani: Because like in the clinic right now our project is using this iPad to input some of your data, and that will be used by you, so you are going entering the information.

J: What, how you've been over the past three months or…?

Amani: Yes

J: That kind of information and would you have the iPad with you?

Amani: Yes

J: So, it would be, you would have it and you would complete it on a daily or weekly basis, would you? And then the consultant would now how your feeling, how you've been?

Amani: No actually at the moment this iPad will be given to you at the clinic, you shouldn't have one, and then we are going to ask you to fill some sort of questionnaire on it and after that the questionnaire will go directly to the computer to the consultant computers and then they can track you, your progress, through his screen and this is the whole idea about our project.

TT: And he will have that information then so that when you go in and see him, he's already got it?

Amani: Yes

TT: So, it is saving him time?

Amani: Yes

DR: Well, you may not go and see him; you may just contact him on that

TT: No because that will be in the clinic

DR: Well presumably you will have that at home

TT: No that is in the clinic

Amani: Yes

MJ: But one of the things that is important in terms of your medical treatment is not only just the sharing of factual information, it's the professional relationship and the kind of confidence and well the confidence you've got in the person whose treating you and the organisation that he's within. So, I do not think you should just move over to computers without taking into account the need, the importance of the professional relationship.

Amani: I think, we are not going to take any like, your consultation time, time with your consultant away, we are not going to take any of them, you are still going to see your consultant. You are going to be still seeing your consultant, but this is going to be an additional thing, you're going to supplement

your consultations with your doctors. Like give him more information's about your case, how you're prognosis and all of this stuff. So…

TT: Is this a situation where you'll see a screen and there'll be questions where you put yes or no, or do you put relating to it all?

Amani: Actually, I'm going to show you how the content of it, when we come to this question. Then, how comfortable are you using the technology?

E: How what?

Amani: How comfortable are you when using the technology? Are you very…?

MJ: Not very, some to a degree but not totally

TT: I'm like Mary really, I mean I can go on to the computer and do things and that, but I am of an age where we didn't have computers at school so what I know is what I've picked up as I've gone along and I'm not brilliant at it really

Amani: So, but at least you know the basic thing about how to use a computer or the iPad the smartphone.

TT: Yes

Amani: Okay great, and you?

E: Yes, I think we would manage

DR: We have got an iPad we use the iPad quite a bit but we're not proficient. There's lots and lots of things it does that I wouldn't go anywhere nearby.

E: I don't know I think we do okay

DR: Oh, it does a huge amount that we don't touch

E: No but to do what she is asking, we could look and do that

DR: We do emails we can buy stuff from amazon and stuff like that, but it does a lot more than that doesn't it, I've never done an app

TT: No nor me I don't know what an app is (laughter) to be quite honest

DR: I know what an app is, but I've never done one, I find putting stuff into the computer it gets incredibly frustrating because it never works out quite the way I want it too, it never says ooh yes okay here it is, it says ooh no mistake here.

Amani: Okay, so I'm going to show you the application, actually there is an application designed by a consultant who ran a neurological clinic in Cardiff, and he developed this application to be used in a Parkinson's clinic and to be used by the Parkinson's people. And there is… there is three sections in this application, the first section is a quality of health questionnaire, which is ask you about questions about your general health. Then there is a scale to rate your health at that day from 1-100 and then there is a non-motor symptom questionnaire 30 questions with yes or no answers to cover all your non-motor symptoms like constipation

AH: I used to have a survey for prostate gland, prostate cancer, which is very similar, 8 or 9 pages.

J: And is that an ongoing thing? Or just a one off?

AH: I had it three years ago and I've done two since

J: Oh, you've done two okay

Amani: You did it on paper right?

JM: On paper yes

Amani: So yes, this is like a similar questionnaire, but it is done on the iPad. And then the last section is a finger-tapping test, to assess your tremor.

J: Like doing that but on your iPad?

Amani: Yes, so we going to ask you to tap the screen as fast as you can and after you done with that all the information you already entered will go directly to the consultant computers so when you enter to see him, he will discuss with you all of these things.

TT: Can I just ask when you talk about the consultants, we haven't seen the consultant since the day I was diagnosed, we see Debby Davies over at the clinic, like the Parkinson's nurse, does this relate to her as well?

Amani: The iPad you mean.

TT: Yes

Amani: I don't think so because…

AH: Well, we don't see the consultant I haven't seen the consultant in 10 years we see Debby Davies

E: Have you seen…?

DR: I saw him about five years ago, Dawson

TT: I saw him when I was diagnosed

Amani: Even with like, not only the consultant also the nurse specialist, are you going to see the nurse specialist?

DR: I see her every 6 months

TT: Yes, every 6 months

Amani: Yes so, we are going to use this also, the consultant or the nurse specialist will use the same thing. I will let you see the application, try with it, take a minute.

MJ: Does the computer analyse any of this information itself, you know when you're writing a letter it will suddenly decide you want to use a different word than the one you actually used, does the same thing operate on?

J: I feel terrible, no you don't.

MJ: Do you know what I mean, words that seem the same but don't mean the…

Luke: The questions now that you see are all answered in a yes or no fashion so you will just tap the answer, you won't have to write anything down.

AH: The prostate one it didn't give you any room to explain the questions, at the end of it I put I had Parkinson's disease as well, it had very similar symptoms to prostate cancer. One just gets lost when someone answers the questions.

MJ: These questions are based upon the ones that your doctor or consultant would ask you when he saw you.

Amani: Not really because like, what kind of questions your consultant or nurse specialist ask you when you go, they focus more on your movement things.

TT: Physical things rather than a written down one

Amani: Yes, so this is also focussed more on the other symptoms like if you have constipations if you have like any other symptoms, you can answer it here.

J: So, if you're feeling depressed, something like that, which is something you may not necessarily ask

Amani: Yes

MJ: There's not a risk that you could have, I know I'm sounding like a kind of negative person at this meeting, but you could have too much information that people get so much information they can't find their way through it in a logical and constructive way.

AH: I've got to go I've got another appointment

Luke: Okay that's fine.

Amani: Okay

DR: Take care Alan

J: See you at the next meeting Alan

Amani: Thank you

Amani: So, after you see the application how do you feel about filling in something like this when you go to your appointment?

TT: Obviously when it asks you for a percentage of 1-100 on how you feel today, it's basically a personal thing really and what you might thing is 70 or 80 % quite good obviously 10, 12, 20 % is going to be pretty poor. But it's you who's making that decision isn't it.

Amani: No, you are going to be making the decision because you are going to be rating how you feel this day, like I'm feeling very good, I'm feeling good, no I'm feeling…

TT: Well, is there a tendency for most people to put 50 in as an average

Amani: Okay that's how they feel.

J: But I suppose if you're feeling very low you wouldn't you would put more wouldn't you, I don't know

Amani: So, what about you?

DR: To be honest I can't see an awful lot of advantage that's perhaps my natural scepticism but looking at anything, if it's used for something in excess of what we currently receive I am more than happy with the service I am getting form my Parkinson's nurse at the moment. If the time comes when I need the consultant then I'm sure she would refer me to the consultant immediately, or consult herself with the consultant as to what steps should be taken, that's happened in the past on odd occasions but I think the personal relationship, which I've built up with my Parkinson's nurse over the past five years and previous to that when we lived in Scotland where I had a different nurse it was exactly the same up there. The relationship between the two of us was more important than simple questions. And she spends far more time talking to me "how are you Dave, how do you feel, how are things, what have you been doing" she's getting information because she knows what I'm doing tells her what I can do. She knows if I tell her, I'm having a bit of trouble with whatever I'm, she's picking up, which I'm not sure a machine will necessarily do.

TT: I'm pretty sure the time I personally went to see Debby Davies, the time before the last one, she had a girl who was assisting her, and I sat down with the girl and we did this.

E: She does that nearly every time you go

TT: But I think she was away on medical leave or maternity leave

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DR: I don't think I've ever…

E: You have filled in the form recently with the nurse

DR: I never remember anything like this I mean, it was half a dozen questions and also, she did a blood heart check and blood pressure, that sort of thing, I was weighed

TT: Did she ask you some of the questions that were on the…?

DR: Yes, there were a few questions on it, but I think I've only done that once or twice

TT: I've done it only once

DR: I mean I've seen her 4 times a year for the last 5 years.

MJ: But you see this all indicates we are not treated in the same way, cos I don't see a nurse four times a year on a regular basis.

TT: No, I don't

DR: Well, you have to ask

E: You have to ask

J: We see a consultant though

DR: Do you see a consultant?

J: We don't have a nurse

E: Well, we don't see a consultant we see a nurse

DR: Different health services obviously treat things differently

Amani: Actually, the idea behind this application is not too affect your relationship with your Parkinson's nurse we are going to keep this relationship. This is just to give her like more information about you.

DR: Yes, I'm perfectly happy with that, I would hate to lose any of the contact I have with the Parkinson's nurse

TT: I'd hate to think that you come in every 3 weeks or 6 months and all you do is you come down here and you do it on the computer and you just go away and that's it.

DR: No, I wouldn't want that

TT: No, definitely not.

E: I'd rather carry on…

DR: We only have half an hour with Debbie

TT: She's usually an hour late because she spends more time with people

DR: She's always half an hour late I have never had quite the courage to turn up half an hour late knowing that I would just walk straight in

TT: She would be up to date that day (laughs)

DR: Its never happened but I don't mind, times not something that worries me very much

TT: But as long as it's not replacing that

Amani: Yes, it's not replacing that.

DR: That's fine

Amani: It's just liked an additional thing

MJ: I think it also like how you're feeling today that's fine but in Parkinson's you vary a lot, so they need to know how you've been feeling over a period not just on the one day, because it's almost sods law that you always feel quite well the day you go

DR: But if there's a string of questions, they'll get to that, it won't be just one question and they'll take matters into…they'll read between the lines

Amani: True, then on the nonmotor symptoms questionnaire, the 30 questions they're answered just yes or no, do you think that is enough or do you think you need few more option, to answer?

E: I suppose it depends on what the question is

Amani: You can see the questions.

TT: It says dribbling of the saliva during the daytime, yes or no. Loss or change in your ability to taste or smell. Difficulty swallowing food or drink. So, I think they're…

DR: They're yes, no questions aren't they

TT: I mean you can't go into a great deal last night I nearly choked but that's the only time it happened, I think these are yes or no answers

Amani: And you David what do you think?

DR: I'm perfectly happy with it, I don't want to enter into a dialogue with it. If yes/no is sufficient that's fine, I'm perfectly happy with that.

J: Yes, he's fine, no worries

Amani: Okay no worries, so after you see the application, do you think there is anything that we need to add to the application or take it away from the application.

J: You're talking about symptoms of general Parkinson's?

Amani: Yes

J: Like swallowing or speech?

TT: Does it ask about what medication you're on because at the moment I'm not on any medication

Amani: No, it's not asking about any medication. So, adding like a medication section will be good?

DR: I don't think so

TT: No, I don't think so

MJ: These are actually very good questions, in my opinion.

J: And are they the sort of thing he would ask you?

MJ: Yes, I think they're good questions.

TT: And some of those questions on there Mary I think this is a situation where you'd feel less embarrassed putting them on that machine than that person asking them

J: Yes, face to face

DR: I tell Debbie anything (laughs)

TT: No no some people might…

DR: I think I'd rather tell Debbie than put it on the machine

MJ: I like the one about excessive swearing (laughs) under great provocation.

J: Or no provocation at all (laughs)

Amani: So, Mary are you okay with these yes or no questions or would you like a more range of how often you have had this symptom. Yes or no or you would like rarely sometimes usually, always I have this symptom?

MJ: I think you would have to have time to time sometimes because you don't have them all the time do you, well I don't. Some of the ones I have I don't have all the time.

Amani: So, changing the answer to a bigger range will be better than only yes or no.

MJ: Yes or no if there's a question how often or something.

TT: Periodically

MJ: Well, a question that indicated a simple way of phrasing that.

Amani: Okay also with the previous group they suggested adding a section for the carer so the carer can write or fill out how they're partner could be with their disease. What do you think about this idea?

J: I think that's a good idea, because how the carer feels reflects on how the person feels, reflects on how the carer is and visa versa. So, I think that would be a good idea.

Amani: And how do you prefer these sections look like, like you want blank or some questionnaire?

J: Well, how do you think, I think maybe just general questions, "How was your partner been?"

E: Yes, I'd say just general questions

J: And then "Has anything particularly changed?" and then the consultant could, depending on how you answered it, the consultant could maybe investigate it a bit more in the consultation. Or a nurse

DR: I think if you in a fortunate position of having a carer, or having someone who is identified as a person who cares for you, that's incredibly important and I think the answers from the carer may not always be the same as the answers from the person concerned. I think that's important and that shouldn't be missed.

J: Yes, I agree there

DR: If you ask me do I…and I go no, she might (referring to his partner) go "Well actually a few times you have" so perhaps the answers not the same. So, I think as a source of information for the clinician it will be important to include a carer where a carer is available. A lot of people don't have carers and that's something that maybe needs looking at.

Amani: Okay great, so actually we designed this application to be used in a waiting room environment so how do you feel about doing that in a waiting room environment?

TT: Do you mean in a general one or a side…?

Amani: In the general waiting room, do you have any worries or concerns doing that in the waiting room?

J: I think it depends on if you want to discuss something with your carer and you might be a bit embarrassed in a general waiting room

MJ: I suppose it depends how much space the general waiting room, because some are quite packed in

Amani: So, it depends on if the waiting room is busy?

MJ: Yes, the space available I suppose.

J: I mean where we go, I think there's always probably a small area we could go and complete it, but where do you go Mon y vale?

DR: Mon Y Vale, I think if, I don't think this should be filled in in the presence of the Parkinson's nurse, because you're taking up Parkinson's nurse time unnecessarily, if we are going to complete a questionnaire of this nature prior, the sensible thing is to do it at home before you come in. That's what I would want to do, so if we could be emailed with that questionnaire at home, we can then do that questionnaire at out leisure and email it back to you, and it would be on the computer when we arrive to talk to the Parkinson's nurse. She'd have the benefit of that information and the benefit of having time to assimilate it.

TT: But then they'd have to manually put it on to the computer wouldn't it

DR: Sorry?

TT: Just emailing it back won't go onto the file, will it?

Amani: Yes

TT: It will?

DR: It goes straight on

Amani: I don't think so.

TT: It'll come back here but it's got to be manually put in from that email onto the computer

DR: It's on, I've heard it, I press send, I press the button and its gone

J: But that's only on an email it's not physically gone to the…

TT: It's not on the file

DR: You have to move it on to the computer

TT: It would have to be manually put on

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DR: Yes right, they don't put everything on manually do they

TT: Well, if you email it, if you send me an email, I can't say to the email move that information on to my computer can I

DR: I don't know can't you email it to the computer

TT: No, you're going to put that on the iPad

DR: It's got to be programmed

TT: Yes, and that'll be transferred off that computer

DR: Yes

Amani: I'm not sure but if you're going to email it back to the nurse, she should manually enter all your information into the file on the computer, and this is the problem

DR: That's a devil of a job isn't it

TT: You can't transfer data off an email onto a computer

DR: But you've got to, you can't produce that information just for the Parkinson's nurse just to for through it and read it, I mean it's pointless

TT: No what will happen is, it will save her time, asking you the information so when you go in on her screen will be what you've put on there

DR: Well, I suppose there's an element of benefit there but surely the huge benefit is for it to go onto the mainframe

TT: Well, it will do off that

DR: Yes that's what I mean

TT: But an email won't.

DR: No

Amani: So then back to the waiting room question, do you have any concern doing that, filling that on the waiting room?

DR: No because I've usually got half an hour waiting anyway so it wouldn't worry me I could do it in the waiting room

TT: And the thing about over there is as long as it's not lunch time you've got the cafeteria down the bottom you can go to sit at one of those

DR: Yes, you could sit in the car and do it, you know it doesn't worry me doing it but I'm just trying to think of more ways of using the information or of ensuring that the information is actually used because if you're going through all this procedure its only worthwhile if the information gets used and information on its own is of no great advantage

Amani: So, going to my next questions to fill this application we found last year it took

J: Sorry shall we go back in the other room now?

Amani: Okay

J: Sorry do you mind, this room is going to get noisy, and that room will be quiet.

Amani: So again, back to my questions, this iPad application to complete from start to finish it take around 12 minute do you think that time will be enough for you to complete this application or maybe you need more time?

DR: Time is of no concern, it doesn't worry me at all, if 12 minutes is fine then fine, if it takes 20 ill do it in 20

J: What would they do, they would give you an appointment for say 3 o'clock and that's when you would complete the questionnaire and then your appointment with the consultant would be quarter past 3 or something? That's how they'd work it?

Amani: No, like if your appointment at 3 o'clock you're going to arrive before 3 o'clock

J: I see so will they tell you on the letter to arrive quarter of an hour early

Amani: Yes

J: Yes okay

MJ: I presume you will test it out so you will get some kind of idea, won't you? How long it takes in reality?

TT: I mean really in all honesty the length of time it will take is depended on the number of questions there are to answer, we don't know at the moment how many will be yes or no and how many might be a bit more detailed. But I mean I don't know 12 minutes sounds as though it will be long enough to me. But I think most people as David says if you've got an appointment at 12 o'clock you always make sure you get there for 11:30 just in case she is running early. So, I don't think anybody turns up at the last minute and expects to walk straight in. So, I think 12 minutes would be long enough.

MJ: You may also need to note the fact that some people with Parkinson's, their manual dexterity aren't very good as well.

Amani: So also, this questionnaire is as I said at the beginning they have a paper form, do you see this paper form before when you go to the appointment?

TT: No

Amani: Or this?

TT: No

Amani: You didn't use it?

TT: No

Amani: So, this is like similar to the questionnaire that we have here and that it covers all the non-motor symptoms and they like a paper form and we wanted to use it in an iPad. So, what do you prefer, using the paper or the iPad, the technology?

TT: The iPad

J: With John I would do it because I'm his secretary (laughs) but I think on the iPad he might do it himself

Amani: Why?

J: People with Parkinson's writing isn't very good and I think they lose confidence in writing. That's a general statement, John's writing isn't very good, and he's lost confidence in his writing

Amani: But he could do it in the iPad, it's going to be easier than the paper?

J: Yes, his writing has got smaller and smaller

MJ: That question we raised before about how often, it does say at the top, in the last month, so that gives you a period doesn't it.

Amani: Yes, and you David?

DJ: No problems as far as I'm concerned, I'll be happy to complete on the computer or on that (gestures to paper) Jeans right I struggle with writing a bit, but it comes and goes you know, some days I'm fine and other days not, but it's not a problem.

J: I mean you've got to remember some peoples Parkinson's is a lot worse than what you're seeing here, some people are very badly…

DR: Well, I've formed the opinion that there is no such thing as Parkinson's because there's so much difference between people. In the 10 years I've been involved in groups like this, I've met people who were incredible affected by it and other people that you wouldn't realise had got it. It's incredibly varied.

Amani: Okay then, my next question is, before we start you gave me this consent form in a piece of paper you sign it, would you mind do that on the iPad instead of the paper?

DR: Doesn't make any difference I don't think

J: Yes fine

MJ: What do you want us to do now, fill in the form on the iPad?

Amani: My question is now at the beginning I gave you this consent form and you sign it, do you mind doing that on the iPad, instead of the paper the hard one?

MJ: I don't see why not it's the same isn't it.

Amani: You don't have like any concern on security or confidentiality because you are going to put our signatures on it?

DR: You can't sign on a…

J: Some you can

Amani: You can sign on it yes.

DR: Didn't know that

J: Technology (laughs)

DR: Well, it wouldn't recognise my signature because my signature is never the same twice (laughs)

J: Nor his

DR: You could do that just as easily as me so; a signature is nothing, absolutely nothing

Amani: So, you are okay with the idea of consent it?

DR: Perfectly okay

Amani: Okay so does anyone have any other comments or feedback maybe positive maybe negative about using the iPad in the clinic in the Parkinson's clinic? Anything that you want to add?

DR: If I'm assured by the clinician that its of value, I'm happy to go with it, if it, I'm not personally convinced of its value to be honest

J: Well, what are you doing because apparently they're going to start in Cardiff and Bridgend?

Amani: Yes

J: Are you using it to see how it goes and then…?

Amani: Actually, we have already piloted this application, trialled this application last year and most of the clinicians they said okay, they accept this idea

DR: Fine

Amani: But they have like some changes you want us to change it, for that we do these discussions to hear from you what you want, what you want the application to look like

DR: I'm perfectly happy with that

Amani: Okay

JM: Why isn't it being done over the Internet?

Amani: This is maybe in the future.

J: Okay at the moment…

Amani: Yes, at the moment we are going to start doing on the app in the clinic, then maybe. And you, Mary, do you have any comments any feedback how to improve this application in the future?

MJ: I was just looking because some of these things of course are not just relevant to Parkinson's are they, that doesn't matter, does it?

Amani: Actually, most of these questions is relevant to the Parkinson's.

MJ: Pardon

Amani: All of these questions is relevant to the Parkinson's.

MJ: They're relevant to Parkinson's but they're relevant to other things as well aren't they some of them.

DR: I don't know give me an example

MJ: Remembering things that have happened recently or forgetting to do things.

J: Yes, I mean that could be dementia couldn't it

DR: That could be anybody

MJ: That's what I'm saying, that's the point I'm making.

DR: But it is relevant to Parkinson's

MJ: Oh yes, I'm not saying it's not but I'm saying its relevant

Amani: Relevant to other conditions yes

DR: But there's nothing sensitive there

MJ: No no no

DR: Not that we wouldn't want anyone else to know sort of thing

MJ: I think that's a good list actually.

Amani: Okay so Luke do you have any questions to add or have I covered…

Luke: I think you've covered it all.

Amani: I've covered it, so thank you very much for your time actually you've been very useful for us.

Luke: Thank you

Amani: Thank you

Appendix 4.9 iPad Application Necessary Modifications Requirements

The qualitative study "Exploring utility of iPad app to collect patient information electronically." Findings identified the following elements needed to be changed or added to the app to improve accessibility and usability of this app:

1. A consent form required to be added at the beginning of the app.

2. Can we add a brief introductory paragraph regarding the purpose of this app? Please see the example below.

"This trial app is designed to provide your clinicians with a snapshot of your general health at the last few months, symptoms or issues that you suffer from during the past month, and a measurement of the speed of your movement. This app will enable your clinicians to collect more data about your condition to aid the consultation. This app can better manage your conditions. This app automatically stored your data into NHS servers so the privacy and confidentially of your data will be protected under their policy. You can also request a report of your app performance at the end of the app. Before start entering your data, please sign the consent form first then press next to go to the first section".

3. Can we add an Automatic time record tool to the app to record the time taken to complete the app?

4. Can we increase the app font size and add one question per page?

5. Can we change the yes or no answers to broader frequency ranges: never, occasionally, sometimes, often, and always?

6. Can we add general instructions that helps the user to navigate the app easily needs to be added to the app? Please see the example below.
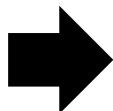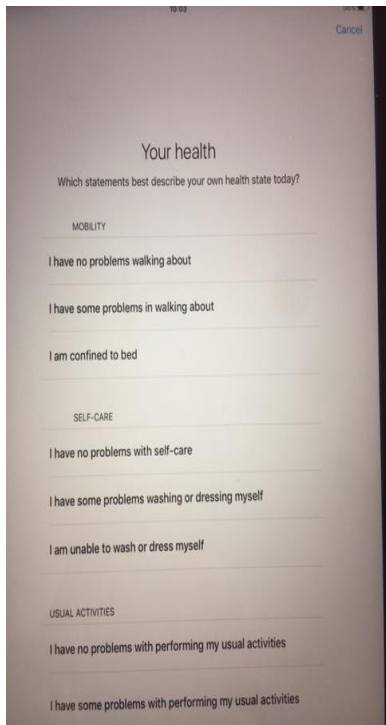
General Health Questions

You are going to see five questions regarding your general health, please read it carefully and choose the better answer that express your health on the last few months.

Tap next to start.

At the end of this section

Tap next to move on or tap Back if you want to change your answers.
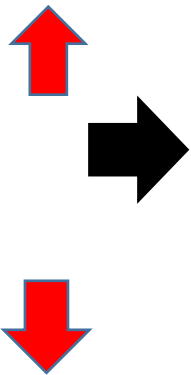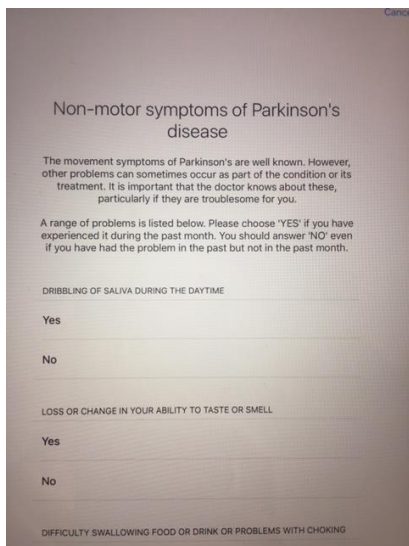
Add the questionnaire introduction on a separate page…… then.

Tap next to start.

Add arrows to reminder the user to move up or down.

Tap next to move on or tap Back if you want to change your answers.

7. Can we change the feature of moving across the questions from scroll up or down to swipe action mimicking turning the page of the book would be preferable?

8. Can we Add a tool that enables the users to rate the top three symptoms on NMS section that they wish to discuss with their consultants or to highlight the symptoms that are concerned them most?

9. Can we add a section with a general question that can be filled by the patient-carer?

10. Can we add an option to give the users a feedback report summary of their performance at the end of the app either through email or add it to the clinic letter? Please see the example below.

"Please pick how do you want to get your performance feedback?

☐ Add it to the clinic letter.

☐ Through email,   Please enter your email address…………………………………………

Appendix 5.1 Phase I Questionnaire

Utility of e-PROMS in Parkinson's care

This survey is to explore your views, as a Parkinson's nurse specialist, on the use of electronic patient-reported outcome measures (ePROMs) in Parkinson's clinics. The PROMs are questionnaires that evaluate the patients' health condition and their well-being according to the patient's own perspectives such as NMSQuest and UPDRS.

If you would like to participate in our survey, please press next (please complete the survey and return it to the researcher). It should take you no longer than 15 minutes to complete.

1. In which geographical area do you work?
   ◯ England   ◯ Northern Ireland   ◯ Scotland   ◯ Wales

2. Have you ever used any form of PROMs that relate to Parkinson's disease before?
   ◯ Yes   ◯ No   ◯ Unsure

Please go to question 6 if your answer was No.

3. If your answer to question 2 was yes, what type of PROM did you use? Tick all that apply.
   ◯ NMSS   ◯ UPDRS   ◯ NMS Quest
   ◯ SCOPA-AUT   ◯ PDQ-39   ◯ PDQ-8   ◯ YH Scale
   Others, please specify……………………………………………………………………………………………
   ……..

4. From your experiences, do you administer or collect PROMs routinely?
   ◯ Yes   ◯ No   ◯ Unsure

5. If your answer to question 4 was yes, from your experience, how often did you use the PROMs to collect patient information?
   ◯ Never   ◯ Occasionally   ◯ Sometimes   ◯ Often   ◯ Always

6. What do you think is the required PROMs scale that needs to be collected routinely during the patient's checkup? Tick all that apply.

○ Scale relating to non-motor symptoms   ○ Scale relating to motor symptoms

○ Scale relating to Cognition   ○ Scale relating to psychosis

○ All of the above mentioned

○ Others, (Please specify) ....
....
....

7. Do you find that using PROMs is an acceptable approach in measuring patients' views of their health status? Please explain your answer.

○ Yes   ○ No   ○ Unsure

8. Do you think using PROMs would be beneficial for Parkinson's disease patients? Please explain your answer.

○ Yes   ○ No   ○ Unsure

9. How do you think the use of technology to collect PROMS would affect data collection processes? Please tick all apply.

○ Make it harder   ○ It would facilitate the process of data collection

○ Be preferable for patients   ○ Improved access to information

◯ Be more time consuming   ◯ Improved Diagnostics & Patient Outcomes

◯ Improved Coordination between healthcare professionals

10. Do you think collecting PROMS digitally (e-PROMs) would have an impact on communication between patients and healthcare professionals during regular consultation?

   ◯ Yes   ◯ No   ◯ Unsure

Please go to question 12, if your answer was No.

11. If your answer to question 10 was yes, how do you think it would impact the communication between patients and healthcare professionals?

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│   │
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│   │
└───┘

12. Which services from the Parkinson's disease multi-disciplinary team do you think would benefit from collecting e-PROMs? Tick all that apply.

   ◯ Physiotherapists   ◯ Speech and language therapists

   ◯ Occupational therapists   ◯ Specialist doctors

   ◯ Specialist nurses

   ◯ Others, please specify……………………………………………………………………………………

      ………

13. When do you think would be the best time to collect the e-PROMs?
   ◯ While the patients are waiting for their consultations.

   ◯ Before the patients comes for their appointment. If so, how long before ……………

      ………..

   ◯ Others, please specify………………………………………………………………………………………

14. Would you have any concerns that would prevent you from using an e-PROM tool?
   ◯ Yes   ◯ No   ◯ Unsure

Please go to question 16, if your answer was No.

15. If your answer to question 14 was yes, what would concern you regarding using the e-PROMs tool? Tick all that apply.
   ◯ It would affect the workflow at the PD clinics.

   ◯ It would increase the staff workload at the PD clinic (e.g., training, demonstrating, and querying from the patients).

   ◯ There is no electronic health record system used at the PD clinic to be compatible with the e-PROMs tool.

   ◯Other,(please   specify)………………………………………………………………………
……

16. Do you think training to use e-PROMs tool would be required before you or the people with Parkinson's could use the system?

For Patients:

        ◯ Yes   ◯ No   ◯ Unsure

For Healthcare professionals:

        ◯ Yes   ◯ No   ◯ Unsure

17. If your answer to question 16 was yes, what kind of training do you think would be suitable?
   ◯ One hour online tutorial   ◯ Short instruction leaflet   ◯Both

   ◯ Others, please specify………………………………………………………………………………

18. Overall, would you be interested in using e-PROMS? Please explain your answer.

     ◯ Yes   ◯ No   ◯ Unsure

Thank you so much for taking the time to complete our survey. If you would be interested in taking part in the second phase of this study to explore the views of healthcare professionals (geriatricians, neurologists, Parkinson's disease nurse specialists, pharmacists, speech therapists, and physiotherapists) on using technology to collect patient-reported outcome measures (PROMs) with Parkinson's services across Wales. Wherein, we would like to conduct face to face interviews to gather information and views from currently practicing healthcare professionals, please leave your contact details so that we can get in touch with you.

Name: **Email address:**

Appendix 5.2-Phase I Participant Information Flyer

Appendix 5.3- Phase I School Ethics Approval

SPPS Ethics Approval Notification (EAN)   8/9/14 v12

Cardiff School of Pharmacy and Pharmaceutical Sciences, Research Ethics Approval

This form has been signed by the School Research Ethics Officer as evidence that approval has been granted by the Cardiff School of Pharmacy and Pharmaceutical Sciences Research Ethics Committee for the following study:

Project title:	1819-10 Utility of e-PROMs in Parkinson's care

This is a/an:	Undergraduate project	X
	ERASMUS project	
	Postgraduate project	
	Staff project	

Name of researcher: (PG/Staff projects only)	
Name of supervisor(s):	Emma Lane

STATEMENT OF ETHICS APPROVAL

This project has been considered and has been approved by the Cardiff School of Pharmacy and Pharmaceutical Sciences Research Ethics Committee

Signed ▮▮▮▮▮▮▮▮ Name R Deslandes   Date 20/11/18
(Chair, School Research Ethics Committee)

Appendix 5.4- Phase II Interview Topic Guide

Research Project Topic Guide

1. Welcome, introduce myself, explain where I am from, and ensure they're comfortable.
2. Check understanding of the purpose of the interview, give an opportunity for questions: "Before we start, I wonder if you have any questions about this study or about why I've come to talk with you today?"
3. After establishing what is understood about the study, and answering any questions, explain that the interview will be recorded and all personal information will be anonymized.
4. Obtain consent for the interview and the recording. Set up and switch on the recording device while the interviewee signs the consent form.

Opening questions.

Would you mind telling me a bit about how your clinic runs, how many people with Parkinson's disease you see and how frequently they come to clinic? How do you record clinical data in general and how user friendly is it?

- **Routine Data collection.**

"What kinds of data (questionnaires) do you think it should be collected before you see a patient with Parkinson's during regular consultation or follow up?" (Prompt 1: What kinds of data would be valuable to you to better assess the patients: motor, non-motor, cognitive, or psychiatric need? Prompt 2: How do you currently assess this information and is it recorded? Prompt 3: How do you then access and use this information in the consultation or in advance?).

"How do you regularly assess the non-motor symptoms of Parkinson's in your clinics?" (Prompt1: How do you record the data and how is it used? Prompt2: Do you think this is adequate to capture the needs of your patient?).

- **Technology use.**

Introduce the idea of digital data collection and explain needs for developing an iPad app.

- Explain use so far, and future-how info held, who sees.

"So, at the moment, some of the hospital clinic stored patient's data as an electronic health record on the computer. However, the paper version of the patients reporting outcomes measures (PROMs) such as NMSQuest and UPDRS has been used to assess the non-motor symptoms and motor symptoms before the patient's appointment. I would like to explore your views around the use of digital technology tool, such as a tablet-based app, to collect patient data at the clinic setting".

"How do you feel about the use of technology to document PROMs in your clinics?" (Prompt: Would you be happy for your patients to use this kind of data collection tool before their consultations with you?)

"What kinds of data do you think would be useful to be collected electronically in your clinics?"

(Prompt: How do you find using an iPad app to collect the PROMs? Or "Would you be interested in using a tablet-based app in your clinic? Please explain).

"When do you prefer to get the ePROMs immediately before the patients' appointment or one week before?" (Prompt 1: How far ahead of the patient clinic visit? Prompt 2: when would be the best time for you to get the information from patient?).

- **Patient type.**

"Do you think people with Parkinson's would be able to use a digital device to input their data?"

"Do you think people with Parkinson's would be willing to use a digital device to input their data at the hospital clinic setting?"

"Are there any particular demographic of patient that might find the electronic patient reported outcome measures (ePROMS) tool most useful? (Prompt: age groups, patients at different stages of Parkinson's. Why?)

- **Barriers and Perceived benefits of technology use.**

"What possible advantages and disadvantages do you foresee for collecting PROMs digitally in a hospital clinic?"

"Is there any barriers that could impact the implementation of such device at your clinics?"

"Do you think this type of data collection could lead to enhanced management of your patients? (Prompt: "Would it influence your decision making?" Or "Do you think it would change the way you have used to manage your patients?" Please explain).

"Do you think collecting PROMs digitally before patients' appointment would have an impact on communication with your patients? (Prompt: How would it affect communication?)

"Do you think collecting PROMs digitally would affect the workflow at your clinic? If so, How?

"What benefits do you think there might be for both patients and clinicians using this kind of data collection tool?"

- **Desired app features.**

"What kind of app features do you think would be most useful for both you and People with Parkinson's?"

"What kind of data that you would want the app to collect?"

"Is there anything else that you would want the app to collect? If so, What?

- **Usefulness of electronic informed consent.**

"What do you think about consenting patient electronically by using a tablet-based app instead of the paper-based informed consent?"

"Do you think the patient would be fine with that?"

Feedback

Opportunity for further questions. Anything we have missed that you think is important.

Closure and thanks for participation.

Appendix 5.5- Phase II Gatekeeper Invitation Email

My name is Amani Khardali; I am a Ph.D. student at Cardiff University School of Pharmacy and Pharmaceutical Sciences. I am currently working alongside Dr. Emma Lane and Dr. Louise Hughes on exploring the views of healthcare professionals (geriatricians, neurologists, Parkinson's disease nurse specialists, pharmacists, speech therapists, and physiotherapists) on using technology to collect patient-reported outcome measures with Parkinson's services. This study has been approved by the Cardiff School of Pharmacy and Pharmaceutical Sciences Research Ethics Committee.

As part of the project, I would like to conduct face to face interviews to gather information and views from currently practicing healthcare professionals.

I am emailing to invite you to take part in the study and to ask if you could please pass on this email and attached information to your contacts who are currently practicing as geriatricians, neurologists, Parkinson's disease nurse specialists, pharmacists, speech therapists, and physiotherapists to try and recruit participants for my interviews. I plan to carry out the study in November 2018.

There is an information sheet, invitation letter, and consent form attached which contain further information for you and your colleagues - if you have any further questions, please don't hesitate to contact me (KhardaliA@cardiff.ac.uk, **Tel: 07474911856).**

If anyone wishes to take part, they are asked to contact me directly, so there is no need for you to follow-up with them. I will be happy to respond to any queries.

Your help on this matter is greatly appreciated.

Yours faithfully,

Amani Khardali

Appendix 5.6 Phase II Participant Information Sheet

Project title: Use of digital technology in Parkinson's disease clinics: A qualitative study of the staff perceptions.

I would like to invite you to take part in my research study and this study is being undertaken as part of a PhD project. Before you decide, it is important that you understand why the research is being done and what it would involve for you. Please take time to read this information and discuss it with others if you wish. If there is anything that is not clear, or if you would like more information, please contact me.

What is the purpose of the study?

The purpose of this study is to find out more about the opinions of healthcare professionals on the digital collection of the patient-reported outcome measures (PROMS) in a clinic environment. Currently, patient information is often collected using paper-based questionnaires (for example NMSQuest or UPDRS). However, we are trying to develop a digital tool to improve the process of PROMS collection in hospital clinics. The information we gather from this study will be used to help create this digital tool to collect PROMS and ensuring that it is suitable for use in clinics.

Why have I been invited?

You have been invited to participate because you are one of the Healthcare professionals who is currently practicing his/her work with people with Parkinson's. In particular, we are seeking the views of geriatricians, neurologists, Parkinson's disease nurse specialists, pharmacists, speech therapists, and physiotherapists). We hope you will be able to share your thoughts and experiences of using a new type of technology.

Do I have to take part?

No, it is up to you to decide. Choosing to take part will have no direct effect on you or your career. This information sheet, which is yours to keep, provides the main information about the study but you are welcome to ask any questions you might have. If you decide to take part, we will ask you to sign a consent form to show that you have agreed to take part. You are free to withdraw at any time without giving a reason.

What will happen to me if I take part?

If you agree to take part, I will contact you to confirm attendance. At the beginning of the one-to-one interview, I will ask you to complete and sign the consent form. Then I will ask you some questions about your opinions on using technology to collect the PROMS in PD clinics, the appropriate format of a future application, and how you usually assess the non-motor symptoms. If you feel uncomfortable with any questions, you can refuse to answer these questions. The interview will be informal and will

be audio recorded for my research, and you may be quoted, although this will be anonymised. The interview will either be done face to face at your clinics or another convenient location. The interview will typically last around 30 minutes. The original recording will be kept for no longer than 15 years after the study ends then it will be deleted.

Expenses and payments

No payment or any incentives are offered or given if you decide to participate.

How will the information collected be used?

Confidentiality will be ensured at all stages of the research process. The audio files of the interview will be kept on password protected computer laptop before transcription. The transcripts will be anonymized. Consent forms, transcripts, and recordings will be kept securely in the School of Pharmacy & Pharmaceutical Sciences at Cardiff University. Any information retained on password protected computer laptops will be anonymized (containing a reference code in place of personal data).

Any personal details that are collected during the study will only be seen by the research team and will not be kept for any longer than is needed to complete this study. It is anticipated that this will be no longer than 3 months.

Cardiff University is the sponsor for this study based in the United Kingdom. The University will act as the Data Controller for this study. This means that they are responsible for looking after your information and using it properly. Cardiff University will keep identifiable information about you for one year after the study has finished (namely consent form).

Under data protection law, the University has to specify the legal basis that we are relying on to process your personal data. In providing your personal data for this research, we will process it on the basis that doing so is necessary for our public task for scientific and historical research purposes in accordance with the necessary safeguards and is in the public interest. The University is a public research institution established by royal charter to advance knowledge and education through its teaching and research activities. The charter can be found on the Cardiff University website.

Your rights to access, change or move your information are limited, as your information needs to be managed in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, Cardiff University will keep the information about you which has already obtained. To safeguard your rights, Cardiff University will use the minimum personally identifiable information possible.

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. The University has a Data Protection Officer who can be contacted at inforequest@cardiff.ac.uk. Further information about Data Protection, including your rights and details about how to contact the Information Commissioner's Office should you wish to complain, can be found at the following: https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection.

What will happen to the results of the research study?

The results of this study will be written up, used for the researcher report and may be published in peer-reviewed journals, but all information will be anonymized. This means that neither you nor anyone involved will be identified in the report. Let us know if you would like to see a copy of the report.

What will happen if I don't want to carry on with the study?

Your participation is voluntary, and you are free to withdraw from the study at any time without giving a reason.

What do I do if I have a problem or complaint?

If you have any questions or concerns about any aspect of the study, please contact the study supervisors at Cardiff University, Dr. Emma Lane (Laneel@cf.ac.uk, 02920874989) or Dr. Louise Hughes (HughesML@cf.ac.uk, 02920876432). If you wish to make a formal complaint, you can contact the Director of Research at Cardiff School of Pharmacy and Pharmaceutical Sciences, Prof Andrew Westwell (WestwellA@cardiff.ac.uk).

How do I let you know if I want to participate?

If you have read this information and wish to participate, please get in touch with the researcher so we can make arrangements.

Thank you for taking the time to read this leaflet, if you have any further questions, please get in touch with the researcher, Amani Khardali (KhardaliA@cardiff.ac.uk, **Tel: 07474911856).**

Appendix 5.7- Phase II Invitation Letter

Cardiff School of Pharmacy and Pharmaceutical Sciences

Cardiff University

Redwood Building

King Edward VII Ave

CF10 3NB

Dear Sir/Madam,

I am undertaking a research project at Cardiff University into **"Use of digital technology in Parkinson's disease clinics: A qualitative study of the staff perceptions"** which is part of a larger study looking at the use of digital technology to collect patient-reported outcome measures in Parkinson's disease clinics supervised by Dr Emma Lane (Laneel@cf.ac.uk) and Dr Louise Hughes (HughesML@cf.ac.uk).

I would like to invite you to take part in one-to-one interview.

The interview is expected to take around 30 minutes and will take no longer than one hour.

In the interview, I will be asking about your opinions on using technology at the clinics to input patient information before the appointment. In particular, we would like to know your opinions on using this new method to collect patient reported outcome measures and its potential for future use. The interview will be audio-recorded and your information will be held confidential.

Your views will be used to help us develop this new method for collecting patient reported outcome measure questionnaires.

More background information can be found on the attached information sheet.

If you would like to take part in the Interview, please let me know by contacting me **Tel: 07474911856**

Or e-mailing **Email: _KhardaliA@cardiff.ac.uk_** by (*date and time*) at the latest so that arrangements can be finalized.

Yours faithfully

Amani Khardali (PhD. researcher)

(In association with Dr. Emma Lane and Dr. Louise Hughes)

Appendix 5.8 Phase II School Ethic Approval

SPPS Amendment Approval Notification (AAN)   11/10/14 v1

**Cardiff School of Pharmacy and Pharmaceutical Sciences,
Research Ethics Approval**

AMENDMENT APPROVAL

This form has been signed by the School Research Ethics Officer as evidence that approval has been granted by the Cardiff School of Pharmacy and Pharmaceutical Sciences Research Ethics Committee for amendment(s) to the following study:

Project ref and title:	1718-22 Use of digital technology in Parkinson's disease clinics: A qualitative study of the staff perceptions.

Name of researcher: (PG/Staff projects only)	Amani Khardali
Name of supervisor(s):	Emma Lane, Louise Hughes

The amendment(s) dated 17 September 2018 have been reviewed and approved.

Any further amendments will require approval.

STATEMENT OF ETHICS APPROVAL

The proposed amendment(s) have been considered and approved by the Cardiff School of Pharmacy and Pharmaceutical Sciences Research Ethics Committee

Signed _____   Name   R Deslandes   Date   18/10/18
(Chair, School Research Ethics Committee)

Appendix 5.9- NHS approval

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Dr. Emma Lane
Senior Lecturer in Neuropharmacology & Director of
Postgraduate Research
Cardiff University
Redwood Building
King Edward VII Avenue
Cardiff
CF10 3NB

Email:
Research-permissions@wales.nhs.uk

23 October 2018

Dear Dr. Lane

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title: Use of digital technology in Parkinson's disease clinics: A
                        qualitative study of the staff perceptions.
IRAS project ID: 251006
Protocol number: SPON1685-18
REC reference: 18/HCRW/0011
Sponsor   Cardiff University School of Pharmacy & Pharmaceutical
                        Science

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has
been given for the above referenced study, on the basis described in the application form, protocol,
supporting documentation and any clarifications received. You should not expect to receive anything
further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and
Wales, as well as any documentation that has been updated as a result of the assessment.

Appendix 5.10 Consent Form

Project: Use of digital technology in Parkinson's disease clinics: A qualitative study of the staff perceptions.

Name of researcher: Amani Khardali

Please initial all boxes

I confirm that I have read and understand the information sheet for the above project dated 03/07/2018 (version 1). I have had the opportunity to consider the information, ask questions, and have had them answered satisfactorily where appropriate……………………………………………………………………………………………

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason…………………………………………………………………………..

I agree to the interview being audio-recorded……………………………………………………………

I understand that any information given by me, including direct quotes, may be used in future reports, articles or presentations by the project team; however, no identifiable data will be reported…………………………………………………………………………………………………

I agree to participate in an interview for the above project……………………………………………………

_____   _____   _____

Name of Participant   Date   Signature

_____   _____   _____

Name of Person taking consent   Date   Signature

Please tick the relevant box below if you:

☐ Geriatrician   ☐ Neurologist   ☐ Parkinson's disease nurse Specialist   ☐ Pharmacists
☐ Speech therapists   ☐ Physiotherapists

Appendix 5.11- An example of Phase II Interview Transcript

Amani: Just to start our interview could you please tell me a bit about how your clinic runs, as how many people with PD you see regularly and how frequently they come and the allocated time for each patient?

GC2: Sure, okay. So, I'm a consultant geriatrician. I've been running the Parkinson's clinics for approximately ten years as a consultant and fifteen years including my time as Registrar. So, I run clinics twice a week. One of them is a specialist Parkinson's, so the clinic in Rookwood where we have between twenty-eight and thirty-five patients. There's also an additional consultant, two nurse practitioners and a PD nurse specialist then. We occasionally have pharmacists and medical students as well as registrars, and my clinic is usually a general medical clinic where I'd have about twelve patients of which seven or eight will be Parkinson's. The rest will be general medical and it's just me on my own in that clinic. Sorry, what else did you ask?

Amani: How frequently the people with PD come to this clinic?

GC2: Every six months on average, if it's a very stable Parkinson's, but if someone is unstable, I could see them as quickly as two weeks or a month from their last consultation.

Amani: The allocated time for each patient?

GC2: There's no allocated time as such, but for a new patient it's generally we take it to be about forty-five minutes to an hour. For a follow up it's about twenty minutes but it's a very flexible thing in terms of patient's needs.

Amani: What kind of data that you used before you see the patients during the consultation?

GC2: Most of the pre-patient information is collected by the GPs. So, the GP letter, what drugs they're on. Their past medical history. We have access to a clinical portal which will tell me about their past medical histories that we have available on the NHS computers. So that would be the Pre- assessment history that we usually have.

Amani: Then what do you think about using the PROM, Patient Reported Outcome Measures, to be collected like in daily practice?

GC2: Can you give me a few examples of the ones that you mean then?

Amani: The UPDRS, the non-motor symptom questionnaire or non-motor symptoms scales?

GC2: Sure. So, there's a few issues in doing that pre-diagnosis because most of these questionnaires are only about related to four people with Parkinson's. So, in my Movement Disorder Clinic in Rookwood for every eight new patients I only see one or two will have Parkinson's. The other six would have a combination of non-Parkinson, tremors, essential tremor, drug induced, vascular Parkinsonism or some gait and balance problems. So, if you try and administer validated Parkinson's scales on non-diagnosed Parkinson's patients that would cause multiple

issues and inaccurate anyway. The second point of notice UPDRS is a clinician administered scale. So again, that wouldn't be suitable for our patient's administration. You could use the non-motor questionnaire but again, like I said, you would need to know the person has been diagnosed with Parkinson's, and particularly just thinking about the new patients with Parkinson's…

Amani: So, what about the patients who come for the follow up?

GC2: Follow up patients potentially again you can't use UPDRS because you'd have to administer that to get…it's a five-point scale and you would need to do examination assessments, etc. You could use a non-motor questionnaire, a quality-of-life questionnaire. The two main issues that comes there is, one is that you have to have a system and a mechanism to administering and applying this, and the second issue is that you have to collect, once you've generated data which is what the patient is giving you then you need to act on the data and collect it. Store it and act on it. I don't think the systems are sophisticated enough to do that at the moment. The second issue is that time itself is a priority. So, if I get a huge amount of data, I may not have the time to go through all of that. The third point here is in mitigating all of that is that when I meet patients, I spend my time talking to these patients and going through their symptomatology and directly or indirectly I would go through most of the non-motor symptoms during my consultations. So, I'd like to think that it addressed their non-motor symptoms and their quality of life issues, but you're absolutely right. If you had a validated tool that could be applied, so if I had somebody who would administer the tool, collect the data and make sure it's all recorded I think that would be a great thing, but it's time resources that stops us from doing this.

Amani: So then for the issues of using the PROM in daily practice, is there any other advantages you can think about using it during the consultation as it could impact the management of the patient, the patient's care? The communication or interactions between you and the patient?

GC2: I mean, of course yes, I think it's useful because apart from all the things that you mentioned it's also an educational tool in a way. So people would get to know their condition better and describe their condition to you, but as I mentioned, I think all those things that you said are useful and if we had more time, if we had appropriate resources I think we would try and do those sort of things, but I think it's purely time resource that's stopping from using those sort of tools, and also probably from a research point of view it would be quite a useful thing because you collect this data. In a years' time you would know whether this person is worse or better and that sort of thing. So that would be useful as well.

Amani: Also, for you personally what role collecting and using PROM in daily practice would come to prioritising what you need during the consultations with PD patients?

GC2: Sorry, could you just repeat the question?

Amani: What PROM can play a role in prioritising things for you during consultations?

GC2: So, especially thinking of the non-motor questionnaire in particular then they could be highlighting symptoms of the patient who probably wasn't aware it was a problem for them. So that could be potentially you could highlight some of the problems especially say, for example, some of our Parkinson's patients don't recognise that sleep is an issue, and it could be related to Parkinson's, or constipation for example or some of their sexual dysfunction. So, all those things it might serve to highlight some of those problems before the clinician has

actually picked it up. How the patients respond and are aware that this could be obviously Parkinson's.

Amani: Then what about the collaboration or the communications between you and the other MDT Team?

GC2:   Yes. So that goes to an individual service. For example, in our service any patients that have particular issues or problems, so we discuss them proactively in the MDT. So, I don't think it could enhance the communication in that sense because we proactively discuss every patient after clinic anyways, and if patients get in touch with the nurse practitioners they also put on the list for discussion. So I'm not sure if it would enhance communication because of the system, but maybe for our Team, say for example, if you have different members of the team looking after these patients then perhaps a tool that they can refer back to when they come the next time, but because we only have four core members that see these patients and we discuss between…most of the time we like to think that we know about their problems.

Amani: Because some, the other clinicians that I talked with they said it could improve the referral of the patients to the other health professionals, like physiotherapist, occupational therapist.

GC2:   Again, this probably is a very biased view because of how we run our service. We refer all our patients who are diagnosed the first time around to a physio and occupational therapist for a baseline assessment and the patients that we have are also seen every three months in the Parkinson's day which is a multidisciplinary led, nurse led participatory combined assessment in the day hospital. So, because we have that, so we do tend to pick them up early. So hence we don't particularly need tools like that to highlight that because they've been in a follow up review already.

Amani: Yeah okay. So, from your experience have you ever used a non-motor symptom scales before the clinic?

GC2:   Yes, I have. Mainly in the form of small clinical trials and that sort of thing, and some of the patients need help to fill out those, so you have a surrogate helping them to fill in because they find that it's too much.

Amani: Which one?

GC2:   The non-motor scales we've used. We've used the Epo sleep scale. We've used the PDQ39. The UL, the European Quality of life scale. Then we've used wearing off questionnaire and the Carer Burden scale. So, we've used quite a few.

Amani: You use it on paper version or electronic version?

GC2:   In the paper version generally. One of them I think when we did the trial with the finger tapping and things like that, I think we used an electronic version as well in quality of life and the non-motor scale we used the electronic version as well but both of them. With the paper version or the electronic version some of the patients either for reasons for dexterity they can't use their hands. They need help or because of reasons of cognitive ability or condition they need a surrogate to help. Some of them are able to do it independently.

Amani: Then how do you think using electronic device to collect the PROM before the clinic is going to impact the process of the data collection in general?

GC2:   I think in terms of the data collection I think would be really useful because I think it enters a degree of authenticity to the process, so you don't have to have that person remembering to send that thing off to the patient to collect and then file it. So, it takes away that entire layer of bureaucracy and eases the process. So that simplifies it. The patient comes in the clinic and the nurse booking in could check their weights and blood pressure and things and say, while you're sat there could you fill this up. So, I think that would be really, really useful.

Amani: **What factors it could impact the implementation of electronic device to collect the PROM?**

GC2:   You just need a secure network really. That's what stopped us from doing it the first time around. So, we didn't have a Wi-Fi that was secure that could transmit the information that's collected to our records, and it's got to be integrated. So, whatever has been collected has to be integrated into the records or there's no point doing it. Having a different piece of paper. It's got to be retrievable when you need to look at it.

Amani: **From the managerial and administrative level is there any other factors it can impact, or it can facilitate?**

GC2:   If it was collected and it was available to hand it would be an extremely useful clinical tool. I mean, the reason we are saying that we're not using it is not because we don't think it will be a useful clinical tool. We're saying we're not using it because we haven't had the time or the resources to manage it, but if it was already collected and was available in the case notes when I saw the patient it will allow me to skim through and say okay, we can look at this and this, but we can't look at this. We could target the consultation a little more, I guess.

Amani: **Do you have any financial barriers that could impact the communication?**

GC2:   Our clinic in particular wouldn't have a financial barrier. You would need two or three iPads or something like that or an iPad like devices. We've already got an electronic system that we've integrated, and I think the Wi-Fi is not an insurmountable problem. So, I can't see any financial barrier that would…

Amani: **I was told that the NICE Guidelines recommended to use the UPDRS to at least once a year.**

GC2:   Apart from research clinics I don't know of any other clinics that actually do it because to do a full UPDRS it would take about thirty to forty minutes. Thirty minutes is the minimum. So, I don't know any clinic that has that. I mean, to collect that and if you are seeing patients every six months probably too soon and whilst you are collecting that you are looking at one consultation where each patient will be seen. Thirty-five patients in the morning it's practically impossible.

Amani: **As you know in the iPad application that Dr Mark developed it includes the non-motor symptom questionnaire, but one of the neurologists recommended to change the non-motor symptom questionnaire to the part two of the UPDRS, What do you think about that?**

GC2:   In terms of the general use of non-motor questionnaire it's very much validated as a screen for non-motor. My understanding is that the UPDRS is validated in its entirety not as a single non-motor symptomatology score. So, in that sense I would support the non-motor scale rather than the UPDRS too.

Amani: **Then for you personally if you are going to develop an electronic application to collect the PROM what kind of PROM that you want this application to include?**

GC2:   So, because we are dealing with both younger and older applications most of the older patient's problems relate to…I mean, I think the non-motor questionnaire is a good starting point, but things to do with falls, bone health will be important. Cognition is really important. I think those are the biggest things that we deal with and social and carer stress burden is really important because these are the three big things that our patients falling and breaking bones and fractures, cognition, dementia and the carers strain and managing at home. So those would the three key things which in its entirety is not looked into in any of the questionnaires.

Amani: **What about the medication?**

GC2:   The medications are something we routinely always check anyways. So, any time I do a consultation one of the key aspects of my consultation is the medication. What do you take? How are you taking them, and does it work? So, I wouldn't be too fussed about that. Also, the other thing is we have the advantage that we can check what the person is prescribed by using the GP records and we also have the electronically recorded medication lists. So, I don't think I'm too fussed about the medications.

Amani: **Do you think the clinical stuff and the patient themselves would need training to use this electronic device?**

GC2:   They need support because, as I said, from our limited experience of using this electronic I think only about 20% or 30% could use it on their own from my memory. The rest of them needed some sort of guidance or counselling or support to complete it. That might be an additional resource that you factor in, but also the fact that the clinical time because you might then find that the clinic nurses is spending their time doing this, rather than checking in the patient. Taking their weights and all those and booking them in to the clinics.

Amani: **Then when do you think is the best time to collect this kind of data?**

GC2:   I think that it should be periodically, so once every six months, every twelve months. Twelve months is probably more appropriate. Pre-clinic because a set of patients are waiting for a long time and if they could do it in the comfort of their own homes that would be the best clearly, but if not when they come into clinic and they are waiting for the consultation they could do it then.

Amani: **So then back to the PROM itself one of the consultants told me that using the PROM it could help them in prioritising their clinic waiting list.**

GC2:   I'm not so sure about that because at any point in time you've got about 70, 80, 100 patients on our waiting list. So, I can't see how I would look at a patient related outcome measure and then prioritise my waiting list. What I tend to rely on to prioritise my waiting list if I get a second letter from a GP or an expedite letter, I always use that as a priority generally.

Amani: **Then coming to the patient themselves do you think people with Parkinson's disease would be willing and interested in using technology to input their data?**

GC2:   I think so. Yes, I believe so because all the evidence that we've collected so far is very limited. We've done one study with Cardiff University which showed that they appreciated the technology and another survey and all the people all of them seemed to appreciate the available technology. In our recent studies with Parkinson's KinetiGaph, the watch device, do mention Parkinson's tremor and also has a good uptake and we had very few people struggling

with the technology side of things once they had appropriate support in place. So, yeah, I think so.

Amani: Also, is there any demographic factor or characteristic that could hinder them from using the electronic device?

GC2: Just cognition and dementia are the main thing. So, if they've got dementia clearly that's going to be difficult and if they've got cognitive impairment and somebody needs to help them to support them through the process.

Amani: So, this is all my questions. Is there anything you want to add regarding the use of PROM, advantages and disadvantages that I didn't ask?

GC2: No, no. I think the main thing and the bottom line remains that if there is a process in place you could end up collecting a lot of data which would just sit somewhere and gather dust, and I think it's really important and there's lots and lots of questionnaires you can use in Parkinson's. Anything from wearing off to dyskinesia to falls and cognition. Whatever you wanted but unless you're going to act on it some of these questionnaires can heighten the anxiety of patients as well. So you've got to make sure that whatever information you're collecting has got to be targeted and once you collect information you've got to act on it and give feedback to patients, because most of the time in our studies that we've done so far what irritates patients the most is when you collect information from them or you do I test and you don't feedback to them and they think what's the point in doing that.

Amani: Okay. Thank you,

GC2: You're welcome.

Appendix 6.1-Phase I Questionnaire

School of Pharmacy and Pharmaceutical Sciences
Cardiff University, Redwood Building,
King Edward VII Avenue, Cardiff, CF10 3NB, UK.

Dear Participant,

You are invited to participate in a survey of "**An exploratory study of people with Parkinson's perceptions regarding the use of technology to improve medications reporting".**

I hope to learn your views on the use of digital technology (devices such as iPads and the applications on them) to support you with managing Parkinson's medications. Any person with a diagnosis of Parkinson's disease is eligible to complete the questionnaire.

By completing and submitting the questionnaire you are consenting to share your data with us be involved in this study. This questionnaire is designed to help us understand how you take your Parkinson's medications**. It should take you no longer than 15 minutes to complete** and a partner or carer may help you to complete it if you wish. There are no direct benefits to you for answering this questionnaire, but your answers will help us understand your needs and preferences regarding the use of technology.

At the end of this questionnaire, you will be asked if you would like to take part in the second phase of this study (face-face interview); if you would like to take part in an interview there will be a link to click to submit your contact information (**Please provide your contact information at the end of this questionnaire).** You do not have to take part in the interview if you do not want to, you can still complete the questionnaire.

Any information that is obtained from this study and that can identify you will remain confidential and will not be disclosed to anyone except the research team. The data will not be shared with your health care team (e.g., consultant, GP or Parkinson's Nurse).

If you have any questions, please contact me, Amani Khardali (KhardaliA@cardiff.ac.uk, Tel: 07474911856). If you wish to make a formal complaint, you can do this by contacting the Director of Research, Cardiff School of Pharmacy and Pharmaceutical Sciences, Redwood Building, King Edward VII Avenue, Cardiff CF10 3NB, (phrmyresoffice@cardiff.ac.uk).

It is completely your choice whether to participate or not. If you would like to participate in this questionnaire, please press next.

A. Please provide the following demographic information.

6. Please indicate your age.

◯ 30-40   ◯ 40-50   ◯ 50-60   ◯ 60-70

◯ 70-80   ◯ 80-90   ◯ 90-100

7. Please indicate the gender you ascribe too.

◯ Male   ◯ Female   ◯ Rather not say

8. A) How long has it been since your diagnosis of Parkinson's?

……………… Years

  B) How long before this do you believe you were experiencing symptoms of Parkinson's?

……………. Years

9. Please tick the box against each medication you are currently using. Please use the grid to indicate how many times per day you take it. If you are unsure of the specific brand name, please just complete one row of the correct drug.

Medications	Check here	Frequency (how many times per day you have to take it)
Madopar® **Levodopa and Benserazide**		① ② ③ ④ ⑤ ⑥
Co-beneldopa		① ② ③ ④ ⑤ ⑥
Caramet® **Levodopa and Carbidopa**		① ② ③ ④ ⑤ ⑥
Co-careldopa		① ② ③ ④ ⑤ ⑥
Half sinemet® **Levodopa and Carbidopa**		① ② ③ ④ ⑤ ⑥
Sinemet® **Levodopa and Carbidopa**		① ② ③ ④ ⑤ ⑥
Lecado® **Levodopa and Carbidopa**		① ② ③ ④ ⑤ ⑥

Apodespan® Levodopa and Carbidopa		①	②	③	④	⑤	⑥
Duodopa® Levodopa and Carbidopa		①	②	③	④	⑤	⑥
Sastravi® Levodopa, Carbidopa, and Entacapone		①	②	③	④	⑤	⑥
Stalevo® Levodopa, Carbidopa, and Entacapone		①	②	③	④	⑤	⑥
Stanek® Levodopa, Carbidopa, and Entacapone		①	②	③	④	⑤	⑥
Azilect® Rasagiline		①	②	③	④	⑤	⑥
Eldepryl® Selegiline		①	②	③	④	⑤	⑥
Zelapar® Selegiline		①	②	③	④	⑤	⑥
Xadago® Safinamide		①	②	③	④	⑤	⑥
Comtess® Entacapone		①	②	③	④	⑤	⑥
Tasmar® Tolcapone		①	②	③	④	⑤	⑥
Ongentys® Opicapone		①	②	③	④	⑤	⑥
Mirapexin® Pramipexole		①	②	③	④	⑤	⑥
Oprymea® Pramipexole		①	②	③	④	⑤	⑥
Pipexus®		①	②	③	④	⑤	⑥

Pramipexole		
Ipininnia® Ropinirole		① ② ③ ④ ⑤ ⑥
Ralnea® Ropinirole		① ② ③ ④ ⑤ ⑥
Raponer® Ropinirole		① ② ③ ④ ⑤ ⑥
Requip® Ropinirole		① ② ③ ④ ⑤ ⑥
Repinex® Ropinirole		① ② ③ ④ ⑤ ⑥
Ropilynz® Ropinirole		① ② ③ ④ ⑤ ⑥
Spiroco® Ropinirole		① ② ③ ④ ⑤ ⑥
Adartrel® Ropinirole		① ② ③ ④ ⑤ ⑥
Neupro® Rotigotine		① ② ③ ④ ⑤ ⑥
Trihexyphenidyl		① ② ③ ④ ⑤ ⑥
Amantadine		① ② ③ ④ ⑤ ⑥
Apogo® Apomorphine		① ② ③ ④ ⑤ ⑥

Please write your medications if it is not included in the table

……
……
……
……….
……

10. How many additional medicines do you take per day for conditions other than Parkinson's? (e.g., diabetes, high blood pressure)
Number of non-Parkinson's medicines: ……………………………….

B. The following questions are intended to find out about your views and experiences of smart devices like computers, tablet iPad, and smartphones. Please, read each question carefully and tick the most appropriate answers:

6. Do you own a computer or smart device (phone/tablet/iWatch)?

◯ Yes   ◯ No

7. Have you ever used a computer or smart device?

◯ Yes   ◯ No

8. If you answer 'yes' to questions 6 & 7, please tick the types of technology **you own or you have used** (you may tick as many as apply).

Smart Devices	Used	Own
Mobile Phone	☐	☐
Computer (laptop/desktop)	☐	☐
Tablet IPad	☐	☐
Kindle/e-reader	☐	☐
Smart watches (e.g., Apple watch, fitness trackers as Fitbit)	☐	☐
Applications (Health app/Game app)	☐	☐

8.a) If you answer 'yes' to question 8, what general activities do you use these devices for currently? (You may tick as many boxes as apply).

◯ Making phone calls   ◯ Sending messages/ e-mails   ◯ Checking the weather

◯ Taking pictures   ◯ Online shopping   ◯ Watching TV/films

◯ Searching the internet   ◯ Playing games

◯ Others, please specify……………………………………………………………………………………………

◯ To understand more the diagnosis of your health condition,

◯ To understand more about the disease

◯ To look for treatment options

◯ To look up side effects from your medications

◯ To manage your symptoms

◯ To record your symptoms

◯ To manage your medications

◯ To communicate with others who have Parkinson's (e.g., forums websites)

◯ To look up ongoing research and potential treatments

◯ To become involved in research as a participant in a clinical trial

◯ To look for other opportunities to become involved in research that is not a clinical trial

◯ Others, please specify……………………………………………………………………………………………….

9. Beyond your current use, would you be interested in using a computer-based application or smart device application to help you with your Parkinson's medications?

◯ Yes   ◯ No

10. If you answered "No" to question 9, could you please expand on what would prevent you from doing so? (You may tick more than one box).

◯ You do not know how to use these technologies (smart devices or computers).

◯ You do not find an application that satisfies your medical and health needs or requirements.

◯ You do not know how to use or navigate the specific applications.

◯ Your clinician's/nurses have not suggested any applications for you to use.

◯ You are not interested or willing to use these kinds of technology

◯ Others, please specify……………………………………………………………………………………………………….

11. Would you find using technology such as a computer or smart devices useful to help you? (You may tick more than one box).

◯ Take medications on time.

◯ Record when you take your medications.

◯ Record the side effects from medications.

◯ Record the symptoms of your conditions.

◯ Educate yourself about your medications.

◯ Educate yourself about your conditions.

◯ Communicate about your health condition or your medications list with your healthcare providers.

◯ Others, please specify……

C. The following questions relate to how you take your Parkinson's medication. Please, read each question carefully and tick the most appropriate answer (Yes/No). As a reminder, this data will not be shared with your medical team so please answer as honestly as you can.

Answer

Question	Yes	No
1. Do you ever forget to take your Parkinson's medicines?		
2. Do you ever have problems remembering to take your Parkinson's medicines?		
3. When you feel better, do you sometimes stop taking your Parkinson's medicines?		
4. Sometimes if you feel worse when you take your Parkinson's medicines, do you stop taking it?		

Thank you so much for taking the time to complete our survey.

If you have any questions or concerns about your condition or taking your medications, please speak to your healthcare providers or Parkinson's nurse specialists.

If you are from Wales and would you take part in the interview study to explore the perceptions and views of people with Parkinson's regarding the use of digital technology to support medication management? **Please provide your contact information in the section below and then detach it and pass it to the Parkinson's UK member or chair of your group that has provided you with the questionnaire (Please click the link below). If you choose to provide your contact details these will not be linked with the data, you have provided. By providing your contact details you are agreeing to us holding this information for the purposes of contacting you with regards this study alone.**

………

I would like to take part in the Phase 2 interview, and I am happy for the research team to contact me.

You only need to provide your preferred way to be contacted. By providing your contact details you are agreeing to us holding this information for the purposes of contacting you with regards this study alone.

Name of participant: ……………………………………………………..

Signature of participant: ……………………………………………….

E-mail address: …………………………………………………………

Telephone number: ………………………………………………......

Appendix 6.2-Phase II Interview Topic guide

Research Project Topic Guide

5. Welcome, introduce myself, explain where I am from, and ensure they're comfortable.

6. Check understanding of the purpose of the interview, give an opportunity for questions: "Before we start, I wonder if you have any questions about this study or about why I've come to talk with you today?"

7. After establishing what is understood about the study, and answering any questions, explain that the interview will be recorded and all personal information will be anonymized.

8. Obtain consent for the interview and the recording. Set up and switch on the recording device while the interviewee signs the consent form.

Opening questions.

1. Has the importance of your Parkinson's medication been explained to you? How would you explain the importance of taking that Parkinson's medicine?

Prompts:

- How much do you feel you know about your Parkinson's could you explain to me how you understand your condition?

- Can you tell me about your medication? What makes Parkinson's medication important for you? In what ways do you think it is important?

2. What kinds of things would prevent you from taking your Parkinson's medicine?

Prompts:

- Do you have any trouble remembering to take your medicine?
- What do you do to help you remember to take your medicine? Is there anything you are using to help you keep track of or remember to take your medications?

3. If you notice any side effects from your Parkinson's medicine, how and to whom you usually report it?
4. What do you think about using a mobile phone application to help you manage and remember to take your medications?

5. What do you think about using a mobile phone application to help you report the side effect from Parkinson's medications?

Prompts:

405

- Can you think of any reason that you would not want to use a mobile phone application to help you manage and remember to take your medications?

Case example: "Parkinson's Tracker App" Show them a picture of the app

o What do you think about using an app similar to this app to help you with your Parkinson's medications?

o Do you think using a mobile app like this could be more/less beneficial to you than your other methods for keeping track or remembering your medications?

o After you see the different sections of this app, which features of the app do you think would be most useful to you? (Why is it good or not?)

- Are there any other features do you think it is important that have to be added to such an app?

- What do you think about adding an education section on your medicine?

- How do you want to communicate the information from an app? (Directly with the pharmacist/ Consultants).

- What about adding a feature that enables you to report the side effects from your Parkinson's medicine?

- If there is an app like this available for you; what would make you more likely to use the app over your current strategies?

6. Usability

o Can you tell me more about things that might prevent or hinder you from using a mobile phone app to help you to manage to take your medications? What would make you keep/stop using such an app?
   - What would be a barrier to your using it?
   - What could make an app easy to use for you?

o How would you feel about your pharmacist/clinicians contacting you with ways to improve how you take your medications based on the data you put in the app?

Feedback

Opportunity for further questions. Anything we have missed that you think is important.

Closure and thanks for participation.

Appendix 6.3- Phase II consent Form

Project: An exploratory study of people with Parkinson's perceptions regarding

the use of technology to improve medications reporting.

Name of researcher: Amani Khardali

Please initial all boxes

I confirm that I have read and understand the information sheet for the above project dated 15/06/2019 (version 2). I have had the opportunity to consider the information, ask questions, and have had them answered satisfactorily where appropriate……………………………………………………………………………………………………	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	
I agree to the interview being audio recorded.	
I understand that any information given by me, including direct quotes, may be used in future reports, articles or presentations by the project team; however, no identifiable data will be reported.	
I agree to participate in an interview for the above project…………………………………….	

_____   _____   _____

Name of Participant   Date   Signature

If you are signing to provide data on behalf of someone else, please add your name and signature here to confirm that they have agreed

_____   _____   _____

Name of Person taking consent   Date   Signature

Appendix 6.4- Phase II Participant Information Sheet

Project title: An exploratory study of people with Parkinson's perceptions regarding the use of technology to improve medications reporting.

I would like to invite you to take part in my research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you. Please take time to read this information and discuss it with others if you wish. If there is anything that is not clear, or if you would like more information, please contact me.

What is the purpose of the study?

The purpose of this study is to find out more about the opinions of people with Parkinson's on using digital technology such as an application to support them with their Parkinson's medication. Currently, there are several methods that could be used to manage and report Parkinson's medication such as electronic and paper dairies. However, we are trying to understand Patients' needs and preference regarding the use of digital technology to help them to remember to take their medicine and report any side effects. Your opinions could help researchers and application designers in developing the most effective method to support you with managing Parkinson's medication.

Why have I been invited?

You have been invited to this phase of this study as you have Parkinson's and also you have previously agreed for us to contact you when you took part in our first phase survey. We hope you will be able to share your thoughts and experiences of using a new type of technology.

Do I have to take part?

No, it is up to you to decide. Choosing to take part will have no direct effect on you. This information sheet, which is yours to keep, provides the main information about the study but you are welcome to ask any questions you might have. If you decide to take part, we will ask you to sign a consent form to show that you have agreed to take part. You are free to withdraw at any time without giving a reason.

What will happen to me if I take part?

If you agree to take part, I will contact you to confirm attendance. At the beginning of the one-to-one interview, I will ask you to complete and sign the consent form. Then I will ask you some questions about your opinions on using technology to support you with Parkinson's medication, the appropriate content and format of a future application, and how you usually report or track your medication. If you feel uncomfortable with any questions, you can refuse to answer these questions. The interview will be informal and will be audio recorded for my research, and you may be quoted however your name and point of view will be made anonymous so as not to identify any individual from any results (see page 3). The interview will be done face to face at any convenient location that you choose (e.g., local community centre, your house, and Cardiff school of Pharmacy). The interview will typically last around 30 minutes and no longer than 1 hour.

Expenses and payments

No payment or any incentives are offered or given if you decide to participate. However, reasonable travel expenses will be reimbursed.

How will the information collected be used?

Confidentiality will be ensured at all stages of the research process. The audio files of the interview will be kept on password protected computer laptop before transcription. The transcripts will be anonymized (i.e., name and contact details). Consent forms, transcripts, and recordings will be kept securely in the School of Pharmacy & Pharmaceutical Sciences at Cardiff University. Any information retained on password protected computer laptops will be anonymized (containing a reference code in place of personal data).

Any personal details that are collected during the study will only be seen by the research team and will not be kept for any longer than is needed to complete this study. It is anticipated that this will be no longer than one year.

Cardiff University is the sponsor for this study based in the United Kingdom. The University will act as the Data Controller for this study. This means that they are responsible for looking after your information and using it properly. Cardiff University will keep identifiable information about you for one years after the study has finished (namely consent form).

Under data protection law, the University has to specify the legal basis that we are relying on to process your personal data. In providing your personal data for this research we will process it on the basis that doing so is necessary for our public task for scientific and historical research purposes in accordance with the necessary safeguards and is in the public interest. The University is a public research institution established by royal charter to advance knowledge and education through its teaching and research activities. The charter can be found on the Cardiff University website.

Your rights to access, change or move your information are limited, as your information needs to be managed in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, Cardiff University will keep the information about you which has already obtained. To safeguard your rights, Cardiff University will use the minimum personally identifiable information possible.

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. The University has a Data Protection Officer who can be contacted at inforequest@cardiff.ac.uk. Further information about Data Protection, including your rights and details about how to contact the Information Commissioner's Office should you wish to complain, can be found at the following: https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection.

What will happen to the results of the research study?

The results of this study will be written up, used for the researcher report and may be published in peer-reviewed journals, but all information will be anonymized. This means that neither you nor anyone involved will be identified in the report. Let us know if you would like to see a copy of the report.

What will happen if I don't want to carry on with the study?

Your participation is voluntary, and you are free to withdraw from the study at any time without giving a reason.

What do I do if I have a problem or complaint?

If you have any questions or concerns about any aspect of the study, please contact the study supervisors at Cardiff University, Dr. Emma Lane (LaneE1@cf.ac.uk, 02920874989) or Dr. Louise Hughes (HughesML@cf.ac.uk, 02920876432). If you wish to make a formal complaint, you can do this by contacting Director of Research, Cardiff School of Pharmacy and Pharmaceutical Sciences, Redwood Building, King Edward VII Avenue, Cardiff CF10 3NB, (phrmyresoffice@cardiff.ac.uk).

How do I let you know if I want to participate?

If you have read this information and wish to participate, please get in touch with the researcher so we can make arrangements.

Thank you for taking the time to read this leaflet, if you have any further questions, please get in touch with the researcher, Amani Khardali (KhardaliA@cardiff.ac.uk, **Tel: 07474911856).**

Appendix 6.5-An example of interview Transcript

I: I'm Amany Khardali. I'm a PHD student from School of Pharmacy at Cardiff University and I'm here today to interview you about my study which is about using technology to help people with Parkinson's Disease and reporting their medications and what side-effects from their medication.

R: Right.

I: So, before we start do you have any questions, or you want me to start the interview?

R: Just go ahead.

I: Okay. So, my first question just to start our conversation is how much do you know about your Parkinson's or your condition?

R: How much I know about it?

I: Yes.

R: Well, I know it's a disease or condition that affects different sufferers in slightly different ways. I tend to think of a long list of things that it could affect and suffering with it and it seems to me that you have that one, that one and that one and that one but there's a list of many other side-effects and conditions that similar people might have, but there is similar disease would be common to most people, like a slight tremor or whatever. So that's the general view of what I know about Parkinson's.

I: So then how is the importance of your medication, Parkinson's medications? Did anyone explain the importance of taking your medication?

R: Yes, from the time I was diagnosed I understood that it was medication that would help to slow down the regression. So, I've been fairly or quite fastidious, quite serious about taking the medication at the appropriate times, but there was a proviso that concerned me right at the beginning whether I could wait a while before taking the medication. Doing that on the basis that eventually it stops working or stops working so efficiently and I thought maybe I could delay the onset of that, but the Parkinson's doctor, the specialist led me to believe that that didn't come into it. I should take the medication straightaway which I did.

I: So, my next question, did you take your Parkinson's medication on time?

R: I try to but it's a question of three times a day and before having food is not always easy to plan out on each day, because I do still work. I was working this morning on a part-time basis. I work shift work. So, trying to get the timing just right and some mornings I get up much earlier than other mornings, but more or less yes.

I: Is there anything that prevents you from taking your medication in time?

R: Preventing me?

I: Yeah.

R: Well, if I'm working, I have to find a way of going and swallowing a tablet. It's no big deal, but I have to find somewhere to go and do that.

I: **Do you have any trouble remembering to take your medication on time?**

R: Generally, no. It is three and a half years since I started the medication, and I was diagnosed now. So, in that time I've rarely forgotten. It's just the exact time between one and the next lot has sometimes varied a bit.

I: **So, then what did you do to remember to take your medications in time?**

R: Just relied on my memory. I think I'm quite good at remembering to do it.

I: **So, you didn't use any method, like the dose boxes or the pill counting or any application?**

R: No, nothing like that at all.

I: **On your phone, like an alarm of something to remind you to take your medication on time?**

R: I did take part in…I haven't brought the details, a system which had like a watch on your wrist and that buzzed. It was an experimental thing. Sorry, I've forgotten who provided it, but it came via the Parkinson's Clinic. They said did I want to trial it. So, I tried that for a week at a time, you had this watch on and it does give a little buzz at the appropriate times and it has been pre-set, in other words three times a day in my case for one tablet.

I: **Then you stopped using it after the experiment time.**

R: Yes, because at the end of the week you popped it in an envelope and sent it back to the people that had sent it to me. That was at least, the last one was probably at least six months ago now.

I: **So otherwise, you didn't use any method to help you to remind you?**

R: No, I was just relying on my memory.

I: **Okay. So, then what about your side-effects? Did you report your side-effects from the Parkinson's medication if you noticed any side-effects did you report it?**

R: Well, I am very much aware from the beginning that there's a long, long, long list of possible side-effects. All kinds of very outlandish things in some cases and worrying things sometimes, but the basic things I found it hard to identify any particular side-effects of the medication. As opposed to symptoms of the disease. I have quite a few symptoms, but I don't put them down as side-effects of the disease…of the medication I mean.

I: **So, then what do you think about using a phone application to help you to remember to take your medications on time?**

R: I'm always quite happy to take part in a trial. Hence, we're doing this, but I got a bit fed-up of the watch devise on my wrist after a week. I was ready to send it back and got fed-up with it because you had to wear it at night as well. So, a phone reminder, I would be quite happy to try it out and see how I get on with it.

I: **But what about using it for long-term?**

R: Well, who knows? Maybe I'll have to one day. Maybe I won't be able to remember as well as I do now. I mean, it's when you get up in the morning and sometimes in the middle of the day and it's sometime round about tea time is when I take my meds.

I: So, you're saying using the Smartphone application it may be benefit you in the future when your memory or when your disease has progressed more?

R: It could do. I may need help at some stage in the future. I don't know yet, but at the moment no. I do reasonably well, I think.

I: Yeah. So, then also what do you think about using a mobile phone application to report or to write down the side-effects from your medications?

R: Well, I'd have to identify those side-effects first as I just said.

I: So, you have like a problem in identifying these side-effects.

R: I do I think. I can't think of anything specific. Unless you presented me with a list and I might say, oh yes. I do suffer from that but as I say just to repeat, I don't know what a side-effect of the medication is. As opposed to one of the symptoms of PD.

I: So, can you think of any reason that you would not want to use an iPhone application to help you with reporting or managing or remembering to take your medication?

R: Not really. I just have to make sure I had my phone with me. Often, it's in another room. I don't carry it around always in my pocket, like some people do. Like a lot of people do. So that would be the only limitation.

I: From the disease itself, from the Parkinson's itself there is any reason that could be a concern for you using a mobile phone application?

R: No.

I: No there is not. Okay. So, I'm going to show this now. I'm going to show this application. It is not available commercially yet. This is like an example of it. It is especially for Parkinson's Disease and this application this is like the interface of this application. There's many aspects of it that you can click and report. For this one it is about exercising, the daily activities and this is standardised questionnaires if you have any problem with sleep or something like that you can click on it and fill the questionnaire and print the feedback and you can take it with you to the next appointment. Here is it about medication and these are the sections about the medications. You can enter all your medications, all your Parkinson's medications, like the name of it, the dose and how many times you're going to take it per day. Then it sets the reminder and it's going to give you a reminder when the time...

R: On the alarm?

I: Yeah. Alarm when the time comes to take your medications. So, what do you think about using applications like this to help you to remember to take your medications or report your side-effects or report any symptom of your Parkinson's in the future?

R: I can see it being useful because we have these periodical, all of us have these periodic appointments at the clinic, Parkinson's Clinic. I have mine this time next week, for example. The first time since January and that would certainly help to remember things that you wanted

to talk to them about. As it stands now before going, a day or two before I write down…I sit down and think about it and try and remember things I want to talk to them about. I don't usually have many things to talk about to be honest with you, because still I consider at a fairly early stage of the disease. So, I like to jot down some thoughts of things I want to discuss before going there. Planning in other words makes a more effective appointment after all, doesn't it?

I: **Yeah, true. So then do you think using an application like this to remind you to take your medications could be more benefit or less benefit to you?**

R: Well, it's fortunate, and this is why I've agreed to talk with you that I am a bit of a gadget man. So, I have a mobile and I have an iPad. I have a desktop computer. So, I'm quite used to using apps for all kinds of different things. I have a Fitbit watch, but I haven't got it on at this moment because I'm at home, but I wear it at work, and I wear it when I go out and about. So, I'm used to the concept of this because it measures my steps and sleep patterns and stuff like that. So short answer yes.

I: **Yes, okay. So, in general if we are going to develop applications to help people with Parkinson's Disease what do you want the applications to look like or the content, the feature of the applications, how do you want it to be?**

R: Well, there's one thing it can't be because of the technology that's being used today. Touch technology isn't really the best thing in the world for sufferers with Parkinson's Disease with tremors because your finger goes all over the place sometimes. So that's an obvious thing, but there again you can't change the whole worlds chosen technology at the moment which is touch screen. So, we're stuck with that. So, I use a little pointer thing sometimes to these things because I find the screen is too small. I bought myself a bigger screen so I could use it easier. Have I strayed off the point here?

I: **Yeah.**

R: Sorry. Bring me back.

I: **It's fine. What do you want if we are going to develop applications like this in the future to help you to managing your condition, like the side-effects, the symptoms, the medication reminder? What do you want this application to look like and what do you want the content of the application, what kind of information do you want us to involve in this application?**

R: Well more or less you've covered those on what you've suggested already. Medication timings and so on and maybe sleep patterns. Side-effects and things to talk to at the next clinic. Things to talk about I mean.

I: **So, you don't mind involving a questionnaire in this application and then you can answer this questionnaire before your next appointment with the consultant.**

R: That would be handy yes. None of us like filling out questionnaires day after day. There's no fun in that.

I: **Not at all.**

R: But immediately preceding the next appointment at the clinic that would be useful because it would question me. It would remind me of things I needed to discuss.

I: **What about adding sections, educational sections about Parkinson's, the importance of Parkinson's medication to take it on time in this application?**

R: You mean in general about your own information?

I: **General background information or instructions about how to use this application, like this.**

R: Well, my fellow sufferers are probably, generally at different stages of the progression or regression of the disease and would find perhaps the idea of using an App more difficult or using a mobile phone even perhaps more difficult as the condition deteriorates or regresses. Not least because of the touch screen technology. So, whilst I wouldn't need too much background now because it's three and a half years since I was diagnosed. I did a lot of background research myself as I was able. I was provided with lots of information. I've been on various groups and therapies and so on over the last three years so I've picked up a lot of information. I guess there's always room for more. Provided it's not the same old information. The organisation called Parkinson's UK which I assume you know about, has a very good website with much information and they also send literature out to you in the post every now and again. So, you keep up with what's going on. So, I would have thought the application on a mobile would have less need of lots of background information on it. I would have thought my source of that information would be elsewhere on the Internet.

I: **So then how do you want to communicate the information that you get from this application directly with your consultant, the nurse specialist, or the pharmacist?**

R: Well, I would have thought the consultant, but I hesitate to imagine that would be feasible because he will be inundated with data. I'm not sure how useful it would be to them.

I: **If you have any problems from your medications or if you have any issues do you have direct contact with the nurse specialist?**

R: There are Parkinson's nurses at the clinic. I have the numbers. Fortunately I've never had reason to call them. So, I just go between appointments. The only contact I have with them.

I: **Then the relation between you and the pharmacist who dispense the PD medication to you, so you have any good communications with them or no?**

R: Well, I'll be honest here, my wife actually goes and gets my medication from the supermarket pharmacy department. Usually in Sainsbury's.

I: **What do you think, is there is like any space for the pharmacist to be involved more in the Parkinson's regarding the medication?**

R: Only at moments of crisis brought on by counting out that you haven't got enough tablets, capsules to last you the holiday that you're just about to go on. Sometimes in the last couple of years we've had to get emergency supplies from the pharmacist which has been okay. We managed to do it. I've not missed out, but it's a question of having enough of the tablets on hand because you get a month's supply the way I'm doing it. Well, the risk of repeating myself sometimes you can run out if you're away from your normal home.

I: **Also, then, and this application that I showed you there is no sections about reporting side-effects from the medications. So, what do you think about adding a section because already you told me that you don't know the specific side-effects for each one, like an information**

section about the possible side-effect of each one and then a section to report if you get the side-effect it would be helpful for you?

R: It would be so long as there's not a list that long of things because that would be an onerous task to do very often. To do one prior to an appointment, in other words six or twelve monthly would be okay because it might answer a few questions, a few thoughts in your mind that oh this is something I should talk about.

I: **Then my final question, what would make you in the future or right now to use an application like this to help you with managing your Parkinson's medication?**

R: I'd be quite happy to give it a go. How advanced is this particular app? You say it's not commercially available.

I: **It is not commercially available yet.**

R: Is it likely to be in the near future?

I: **Hopefully. Also, there is other applications for the medication management available, like Medisafe. There are several applications. So, what do you think about these applications now or in the future, rather than just…?**

R: I did look at. This just reminds me three or four years ago when I was leading up to the diagnosis for this condition, I did do a lot of reading on the Internet and I looked at lots of apps on my phone. I've forgotten the name of them now because I never actually continued to use any of them, but I did look to see what was available at the time.

I: **If the clinician, the consultant, or the nurse specialist recommend an app for you to use it that will motivate you or encourage you to use it?**

R: Oh yeah.

I: **So, the recommendation from the clinicians it will be.**

R: Yes, and if you can get them on board with a particular app. I don't know how you would do that, but that's another story. That's your concern, isn't it?

I: **Yeah. So, in general I know you said you are okay with using an app in the future or right now to help you with your medications. Is there any concern that you think that people with Parkinson's, not you only, other people with Parkinson's Disease that may concern them or prevent them from using applications to help them with their medication?**

R: Again, apart from the touch technology which is obviously an issue. Some of them might be concerned about data that you're sending up. I know you've mentioned data here and the precautions surrounding its storage and so on, but that's an increasingly contentious issue today, isn't it?

I: **The privacy do you mean?**

R: Yeah.

I: **Okay.**

R: Well, the whole thing. The Data Protection Act and all the rest of it, to make sure you look after our data.

I: **Then if you decide now to use any type of applications to help you with your medications what is going to motivate you to keep using this application?**

R: If I found that the information isn't gathered between appointments at my clinic, was summarised in some way on request on the app and also perhaps printable and then I could go in with a list to the clinic and talk sensibly about things that had concerned me, even if it was six months ago that I'd forgotten about. I think I'd find that quite useful.

I: **So, this it could encourage you to use the application and keep using it because it's helped you with the communication during the appointment, your appointment with you clinician?**

R: I'd find that useful. You asked me a moment ago about other people, but obviously I can only speak for myself, but I would imagine that quite a number of sufferers who don't use mobile phones much or certainly don't want to use for this sort of purpose because of their age group. It's a disease of the old, isn't it?

I: **True.**

R: So that's just an observation from the side just thinking.

I: **So, do you think because of their age that would be a barrier for them?**

R: It could be a barrier. You may have found this already because as you get older it's a condition that might afflict you and that's my luck to be afflicted with it, but I come from a background of…well at least half my life of using technology in one shape or a form. Early desktops back in the 1980s, 1990s. So, I've more or less grown up with this stuff, but not everybody does.

I: **Yeah, true. So, this is the end of my questions. Is there anything else you want to add that you think it is important regarding using technology with reporting medications or with managing medications, Parkinson's medication?**

R: I don't think so because we've covered a lot of ground and I've voiced my concerns and the opposite. My happiness or this is a side-effect. I was trying to get the right words. I would be quite happy to use something like this. So, we've talked around it from various angles, and I think I've covered all the ground that occurs to me to be honest.

I: **Okay. Thank you very much. Thank you for being of my research. Thank you.**

Appendix 6.6- School Ethics Approval

SPPS Ethics Approval Notification (EAN)   8/9/14 v12

Cardiff School of Pharmacy and Pharmaceutical Sciences, Research Ethics Approval

This form has been signed by the School Research Ethics Officer as evidence that approval has been granted by the Cardiff School of Pharmacy and Pharmaceutical Sciences Research Ethics Committee for the following study:

Project title:	1819-17: An exploratory study of people with Parkinson's disease perceptions regarding the use of technology to improve medications reporting

This is a/an:	Undergraduate project	
	ERASMUS project	
	Postgraduate project	X
	Staff project	

Name of researcher: (PG/Staff projects only)	Amani Khardali
Name of supervisor(s):	Emma Lane and Louise Hughes

STATEMENT OF ETHICS APPROVAL

This project has been considered and has been approved by the Cardiff School of Pharmacy and Pharmaceutical Sciences Research Ethics Committee

Signed ██████████   Name R Deslandes   Date 19/08/19
9(Chair, School Research Ethics Committee)

Appendix 6.7-Phase II Invitation Letter

Cardiff School of Pharmacy and Pharmaceutical Sciences

Cardiff University

Redwood Building

King Edward VII Ave

CF10 3NB

Dear Sir/Madam,

I am undertaking a research project at Cardiff University into **"Use of digital technology to support people with Parkinson's in managing their medication: An exploratory study of PD patient perceptions" supervised** by Dr Emma Lane (Laneel@cf.ac.uk) and Dr Louise Hughes (HughesML@cf.ac.uk).

Thank you for completing our Phase I questionnaire; I would like to invite you to take part in one-to-one interview.

The interview is expected to take around 30 minutes and will take no longer than one hour.

In the interview, I will be asking about your opinions on using technology "app" to help you with your Parkinson's medicine. In particular, we would like to know your opinions on using this method to manage and track your Parkinson's medicine, help you remember to take your medicine, report side effects, and your potential for future use. The interview will be audio-recorded, and your information will be held confidential.

Your views will be used to help us understand your needs and preference regarding the use of technology when come to medication management.

More background information can be found on the attached information sheet.

If you would like to take part in the Interview, please let me know by contacting me **Tel: 07474911856**

 Or e-mailing **Email: KhardaliA@cardiff.ac.uk** by (*date and time*) at the latest so that arrangements can be finalized.

Yours faithfully

Amani Khardali (PhD. researcher)

(In association with Dr. Emma Lane and Dr. Louise Hughes)