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Understanding the experience of living with Parkinson's during and in the aftermath of the COVID-19 pandemic

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Abstract

Background and aim. Parkinson's is a chronic neurodegenerative condition that requires formal and informal support. However, the COVID-19 pandemic, first reported in the UK in early 2020, disrupted access to this support, causing concern about the acute and long-term implications on the health and wellbeing of people with Parkinson's. It is now important to understand the experience of living with Parkinson's during and in the aftermath if the pandemic.

Methods. A mixed methods approach was adopted. Four studies were conducted: i) a systematic review of the factors associated with the worsened wellbeing of people with Parkinson's during the pandemic, ii) a quantitative (hierarchical regression and moderation) analysis investigating the role of social engagement with friends and family in the wellbeing of people with Parkinson's during the pandemic, iii) an interpretative phenomenological analysis of Parkinson's-related healthcare experiences of people with Parkinson's in Northern Ireland before, during and after the pandemic, and iv) a dual perspective (people with Parkinson's and healthcare professionals) thematic analysis of experiences with telemedicine across the UK before, during and in the aftermath of the pandemic.

Results. In the psychological wellbeing review, psychological wellbeing outcomes during the pandemic were the most consistently associated with symptom-related variables and physical activity. Building on an identified gap in the investigation of psychosocial predictors of wellbeing, its prediction by social engagement with i) family and ii) friends was investigated. Regression analysis suggested these distinct constructs were independently and positively associated with wellbeing. However, the findings of a moderation analysis suggested that social engagement with family did not buffer against the negative impact on wellbeing of motor symptom worsening, and that social engagement with friends exacerbated the impact on wellbeing. In the qualitative NI study, consistent with the insufficient investigation of psychosocial variables in quantitative research, participants felt that healthcare in NI was overly focused on the physical aspects of the condition. Moreover, in addition to longstanding resource limitations shaping participants'

healthcare expectations, people with Parkinson's took active self-management roles in pursuing healthcare services to better meet their healthcare needs. Finally, in the fourth study, the increased adoption of telemedicine services during the pandemic was felt, both by people with Parkinson's and healthcare professionals, to improve the quality, flexibility and financial efficiency of services. Despite its perceived advantages, the use of telemedicine was suggested to limit the accuracy and/or depth of healthcare professionals' appraisals of the health and wellbeing of people with Parkinson's. Moreover, concerns were raised about the ability of people with Parkinson's to exercise preference over the mediums through which their healthcare was accessed (e.g., telemedicine, in-person).

Conclusion. The COVID-19 pandemic was associated with poorer psychological (and physical) wellbeing in people with Parkinson's. From the perspective of service users, notable gaps were identified in the understanding and treatment of Parkinson's in UK healthcare services. The successful alignment of health and social care services with the post-COVID needs of people with Parkinson's is challenged by systemic issues. Key challenges include the dominance of biomedical conceptualisations of Parkinson's, difficulty establishing successful multidisciplinary teams, and widespread resource limitations.

Contents

Tables

Figures

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Author's Declaration

I declare that this thesis is my own work and has not been submitted in substantially the same form for the award of a higher degree at this institution or elsewhere.

I declare that ethical approval has been granted for the research presented.

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Statement of Authorship

This thesis is presented as a multi-part thesis in adherence with the guidance outlined in Lancaster University's Manual of Academic Regulations and Procedures. The lead author for each chapter was Hannah Gotheridge (HG), the PhD candidate. The production of the thesis and research was supervised by Professor Jane Simpson (JS), Dr Fiona Eccles (FE) and Dr Craig Murray (CM). Additionally, Rebecca Henderson (RH) provided support in chapter three. A breakdown of the involvement of these key individuals is presented below.

Chapter three: A Systematic Review of the Factors Associated with the Psychological Wellbeing of People with Parkinson's in the COVID-19 Pandemic.

HG, JS, FE and CM contributed to the study design. HG carried out the database search, article screening, quality appraisal, data extraction, data analysis and the production of the manuscript. JS and RH additionally supported quality appraisal. JS and FE provided written feedback on drafts and guidance throughout.

Chapter four: Exploring social engagement and the wellbeing of people with Parkinson's during the COVID-19 pandemic - a hierarchical regression and moderation analysis.

HG, JS and FE contributed to the study design. HG carried out data cleaning, data analysis and the production of the manuscript. JS and FE provided written feedback on drafts and guidance throughout.

Chapter five: Understanding the lived experience of Parkinson's-related healthcare in Northern Ireland before, during and after the COVID-19 pandemic: An interpretative phenomenological analysis.

HG, JS and CM contributed to the study design. HG carried out data collection, data analysis and the production of the manuscript. CM provided one-to-one support with data analysis. JS, CM and FE provided written feedback on drafts and guidance throughout.

Chapter six: Experiences with telemedicine in the aftermath of the COVID-19 pandemic: a dual perspective thematic analysis of people with Parkinson's and healthcare professionals.

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Chapter 1: Introduction

1.1 General overview

Parkinson's, the term preferred by those living with Parkinson's in the UK (Parkinson's UK, n.d.b), is a chronic neurodegenerative condition (Bloem et al., 2021). Most synonymous with Parkinson's are the overt motor symptoms such as tremor, slowness of movement and muscle stiffness (Moustafa et al., 2016; Xia & Mao, 2012). However, people with Parkinson's (pwP) may experience a range of additional difficulties and challenges related to pathophysiological changes, the side effects of treatment, and difficulty living with and adjusting to the diagnosis (Chaudhuri et al., 2011; Maffoni et al., 2017; Simpson et al., 2013). These include cognitive impairments, psychological difficulties, autonomic dysfunction, sensory issues, and speech and swallowing problems. Consequently, to support their psychological and physical wellbeing, pwP commonly rely on (though do not always receive sufficiently) numerous health and social care services as well as support from family and friends (Bloem et al., 2021; Rosqvist et al., 2021; Theed et al., 2017). The experience of informal and formal support by pwP constitutes the broad focus of the present thesis.

More than understanding the experiences and needs of pwP, this thesis focused on the particular context of the COVID-19 pandemic. The spread of COVID-19, declared a pandemic by the World Health Organization (n.d.) in March 2020, was followed by fluctuating lockdown measures (Mathieu et al., 2020), implemented at both national and regional levels, until the pandemic was declared over in May 2023 (Rigby & Satija, 2023). For pwP, the pandemic lockdown restrictions (Mathieu et al., 2020) and requirement to socially distance (The Health Foundation, 2021) reduced access to vital healthcare support (Brooks et al., 2021). Moreover, documented negative impacts on the physical and psychological health of pwP as well as reductions in social contact became clear (Brooks et al., 2021). In addition to the acute consequences of the pandemic, several longer-term impacts have been documented. These include the exacerbation of symptom deterioration

(Baschi et al., 2020; Mai et al., 2022; Saluja et al., 2021; Wolff et al., 2022), difficulty returning to 'normal' (Murray et al., 2024), and denuded (UK) health and social care services (Health and Social Care Committee, 2021).

Understanding the experiences of living with Parkinson's during and in the aftermath of the pandemic is a broad topic and a breadth of relevant and useful research could be conducted. It is, therefore, useful to note a strong influence over the direction in which this research was taken. This thesis was funded as a CASE studentship, a scholarship that encourages collaboration between academic and non-academic partner organisations (UK Research Institution, n.d.). In this case, the research was conducted in collaboration with Parkinson's UK (Parkinson's UK, n.d.c), the UK's largest Parkinson's charity. The organisation aims to support better care, treatment and quality of life, and acts as an interface with pwP to promote their interests. While, of course, the academic merit of the research was the most fundamental consideration of this research, the input of Parkinson's UK helped drive the research in the interests of pwP and, relatedly, the diverse value that could be gained when disseminating research findings.

The UK health and social context constitutes the primary focus of the research. As such, the aims of the four studies (chapters three to six) and the interpretation of these findings in both the respective discussion sections and the thesis discussion section (chapter seven) were informed by and (primarily) applied to the UK health and social care context. However, in the following introduction chapter and throughout the thesis, both the global and UK context (e.g., care practice, response to the COVID-19 pandemic, epidemiological data and research) will be referenced. Because of this, a rigid distinction between UK and global insight was not constructive. Consequently, this thesis will make regional differences in reported data explicit where relevant.

Before presenting the methods of the thesis, the following chapter will firstly outline some relevant information with regards to Parkinson's before it is discussed what it means to live with and support Parkinson's. Then, contextual information regarding COVID-19 is outlined before the acute and long-term impact

of the pandemic on pwP is detailed. Finally, the thesis aims are presented and the chapter summarised.

1.2 The fundamentals of Parkinson's

To contextualise the conducted research and the interpretation of findings, the following section will outline some information fundamental to understanding Parkinson's and Parkinson's-related healthcare.

1.2.1 Symptoms, illness and controversy

Rather than having a single cause and effect, Parkinson's is better understood as a 'spectrum of conditions' relating to the death of cells (Ramsden et al., 2001). The most readily associated pathophysiology is the loss of nerve cells in the substantia nigra, part of the brain (specifically the basal ganglia in the midbrain) responsible for producing dopamine and influential in controlling body movements (Meoni et al., 2020). However, contemporary knowledge regarding the heterogenous causes of Parkinson's is a complex and evolving field (Rocha et al., 2025; Wüllner et al., 2023). Nonetheless, the varied neurodegeneration is most readily associated with the characteristic motor symptoms of Parkinson's, referred to as such across disciplines, including tremor, bradykinesia (slowness of movement) and rigidity (stiffness; Sveinbjornsdottir, 2016).

As well as motor symptoms, pwP experience a range of additional difficulties that are commonly (though not universally) understood to stem from pathophysiological changes and the side effects of treatment. In academia and practice, these symptoms constitute what are generally referred to as 'non-motor' symptoms in theory and practice (Chaudhuri et al., 2011; National Institute for Health and Care Excellence, 2017). These include (but are not limited to) sleep disorders and dysfunctions, fatigue, sensory symptoms (e.g., pain, visual disturbances), autonomic dysfunction (e.g., bladder urgency, sexual dysfunction) and gastrointestinal symptoms (e.g., dysphagia, dribbling; Chaudhuri et al., 2011). Despite James Parkinson's depiction of such aspects of Parkinson's in his seminal outline of the condition (Parkinson, 2002), the drive towards recognising 'non-motor' difficulties in modern medicine was an important progression in

acknowledging the range of difficulties associated with living with Parkinson's (Cronin-Golomb, 2013) and, relatedly, informing how these should be supported with health and social care.

However, there exists disagreement over the classification of some 'non-motor' symptoms. On one hand, the argument that the cause of psychological difficulties such as depression, anxiety, and hallucinations relates to the pathophysiology of Parkinson's is rooted in academic findings suggesting this to be the case in some circumstances (Chaudhuri & Schapira, 2009; Leentjens et al., 2006). However, this stance reductively implies that these, for most people most of the time, have a neurological basis. This perpetuates, in clinical practice (Foley & Mobley, 2025; National Institute for Health and Care Excellence, 2017; Parkinson's UK, n.d.a), a historical conception of illness and Parkinson's (i.e., the biomedical model) that is now often regarded to inform an incomplete understanding of illness and its management (Rocca & Anjum, 2020a). Moreover, it contradicts the experience of such symptoms by the individuals for whom healthcare services are shaped (Brown et al., 1995; Simpson et al., 2013; Todd et al., 2010). Congruent with the biopsychosocial approach with which Parkinson's is understood in the present thesis (see section 2.3.1), the reductive term 'non-motor' symptoms will not be used. Instead, experiences such as anxiety, depression, and stress will be referred to as psychological difficulties. Additional symptoms commonly classified as neuropsychiatric symptoms, such as dementia and hallucinations, will be referred to by name.

1.2.2 Diagnosis

While Parkinson's may be diagnosed before the age of 21 (juvenile-onset Parkinson's) or 50 (young-onset Parkinson's), a systematic review of global data reported that prevalence rates rise with age to an estimated 2.6% in people aged 85 to 89 (Pringsheim et al., 2014). Thus, Parkinson's disproportionally affects older individuals. Given the predominance of pathophysiological changes in areas of the brain responsible for controlling body movements, Parkinson's is typically identified because of changes to motor behaviour (Sveinbjornsdottir, 2016; van der Meer et al., 2025). However, diagnosis lacks a definitive medical test and is

complicated by the overlapping of symptoms with other neurological conditions (Rao et al., 2003; Tolosa et al., 2021). As such, Parkinson's is diagnosed with a clinical examination, often conducted by a neurologist (National Institute for Health and Care Excellence, 2017), that assesses the presentation of motor symptoms and rules out other diagnoses (Rao et al., 2006; Jankovic, 2008).

Receiving and giving a Parkinson's diagnosis is often a challenging experience for those on both sides of the interaction (Anestis et al., 2020; Anestis et al., 2023; Phillips, 2006). In research, the communication of an illness diagnosis is commonly referred to as 'breaking bad news', that is, news that seriously and negatively alters the patients' view of their future (Buckman, 1984). From the perspective of those giving the diagnosis, an interpretative phenomenological analysis (IPA) reported that neurologists experienced a 'balancing act' between the challenges of breaking the news and organisational related factors such as time constraints and insufficient communications training (Anestis et al., 2023). For those receiving a diagnosis of Parkinson's, this experience was likened to 'dropping the bomb' (Phillips, 2006), which vividly captures the destruction caused by the diagnosis. While receiving a diagnosis itself is often challenging, negative healthcare experiences at the time of receiving a diagnosis can also be impactful. Factors that affect this experience include dissatisfaction with the sensitivity of communication, a lack of information, delays and uncertainty, and (lack of) support (Eccles et al., 2011; Warren et al., 2016; Plouvier et al., 2017; Schrag et al., 2018). Though longitudinal studies investigating pwP were not identified, experiences of breaking bad news in individuals with cancer were found to relate to long-term satisfaction with care and psychological adjustment (Schofield et al., 2003; Roberts et al., 1994), highlighting the long-term implications.

1.2.3 Prevalence

In recent years, a rise has been documented in the prevalence of Parkinson's globally (Zhu et al., 2024). Compared to 1990, the number of individuals diagnosed with Parkinson's across the world more than doubled from 2.5 million to 6.1 million in 2016 (Dorsey et al., 2018). More recently, a meta-analysis of studies conducted

in 37 countries worldwide reported growth in the percentage increase of yearly prevalence rates by, most recently, 16.32% from 2004 to 2023 (Zhu et al., 2024).

The documented association between rising prevalence and environmental causes (e.g., pollution, pesticides, Chen & Ritz, 2018) has fuelled societal concern and arguably raised the profile of Parkinson's. Similarly, the more rapid rise in the prevalence of Parkinson's compared to other neurological conditions (Feigin et al., 2020) informed the media-friendly tagline as 'the fastest growing neurological condition in the world' (Open Access Government, 2024; Parkinson's UK, n.d.b). However, it is also apparent that factors such as the ageing of populations, more advanced diagnostic techniques, and increased recognition of Parkinson's in the general population (e.g., through public health campaigns) additionally contributed to the increase in reported cases (Okunoye et al., 2022; Bhidayasiri et al., 2024). As such, rising prevalence rates are likely impacted by a number of factors including the more accurate estimation of the 'true' prevalence in 'observed' estimates.

1.2.4 Treatment, care and progression over time

1.2.4.1 Motor symptoms

The physical symptoms synonymous with Parkinson's and the pervasiveness of the biomedical model of illness in modern medicine (Rocca & Anjum, 2020a) means that treatment predominantly focuses on pharmacological interventions targeted at the most common, dopaminergic pathophysiology of Parkinson's (Stoker & Barker, 2020; National Institute for Health and Care Excellence, 2017). Congruently, (oral) levodopa, which facilitates the replacement of missing dopamine in the brain, is the most frequently used medication (Bogetofte et al., 2020). Other drugs such as dopamine agonists (e.g., rotigotine, apomorphine) or monoamine oxidase-B inhibitors (e.g., rasagiline, selegiline) may also be used, especially when symptoms are milder, or to smooth dopaminergic stimulation, reduce motor complications such as dyskinesia, and provide more continuous symptom control (Armstrong & Okun, 2020; Sivanandy et al., 2021). Exercise-based interventions, such as gait and balance training, strength training, and

dance-based approaches, have also been evidenced to improve physical outcomes (Mak et al., 2017; Zhang et al., 2023). However, in the UK, referrals to physiotherapy services are costly and often occur when physical function declines (Agley et al., 2024). As symptoms become increasingly non-responsive to treatment, advanced and more invasive treatments such as deep brain stimulation[1] and levodopa-carbidopa intestinal gel[2] may be used (Hariz & Blomstedt, 2022; Thakkar et al., 2021).

1.2.4.2 Additional difficulties of living with Parkinson's

Despite the predominant focus of healthcare on the motor aspects of living with Parkinson's, as previously noted in section 1.2.1, pwP experience a range of additional difficulties. Though some 'non-pharmacological' treatments such as occupational therapy or speech and language therapy are recommended, the guidance is minimal (National Institute for Health and Care Excellence, 2017) and not always achieved in practice. Moreover, such guidance commonly under-acknowledges psychological interventions despite the range of potentially suitable options (Zarotti et al., 2021).

While there is increasing recognition of the difficulties of living with Parkinson's beyond the motor aspects (Chaudhuri et al., 2011; National Institute for Health and Care Excellence, 2017; van der Meer et al., 2025; Zarotti et al., 2021), research investigating the experience of pwP suggests that support for these are nonetheless commonly unmet both globally and in the UK (McDaniels et al., 2023; Parveen & Moore, 2023; Subramanian et al., 2021; Subramanian et al., 2022; Rukavina et al., 2021). This is especially the case with psychological difficulties (Ihnen et al., 2024; Read et al., 2019; Subramanian et al., 2021), potentially because of their (previously detailed; see section 1.2.1) conception as (non-motor) symptoms of the pathophysiological changes associated with Parkinson's or side effects of medication. In addition to the impact of biomedicalism, service gaps are also exacerbated by, for example, the insufficient coordination of multidisciplinary

[1] The modulation of neural activity through electrodes implanted in the brain via surgery.

[2] The administration of medication into the small intestine via percutaneous pump.

teams (MDTs), lack of continuity of care, and the insufficient capacity of healthcare services (Danoudis et al., 2023; Hjelle et al., 2024; Ihnen et al., 2024; Pirtošek, 2024; Zaman et al., 2021). Moreover, it has been suggested that the uptake of some services may vary depending on service user's health literacy (Zaman et al., 2021). That is, the literacy and numeracy skills that enable individuals to obtain, understand, appraise, and use information to make decisions and take actions that support access of and engagement with healthcare services (Nutbeam & Lloyd, 2021).

1.2.4.3 The long-term outlook

Parkinson's is a degenerative condition; as symptoms progress, individuals become more reliant on healthcare services as well as formal social care and informal support (Read et al., 2019). The progression of the clinical severity of Parkinson's is commonly quantified by the Hoehn and Yahr (H&Y) scale (Hoehn & Yahr, 1967), a stage measure that classifies (motor) symptom progression. The stages range from one to five, with five representing the most advanced level of symptom progression. The progression of symptoms is also marked by an increased impairment in the ability to engage in activities of daily living (Hobson et al., 2001) such as shopping and dressing (Sperens et al., 2020). As functional independence decreases, the role of social care and support from family and friends becomes increasingly important in maintaining quality of life (Read et al., 2019; Lawrence et al., 2014; Tod et al., 2016). Ultimately, in the latter stage of Parkinson's, healthcare focuses on the maximisation of comfort and support through palliative care (Lokk & Delbari, 2012).

1.2.5 The global perspective

The above depiction of Parkinson's healthcare focused predominantly on an understanding of Parkinson's and related healthcare developed in a high-income, individualistic Western country (UK). Indeed, the majority of Parkinson's research stems from predominantly Western (USA, Europe) and White populations (e.g., Ben-Joseph et al., 2020; Jourdain & Schectmann, 2014). As such, it is important to

acknowledge this positionality and note crucial nuances of Parkinson's healthcare globally.

Firstly, research suggests (Goh et al., 2022) notable disparities exist in the quality and quantity of Parkinson's healthcare between high and low-/middle- income countries (World Population Review, n.d.). For example, levodopa, the most common medication for Parkinson's, was reportedly not available in any low-income countries surveyed (World Health Organization, 2017). Other disparities include insufficient healthcare specialists and a lack of MDT support (Jourdain & Schectmann, 2014; World Health Organization, 2022a). In literature, these disparities have been associated with insufficient education about the true nature of Parkinson's in governing bodies, healthcare professionals and general populations (e.g., Crooks et al., 2025; Subramanian et al., 2021). This lack of condition-specific knowledge has varied impacts including the under-recognition of symptoms, which may be dismissed as 'normal' ageing, and the perpetuation of stigmatised beliefs (Fothergill-Misbah et al., 2021; World Health Organization, 2022a). As such, advocacy and raising awareness about Parkinson's in low-/middle-income countries, with the goal of changing public attitudes and practices, was outlined as a key strategy of the World Health Organization's (2022a) public health approach.

However, it should be noted that insufficient awareness of and stigmatised beliefs about Parkinson's is an issue that impacts Parkinson's-related healthcare worldwide (Crooks et al., 2023). Age stereotypes and general misconceptions about Parkinson's are still commonplace in high-income countries, perpetuated by lack of public awareness and education (Crooks et al., 2025). This is especially important because, with regards to the allocation of funding for healthcare in high-income countries, public opinion often has a large impact on public policy and the allocation of resources (Burstein, 2003; Campbell, 2011). Consequently, misunderstandings about Parkinson's impact the suitability of health and social care services to individuals living with Parkinson's. For example, stigmatised beliefs about Parkinson's as an 'old person's condition' (Fothergill-Misbah et al., 2021) mean health and social care is centred around the needs of older

individuals. Indeed, a study on individuals diagnosed with young-onset Parkinson's found that one of the most common unmet needs related to help with employment issues (McDaniels et al., 2023), which may be seen as less relevant for individuals diagnosed with what is understood to be an age-related condition.

Finally, healthcare in many Western countries such as the UK has transitioned from a model of medical paternalism (where HCPs 'interfere' with the autonomy of service users with the rationale that it is clinically beneficial; Düber, 2015; Dworkin, 2014; George et al., 2022; Scoccia, 2018), to a model where service users are placed at the centre of healthcare. In this sense, person-centred healthcare, sometimes referred to a patient-centred care in clinical settings (Zhao et al., 2016), aims to put service-user preferences, needs and values at the centre of care (Department of Health and Social Care, 2023). However, paternalism remains the dominant model of healthcare in many countries across the world (e.g., Alabdullah et al., 2023; Khosravi et al., 2025; Lazcano-Ponce et al., 2020; Vila Ortiz et al., 2023). As such, the person-centred framing of healthcare practice and research in many Western healthcare systems is less relevant to regions where medical paternalism is the dominant healthcare paradigm.

1.3 Living with and supporting Parkinson's

Given the aforementioned complexity of the symptoms and difficulties that pwP may experience, living with Parkinson's requires the support of various individuals. Though not exhaustive, this section will outline the role of healthcare professionals, pwP themselves, and family and friends.

1.3.1.1 Healthcare professionals

As previously noted in section 1.2.4.2, the successful treatment and management of Parkinson's requires the involvement of various healthcare professionals (see Figure 1). The importance of effectively managing the diverse needs of pwP with MDTs is increasingly acknowledged (Lindop & Skelly, 2021; Pirtošek, 2024; Post et al., 2011; Qamar et al., 2017). Acknowledged benefits include the alignment of care services with the needs of service-users and the improvement of symptom management (Pirtošek, 2024). The Parkinson's MDT commonly includes speech

and language therapists, occupational therapists and psychologists (Lindop & Skelly, 2021). However, the structure of these MDTs varies between countries (Pirtošek, 2024; van Muster, 2022), in part due to the lack of clear guidelines (Radder et al., 2020). For example, the most structured role for Parkinson's specialist nurses exists in the UK where they are central to service delivery (National Institute for Health and Care Excellence, 2017; Thomas et al., 2024).

Within the NHS, managing Parkinson's commonly involves the support of Parkinson's nurses (the first point of access for most pwP in the UK), consultant neurologists, and general practitioners (GPs). Though actual practice varies, regular consultations and reviews with a specialist/neurologist (roughly every six to 12 months) are recommended (National Institute for Health and Care Excellence, 2017[3]). Beyond this, specialist services should be accessible when required, including physical, speech and language and occupational therapists, as well as social workers, dietitians, psychologists, sleep specialists and gastroenterologists (Bloem et al., 2021).

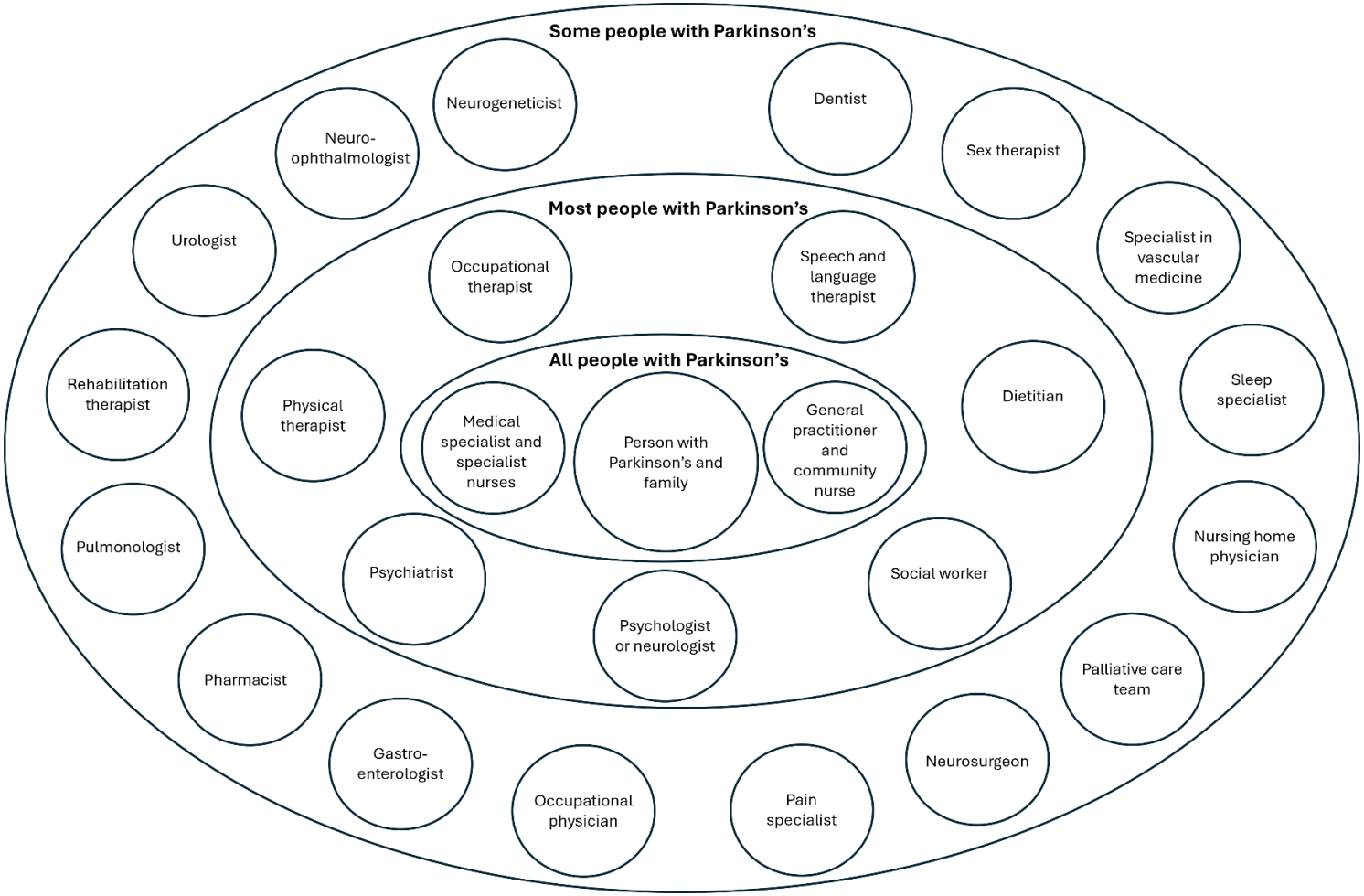
1.3.1.2 The role of people with Parkinson's

As well as HCPs, pwP are key actors in the management of their healthcare, in part because living with the condition necessitates a high level of engagement with various health and social care services (Tuijt et al., 2020). Everyday responsibilities include completing medical tasks, accessing services and maintaining relationships with healthcare professionals as well as managing emotions that arise due to living with the condition and day-to-day management (Corbin & Strauss, 1988). These are sometimes termed self-management, and a number of broader skills and competencies are associated with them including monitoring signs and symptoms, having knowledge of the condition and its management, having confidence in accessing support services, problem solving, and decision making (Lawn & Schoo, 2010; Lorig & Holman, 2003). However, differences exist in individuals' ability to engage actively in self-management behaviours (Schulman-

[3] Scotland previously followed Scottish Collegiate Guidelines Network (SIGN), but this is no longer in use.

Figure 1

The Parkinson's multidisciplinary team (adapted from Bloem et al., 2021)



Green et al., 2016) depending on, for example, the extent of individuals' healthcare knowledge, resources and expertise in navigating the healthcare system. Research suggests that difficulties with self-management are sometimes associated with health literacy (Mackey et al., 2016; van der Gaag et al., 2022; see section 1.2.4.2). Because of this, self-management competency can affect the success of healthcare. For example, a systematic review of studies investigating the self-management of individuals with chronic illness reported that low health literacy was associated with reduced adherence to treatment (e.g., taking medication; van der Gaag et al., 2022).

Though self-management responsibilities are often essential (e.g., correctly taking medication), the role that pwP take in their interactions with healthcare services varies with regard to active decision making related to treatment. Culturally Western, person-centred healthcare models support service users in taking an active role in, for example, deciding which treatment options are pursued (NHS England, n.d.). This is central to the ethos of the NHS, as the constitution pledges to ensure service users have the ability to make informed choices, be involved in the planning and access of care services and work in partnership with HCPs (Department of Health and Social Care, 2023). However, service user preference regarding the level of involvement in decision making varies. For example, in a study investigating shared decision making in the Netherlands, 28% of pwP report having to take a more active role than they would like (Nijhuis et al., 2019). This highlights the importance of shaping the provision of services around the particular needs and preferences of those using them.

1.3.1.3 The role of family and friends

Family and friends, particularly spouses/partners, often provide informal care and support to pwP. In literature, these are often referred to as 'carers' or 'caregivers', though such terms have been argued to devalue the relationship between those receiving and providing support (Molyneaux et al., 2011). Importantly, although 'family and friends' are commonly referenced collectively, a study conducted in the Netherlands suggests that 90% of individuals providing care are partners or spouses (Geerlings et al., 2023). Moreover, as the condition progresses, pwP often

socially withdraw from friendships because of, for example, perceived stigma (i.e., personal feelings such as embarrassment or shame and the projection of these feelings onto others; Mickelson, 2001) and difficulties with the physical and cognitive symptoms of Parkinson's (Ahn et al., 2022).

As a family member or friend, providing support to pwP generally revolves around supporting quality of life by aiding engagement in daily activities, supporting self-management, and providing emotional support (Hand et al., 2018; McLaughlin et al., 2011; Radder et al., 2020). Support has commonly been conceptualised as a 'buffer' against the negative impacts of living with chronic illnesses like Parkinson's on wellbeing outcomes (Barrera, 1986). With reference to social support theory, pertinent support is categorised as emotional (empathy, love), informational (advice, guidance, information finding), appraisal (evaluation support) and instrumental/tangible (practical assistance; Thoits, 2011) components. In theoretical terms, therefore, the support provided by friends and family generally centres around instrumental and emotional support. Notably, research suggests differences in the nature of support provided depending on the nature of the relationship (e.g., partners and spouses versus friends; Uchino, 2009).

Given the degenerative nature of Parkinson's, informal support often increases over time (Wu et al., 2025). Providing care to a partner or spouse can have a negative impact on psychological wellbeing, especially as the condition progresses and support needs increase (Aamodt et al., 2024). However, the support needs of partners and spouses (Duits et al., 2020) are generally underacknowledged.

1.4 The COVID-19 pandemic

COVID-19, first reported in the UK at the beginning of 2020, resulted in significant challenges for healthcare systems (Propper et al., 2020). The sudden demand on acute healthcare services, which strained resources and necessitated the redeployment of staff, had a negative impact on the delivery of care services to the wider population (Propper et al., 2020). In addition to such systemic impacts, social distancing and lockdown measures implemented by many countries during

the pandemic (Alfano & Ercolano, 2020) changed the daily lives of general populations globally (Flynn et al., 2020; Haleem et al., 2020) and had a variety of unintended consequences. These included disruptions to daily living (e.g., work, social and leisure activities), worries about the economy, and health concerns that, in part, fuelled the widespread reduction in psychological wellbeing documented during this time (Groarke et al., 2020; O'Connor et al., 2021; Pierce et al., 2020; Wegner et al., 2022).

1.4.1 Living with Parkinson's during and after the pandemic

For people with chronic health conditions such as Parkinson's, the challenges of living through the pandemic were compounded by disruptions to health and social care, informal support, and activities important to the maintenance of physical and psychological health (Brooks et al., 2021). As well as the lockdown measures implemented for the general population, in the UK, pwP were classed as "clinically extremely vulnerable" and advised to practise strict social distancing (The Health Foundation, 2021).

The collective measures and strain on healthcare systems caused by COVID-19 hospitalisations were particularly concerning for pwP because of their increased reliance on various healthcare services as well as formal and informal support (Bloem et al., 2021; McLaughlin et al., 2011; Radder et al., 2020). Specific challenges included the discontinuation of normal appointments, reduced in-home care, reduced social interactions and difficulty or concern about accessing medications (Brooks et al., 2021; Brown et al., 2020; Kumar et al., 2020; Shalash et al., 2020). Additionally, research suggested a notable negative impact on motor symptoms as well as worsening and/or high rates of anxiety and depression (Brooks et al., 2021; Kitani-Morii et al., 2021; Kumar et al., 2020; Palermo et al., 2020). To improve the provision of care, healthcare services increasingly adopted telemedicine to provide at-distance services while reducing risk of spreading COVID-19 and protecting vulnerable individuals (Nittari et al., 2022).

1.4.2 The post-COVID health and social context

I began this thesis in October 2021, over a year and a half before the pandemic was declared over in May 2023 (Rigby & Satija, 2023). As the research in this thesis progressed, countries globally exited the acute, lockdown stage of the pandemic (Alfano & Ercolano, 2020). However, research investigating this acute stage, as well as the current post-COVID health and social care context, is still important for several reasons. The post-pandemic health and social care context was notably altered compared to before the pandemic, and the implications of these changes need to be understood. This includes, for example, the acceleration of pre-pandemic trends towards the adoption of telemedicine (Valdes et al., 2022). Moreover, as previously noted, research suggests the lockdown and social distancing measures prevented many pwP from engaging in health-maintaining activities and research suggests marked motor symptom worsening, cognitive decline and worsened psychological wellbeing (Murray et al., 2024). As such, understanding the impact of the pandemic on pwP and the resultant post-pandemic needs of pwP is vital for shaping services around current healthcare demands. Finally, gaining insight into how pwP experienced the pandemic can inform preparedness strategies in future pandemics or similar contexts.

1.5 Thesis aims and structure

Consequently, the primary aim of the thesis was to explore the experience of living with Parkinson's during and in the aftermath of the COVID-19 pandemic.

Specifically, the research explored:

1. The impact of the pandemic on people with Parkinson's
2. The experience of accessing Parkinson's-related health and social care during and in the aftermath of the pandemic

The progression from broad research aim to actionable studies was achieved, in part, through the collaboration with Parkinson's UK, which provided insight into topics especially important to pwP as well as populations and research areas that were underrepresented. The research took a person-centred approach that sought

to understand the impact of the pandemic and healthcare experiences from the perspective of pwP. However, most fundamentally, the conception and design of these studies was guided by academic considerations such as the identification of notable research gaps and theoretical relevance.

In the following chapters, relevant methodological considerations and decisions will first be outlined with regards to the adoption of a mixed-methods approach, the philosophical stance underpinning the research, the role of theory, academic rigour, and ethical considerations (chapter two). Towards the end of chapter two, the four studies will be summarised, before these are then presented in full in chapters three to six. Finally, in chapter seven, the findings of these studies will be integrated into existing literature and implications for policy, practice and services, and limitations are noted. Then, recommendations for further research are outlined before the contribution to knowledge is considered and final conclusions are drawn.

Chapter 2: Methodology

This chapter provides an overview of mixed methods research, considers the suitability of taking such an approach to achieve the research aims, and key considerations for conducting mixed methods research. Then, it will detail the epistemological and ontological stances within which the mixed methods research was conducted before the role of theory is discussed. In the synopsis of studies section, the aims of the four studies will be outlined, and key methodological decisions will be justified. Subsequently, with reference to fundamental considerations in mixed-methods research, the purpose of the studies and their relative timing will be noted. Finally, quality and ethics are addressed, before the chapter is summarised.

2.1 Mixed methods research

The present thesis adopted a mixed methods approach to investigate the aforementioned research topic. Mixed methods, the most popular term of reference for the application of both qualitative and quantitative methods to investigate a broad research question, is distinct from the multimethod approach that refers to the use of multiple qualitative **or** quantitative research methods (Anguera et al., 2018). A substantial benefit of the mixed methods approach is the ability to overcome the weaknesses of any one method and thus generate a more complete understanding of a research topic (Creswell & Creswell, 2023; Tashakkori et al., 2021). While, for example, quantitative research may address questions on causality or provide insight about the prevalence of phenomena, qualitative methods supplement this with, for example, insight into the nature of experience (Fetters et al., 2013). Other related benefits include the development of rich and contextualised data, flexibility and adaptability in complex research contexts, and enhanced interpretation and theory development (Oranga, 2025).

2.1.1 Alignment of mixed methods with the thesis aims

Given the usefulness of mixed methods in facilitating comprehensive answers (Creswell & Plano Clark, 2017), the mixed method approach is especially apt for

research that is broad, complex and multifaceted (Tariq & Woodman, 2013). This broad insight is valuable for the development of policy and decision-making and is thus especially appropriate for research oriented to such practical applications (Oranga, 2025). As such, the mixed methods approach is increasingly applied to health research where the knowledge gained from these different research methods facilitates a nuanced understanding of the complexity of (physical and psychological) health (Battista et al., 2025; Wasti et al., 2022). Congruently, organisations such as the World Health Organization (Solar & Irwin, 2010) and the American Psychological Association (2020) increasingly adopt and encourage mixed methods.

In addition to having precedence in health research, the application of mixed methods is particularly suited to the present research aims. Parkinson's care is increasingly working towards achieving the principles of person-centred care (Bhidayasiri et al., 2020; van der Eijk et al., 2013; Parkinson's Excellence Network, 2022; Department of Health and Social Care, 2023). Historically, psychology and health research have been dominated by quantitative research methods, partly because of (post-)positivistic thinking that suggests a singular reality that can be known with objective measures (Alise & Teddlie, 2010). Though such an approach undoubtedly yields useful insights, the incorporation of qualitative methods advances person-centred care. This is because such methods are especially suited to, for example, capturing an in-depth understanding of service user experiences (Rocca & Anjum, 2020b; Stewart et al., 2024). The use of diverse research methods is argued to enable, in theory (though not always in practice), the alignment of care services and policies with an informed understanding of the context dependent experiences and preferences of service users, ultimately enhancing the quality of services (Rocca & Anjum, 2020b). As such, mixed methods research is reasoned to be especially appropriate where an established patient-centred multidisciplinary approach, as with Parkinson's, is recommended (Bloem et al., 2021; Glogowska, 2011).

2.1.2 Key considerations of mixed methods research

When conducting mixed methods research, recent guidance advocates for transparency regarding how the research was conducted (typologies) and how the findings (and the studies more generally) are anticipated to be understood in relation to one another (integration/purpose; Bazeley, 2017; Creswell & Creswell, 2023). Typologies attempt to categorise the 'types' of mixed methods research depending on considerations such as the order with which the methods are used and the relative importance attributed to these methods (Doyle et al., 2009). Such typologies are numerous and have varying degrees of specificity and fundamental dimensions that inform the classifications (Doyle et al., 2009; Guest, 2013). With regard to the purpose of developing and adopting such typologies, specific rationales are seldom stated (Guest, 2013). However, arguments for such transparency include supporting the design of studies, establishing a common language, providing structure and legitimacy to the field and supporting learning about the different perspectives of mixed methods (Guest, 2013; Tashakkori et al., 2021). Nonetheless, critics argue they fail to capture adequately the diversity of, yet also simplify, the variability of mixed methods research that exists in the real world in addition to introducing unnecessarily complicated descriptive dimensions (Guest, 2013). Accordingly, the present thesis will not adopt a typology-based approach to transparency regarding how the research was conducted.

With an understanding of the limitations of mixed methods typologies, Guest (2013) suggests a simpler approach to transparency that focuses on the 'points of interface', which refers to any point at which data sets are mixed or connected. This approach reduces the descriptive dimensions to the 'purpose' and 'timing' of integration. Arguably the most influential, and still commonly referenced classification of the purpose of taking a mixed methods approach was established by Greene et al. (1989), though others have since emerged (e.g., Bryman, 2006b). In their review of mixed methods literature, Greene et al. (1989) concluded the purposes of using mixed methods fell into five broad categories: triangulation (seeks convergence of results), complementarity (seeks elaboration, illustration or clarification), development (seeks to use the results from one to develop or inform

the use of another), initiation (seeks the discovery of paradox or contradiction, new perspectives of frameworks or the recasting of questions or results) and expansion (seeks to extent the breadth and range of inquiry by using different methods; Greene et al., 1989). With regards to timing, types are broadly grouped into concurrent (data are analysed separately but close in time; also termed parallel, convergent or simultaneous), conversion (one type of data is transformed into another type of data) or sequential (one data set is collected and analysed prior to the next). Transparency regarding the 'points of interface', purpose, and timing, is provided in section 2.5.

A final consideration for mixed methods research is integration, which refers to how and when the research methods are combined to address the overall research question (Bazeley, 2017). This may occur at the design, methods or interpretation/reporting level (Fetters et al., 2013) and, in the present thesis, findings will be integrated at the interpretation/reporting level in the discussion chapter (see section 7.2). Integration is an important aspect of mixed methods research because it enhances the value of research by facilitating greater depth of knowledge (Bryman, 2006a). At the interpretation/reporting level, which, in the present research, refers to the thesis discussion, integration can take a weaving (discussion of qualitative and quantitative findings on a concept-by-concept basis), contiguous (reported in separate sections) or staged approach (where data are analysed and reported separately) depending on the nature of the mixed methods research (Fetters et al., 2013). The integration of findings, in the present thesis, will, where possible, take the weaving approach where concepts will be discussed referring to both qualitative and quantitative findings. Additionally, the findings will be integrated in congruence with the concept of meta-inferences (drawing additional inferences based on the combined findings of the mixed methods research; Creswell & Creswell, 2023) to provide a sense of the overall findings in relation to the research aims (Doyle et al., 2016).

2.2 Philosophical stance

Historically, the use of both quantitative and qualitative research methods to answer the same research question was argued to be philosophically incompatible, driving the 'paradigm-war' that has mostly subsided, yet is still evident in some academic texts (Bryman, 2006b; Given, 2017). Such debate highlighted the importance of coherence between research methodology and the philosophical stance, also known as a research paradigm or worldview (Creswell & Creswell, 2023; Morgan, 2007). Congruently, the following section will provide transparency with regard to the assumptions underpinning this research.

2.2.1 Ontology and epistemology

Implicit in the application of quantitative and qualitative research methods are underlying assumptions about the nature of reality (ontology) and the nature of knowledge, how it is measured, obtained and used to understand phenomena (epistemology; Kant, 2014; Liamputtong, 2019). On opposing ends of the spectrum of ontological debate are the arguments that an objective reality exists independently of human consciousness (realism) and that reality is a construct of human experience (relativism; Levers, 2013). Similarly, opposing epistemological arguments about the nature of knowledge are that knowledge is independent of human interpretation (objectivism) and that knowledge is constructed through human experience (subjectivism; Audi, 2010).

Ontology and epistemology are closely associated with research methods. This is because the theoretically justified application of qualitative or quantitative research techniques is underpinned by their compatibility with perspectives on the nature of knowledge (derived from research methods) and how this knowledge is associated with reality (Krauss, 2005; Scotland, 2012). A realist ontology and objectivist epistemology would traditionally inform the use of quantitative research methods that seek objectivity, generalisability and the reduction of bias. On the other hand, ontological relativism and subjectivist epistemology are argued to be appropriately informed by qualitative research approaches that seek, for example, to understand multiple realities and the impact of the researcher (Bishop, 2015;

Krauss, 2005). The grouping of sets of internally consistent philosophical beliefs regarding ontology, epistemology, methodology and method resulted in what is often termed research paradigms (Scotland, 2012).

2.2.2 Popular research paradigms

Although various nuanced research paradigms exist (Creswell & Creswell, 2023; Kivunja & Kuyini, 2017; Tashakkori et al., 2021), two of the most dominant and commonly applied by social scientists are (post-)positivism and interpretivism/constructivism (Alharahsheh & Pius, 2020; Feilzer, 2010). Given the association of positivism with realism and objectivism, researchers with this philosophical stance contend the existence of a knowable reality that can be understood using objective and generalisable research methods. Accordingly, quantitative research methods are employed to understand the measurable properties of the world (Creswell & Creswell, 2023; Ikram & Kenayathulla, 2022). Contrastingly, researchers with an interpretivist, and therefore a relativist and subjectivist philosophical stance, commonly argue that knowledge is constructed through the varied and culturally situated meaning attributed to experiences (Hiller, 2016). As such, interpretivists focus on developing in-depth, context driven understanding (Creswell & Creswell, 2023). Historically, and because of the aforementioned beliefs about the nature of reality and knowledge, these research paradigms, and by extension, qualitative and quantitative research methods, were seen as fundamentally opposed (Creswell & Plano Clark, 2017); this became known as the incompatibility thesis (Howe, 1988).

More recently, however, pragmatism and critical realism have offered frameworks within which qualitative and quantitative research methods are philosophically compatible in mixed methods research (Allmark & Machaczek, 2018). Pragmatism is the most commonly described justification for mixed methods research and is often labelled the third research paradigm (Johnson & Onwuegbuzie, 2004; Creswell & Creswell, 2023). Its suitability for mixed methods research stems from its rejection of the conception of research paradigms as a metaphysical stance (metaphysical agnosticism) in favour of the view that they denote a particular belief system and practices within a field (Morgan, 2007). This approach drives the

focus of pragmatism towards practical considerations such as the differing strengths of qualitative and quantitative research methods in particular research contexts (Feilzer, 2010). Pragmatism's focus on functional knowledge and the impact on research and practice (Dures et al., 2011; Maxcy, 2003) makes it especially relevant for real-world applications, as with health research.

However, despite its popularity among mixed methods researchers, its adoption has been acknowledged to have certain limitations (Allmark & Machaczek, 2018). Most relevantly, pragmatism is argued to encourage an underappreciation of the influence of philosophical assumptions on the interpretation of knowledge acquired from different research methods. This is because research paradigms (and their associated philosophical stances) are said to provide a way of interpreting the world, which provides insight that would otherwise be difficult to obtain (Maxwell & Mittapalli, 2010). As philosophical assumptions may facilitate a more in-depth understanding of the research findings, it was decided that pragmatism was not well suited to the present research.

2.2.3 Critical realism and its coherence with the thesis aims

Contrasting the metaphysical agnosticism of pragmatism, critical realism adopts a realist ontology but takes an interpretivist approach to epistemology. As such, critical realism supposes an objective reality where knowledge about this reality is underpinned by subjectivity (Alderson, 2021). Taking the example of the positivist research paradigm as a point of contrast, critical realism opposes the presupposition that the existence of an objective reality means the reality can be objectively known (Alderson, 2021), as was traditionally the case with the equivalence of realism with objectivism. When applied to research methodology, the philosophical positioning of critical realism suggests the utility of knowledge generation using both qualitative and quantitative research methods (Alderson, 2021).

More than being consistent with a mixed methods approach, critical realism is especially well suited to understanding health given its focus on gaining an understanding of the unobservable mechanisms (e.g., culturally/socially

influenced reasoning, motivations or intentions) that contribute to a phenomenon, in this case illness (Koopmans & Schiller, 2022; Sturgiss & Clark, 2020). Congruently, critical realism is an attractive philosophical approach to health researchers because of the layers of reality, also termed ontological depth, conceptualised by Bhaskar (1979). This conceptualisation posits that reality is comprised of three layers: the real (powers and mechanisms that cause empirical and actual events to occur), the actual (events occur but may not be observed or experienced) and the empirical (events are captured in experience, observation and interpretation; Bhaskar, 1979). Consideration of these layers of reality encourages a layered understanding of the experience of living with Parkinson's during and in the aftermath of the COVID-19 pandemic. Consequently, a critical realist research paradigm was adopted.

2.3 The role of theory

The development and application of theory, that is, "a set of interrelated concepts, definitions and propositions that present a systematic view of events or situations by specifying relations among variables in order to explain and predict" (Glanz et al., 1997, p.11), has become increasingly prominent in health research. This has been marked, in part, by the growing development, application and refinement of 'middle range' theories (Brazil et al., 2005). Middle range theories are well suited to research as they are less abstracted and generalised than grand, unified theories (e.g., the biopsychosocial model of illness; Engel, 1997) and more so than individual hypotheses (Liehr & Smith, 2017; Merton, 1968), meaning they are both testable and applicable to multiple contexts.

As seen in prominent health psychology textbooks (e.g., Cockerham, 2020; Ogden, 2019), the application of middle range theory commonly takes a pluralistic approach where multiple theories are applied to shape research questions or understand findings. Such an approach is often apt because of the breadth of potential research foci and aims as well as the varying theoretical traditions from which middle range theories stem (Cockerham, 2020). In this sense, the suitability of the application of middle range theories (and relevance of the resultant insight)

depends on the specific aims of the research. Indeed, in health research, various theories and constructs are adopted to elucidate, for example, the onset of illness, adaption to illness, and illness outcomes (Ogden, 2019; Moss-Morris, 2013). Frequently cited examples of theories relevant to health psychology include the common-sense model of self-regulation (Leventhal et al., 2012) and illness uncertainty (Mishel, 1999). Given the breadth of the research topic - 'understanding the experience of living with Parkinson's during and in the aftermath of the COVID-19 pandemic' - a pluralistic approach to the application of middle range theory in the present thesis was apt.

While the relevance of middle range theories depends on the research aims, their suitability additionally varies depending on the purpose with which they are applied. When conducting research, theories can be applied at several stages including during the development of a hypothesis or research design as well as the interpretation and application of findings (Kelly, 2010; Brazil et al., 2005). In the context of empirical research, theory is commonly understood as being applied deductively (i.e., top-down, from theory to hypothesis to refinement) or inductively (i.e., bottom up, the generation or application of theory in response to that which is observed; Creswell & Plano Clark, 2017). Because of the often confirmatory nature of quantitative research and the exploratory nature of qualitative research, these methods are commonly (though not exclusively) associated with the deductive and inductive use of theory, respectively (Onwuegbuzie & Leech; 2005). Although the adoption of critical realism as a philosophical stance (see section 2.2.3) supports both the deductive and inductive use of theory, the application of theory in the four studies (chapters three to six) will nonetheless be carried out transparently.

In the present thesis, theory relating to the constructs[4] of social engagement and social support (chapter four) was deductively drawn on to develop the quantitative research hypothesis and inform the design of the study. Moreover, multiple relevant theories were deductively applied to understand the findings in the discussion sections of the four studies (chapters three to six). Particular attention

[4] A defined component of the human experience (Middendorp, 1991)

was given to applying theory with the goal of enhancing the relevance of the findings to Parkinson's healthcare. Finally, in the broader context of the thesis, theory was additionally relevant in various sections of the introductory, methods and discussion chapters (chapter one, two and seven respectively). This included the presentation of information fundamental in outlining what it means to live with Parkinson's during and in the aftermath of the COVID-19 pandemic (sections 1.2 and 1.3), the adoption of the biopsychosocial model (a grand theory; Engel, 1997) as a theoretical lens to inform the approach to understanding and interpreting the findings in relation to a broad research topic (section 2.3.1), the interpretation of the integrated findings of the thesis (section 7.2) and implications for policy and practice (section 7.3).

2.3.1 The theoretical perspective

In addition to adopting a mixed methods approach to achieve the research aim, informed by a critical realist research paradigm, it can be useful to adopt an overarching theoretical framework. This practice has been specifically supported in the context of mixed methods research where the application of such theory has been suggested to, for example, guide research or explore causal mechanisms (Evans et al., 2011). Though the predictive power of this grand theory is limited, the present thesis adopted the biopsychosocial model (Engel, 1997), or, more recently, the holistic biopsychosocial model (Wade, 2015), to provide a lens through which the broad topic of 'understanding the experience of living Parkinson's during and in the aftermath of the COVID-19 pandemic' was understood and findings interpreted.

The biopsychosocial model emerged in response to criticism of the biomedical model (Santos et al., 2018), the dominant approach to illness in the twentieth century. Put simply, the biomedical model was argued to be reductionist because of its narrow focus on the biological causes of illness and the associated biomedical approach to treatment (e.g., medication; Rocca & Anjum, 2020a). Contrastingly, the biopsychosocial model was developed in acknowledgement of the diverse causes of illness through biological, psychological and social pathways (Engel, 1997). From this perspective, the causes of illness are argued to be caused

by both traditional biomedical bottom-up causes and psychosocial top- down causes (Ellis, 2012). As such, the biopsychosocial model is argued to facilitate a fuller understanding of illness and outcomes (Engel, 1997; Santos et al., 2018). Despite this, such factors are still commonly underestimated in healthcare (Berthold & Borman, 2024), demonstrating the necessity to advance insight regarding the biopsychosocial causes of illness in Parkinson's. In acknowledgement of this underestimation, the application of the biopsychosocial model of illness to Parkinson's, as with dementia (Spector & Orell, 2010), has been encouraged to guide clinical practice and reduce biomedicalism (Gibson, 2017).

Importantly, and in congruence with consideration of the top-down causes of illness, the biopsychosocial model encourages a holistic approach to healthcare as it highlights the importance of understanding the broader psychological and social circumstance of the individual in addition to the biological cause (Rocca & Anjum, 2020a). This holism, and the associated rejection of the reductionist biomedical approach, is positioned as a central tenet of Engel's (1997) attempt to humanise and increase the agency of service users (i.e., the ability to determine actions through independent choice; Ballou, 1998) through person-centred healthcare approaches (Buetow et al., 2016; Rocca & Anjum, 2020b; Santos et al., 2018; Zhao et al., 2016).

Consequently, the adoption of a biopsychosocial theoretical lens is especially pertinent to the present thesis given the applications are primarily (though not exclusively) relevant to the UK NHS and social care systems because of the services' commitment to providing 'patient' centred care (Department of Health and Social Care, 2023). Demonstrated impacts of taking a person-centred approach include improved communication between service users and HCPs, enabling HCPs to understand better the information that service users present, greater autonomy and service user involvement, and the general improvement of clinical outcomes, especially in multidisciplinary care (Keirns & Goold, 2009; Kusnanto et al., 2018; Kwame & Petrucka, 2021; Larivaara & Taanila, 2001). As such, the adoption of a person-centred, holistic, biopsychosocial approach is an especially useful lens through which to understand the experiences of people with

Parkinson's and those who support them in a post-COVID health and social context.

2.4 Synopsis of studies

The following section aims to provide an outline of the individual studies as well as the purpose of these studies within the context of the overarching thesis aims and broader considerations. Further details of the methods used for each study are reported in the respective chapters. The relationship between studies is justified in terms of Greene et al.'s (1989) categorisation of the purposes of mixed methods research (see Figure 2). For ease of reference, studies one to four will be referred to as the psychological wellbeing review, social engagement study, NI study, and telemedicine study, respectively.

2.4.1 Study 1: Psychological wellbeing review

The first study was a systematic review that sought to investigate the factors associated with the worsened wellbeing of pwP during the pandemic. To achieve the research aim, a systematic review with narrative synthesis (Popay et al., 2006) was conducted. Though other review types were considered, narrative synthesis was deemed most appropriate for a number of reasons. These included the variability of employed research designs (and the importance of incorporating as much data as possible), evident inconsistencies in reported findings, and the potential relevance of contextual factors (e.g., varying lockdown measures) in the interpretation of findings. Indeed, in such research contexts, review methods such as meta-analysis are considered unsuitable (Higgins et al., 2002). Conversely, the narrative synthesis is particularly suitable as it enables consideration in the analysis of divergences across studies (e.g., research design; Popay et al., 2006).

At the time of the study's conception minimal qualitative literature was published and the decision was taken to focus on quantitative research to represent the majority of work. This decision was also taken in acknowledgement of the difficulties of conducting a mixed methods review. Specific challenges include the dilution of important quantitative considerations (e.g., power and research design) as well as the potential for disproportionate weight to be given to (in this instance)

the qualitative findings for which there is minimal evidence (Atkins et al., 2012; Lizarondo et al., 2022). Conversely, the quantitative focus provided an empirical foundation with which to inform the (quantitative) conception and design of the social engagement study (chapter four). Although the qualitative studies were not analysed in the systematic review, they were nonetheless incorporated into the thesis. Specifically, the findings of these studies contributed to decision making about which studies to conduct. Additionally, the findings and conclusions of the studies were commonly referenced to gain insight and contextualise the findings of this thesis.

Congruent with the decision to carry out a narrative synthesis of quantitative data, international studies that reported quantitative analyses of factors associated with psychological wellbeing (see chapter three) outcomes were identified and synthesised by 'type' of predictor (e.g., age, gender). With reference to the overarching aims of the thesis, this study provided research-driven insights to identify the impact of the pandemic on the psychological wellbeing of pwP and, as such, their likely post-COVID healthcare needs.

2.4.2 Study 2: Quantitative survey analysis

The second study used secondary data (i.e., data collected by someone else for another primary purpose; Johnstone, 2014) from an online survey conducted by Parkinson's UK, collaborators of the thesis (see section 1.1). The survey data was collected at a single timepoint shortly after a period of lockdown in 2021 through an online survey sent to Parkinson's UK members. It investigated demographics, changes to medical care/motor symptoms/physical activity and additionally included validated wellbeing/loneliness/social engagement scales. The initial analysis of the survey was reported by Simpson et al. (2022a), where, in order to better understand the impact of the pandemic, these data were additionally compared to the findings of an earlier survey (conducted in March 2020; Simpson et al., 2020). Subsequently, Eccles et al. (2023a) conducted a hierarchical regression analysis and reported that worsened symptoms, social isolation and loneliness significantly predicted psychological wellbeing when controlling for

demographic variables and disease duration. The social engagement study (chapter four) builds on these findings using the same dataset.

The use of this existing database had several benefits. Such benefits included access to data from a large number of participants, increasing the probability that analyses, particularly the moderations, were appropriately powered (Johnstone, 2014; Wickham, 2019). Additionally, the data enabled further investigation of the impact of the lockdown on the outcomes of pwP, which, given the acute, lockdown phase of the pandemic was over by the time the study was conducted, was only possible through retrospective data analysis. Additionally, there is increasing acknowledgement of the importance of ensuring that existing data is thoroughly analysed before new data is collected. This is especially important in populations such as those living with Parkinson's to reduce the burden of taking part in studies (Tripathy, 2013). Further analysis of the impact of the pandemic on the wellbeing of pwP was especially important considering the limitations of (primary) pandemic research (Wickham, 2019) identified in chapter three. These included a lack of theoretical basis for investigation, clear gaps in the focus of research (i.e., psychosocial predictors of wellbeing), and the use of basic statistical analyses.

However, the disadvantages of using secondary data should also be acknowledged, including a lack of control over recruitment methods, ethical implications, and missing data (Tripathy, 2013; Wickham, 2019). These limitations were addressed in a number of ways. Firstly, in section 4.2, transparency was provided with regards to what was known about recruitment, and the potential limitations of this on the findings of the study were noted in section 4.4.1. Additionally, ethical implications pertaining to the use of secondary data was outlined in section 2.7 (e.g., anonymity, ethical approval). Moreover, the addressing of missing data were outlined in section 4.2.4. The most notable limitation of the analysis of secondary data in the present research was that the data were built around the perspective and aims of the original primary researcher(s). In particular, one of Parkinson's UK's key considerations was to ensure the questionnaire was as short as possible so as to not overburden those taking part. Because of this, shorter validated scales (e.g., the Lubben Social

Network Scale-6; see section 4.2.3.2) were preferred. Overall, the dataset (e.g., the choice of measures) was not totally aligned with the needs of the present (secondary) research (Wickman, 2019). Specific details about the implication of this are presented in section 4.4.1.However, after considering the quality of the data, its general suitability to the research aims, and the importance of advancing knowledge regarding the impact of the pandemic on pwP, it was decided to carry out the secondary analysis.

In the study, friends and family were investigated as distinct constructs (see section 4.1 for the justification). Investigation of the relationship between social engagement (with family and friends) and wellbeing could have adopted a number of research designs. Given the relationship between these variables is reportedly linear (that is, a change in one variable is proportional to the change in the other; Monteiro et al., 2024), it was appropriate to use a statistical analysis that assumes linearity, such as multiple regression. Multiple regression additionally enabled potential confounders of the relationship between two variables to be controlled for. As such, this method was suitable to investigate the (linear) relationship between social engagement and wellbeing when controlling for the established relationship between illness-related variables and wellbeing (see chapter three; Cusso et al., 2016; Sagna et al., 2014).

The finding that social engagement has a buffering effect against deteriorating wellbeing (Nimrod & Shira, 2016; Sharifian & Grühn, 2019) suggests the relevance of carrying out a moderation analysis. The suitability of this statistical design is further supported by the conceptual closeness between social support and the present social engagement measure (see section 4.2.3.2). Indeed, social support theory (Barrera et al., 1986) argues that 'types' of social support (see section 1.3.1.3) buffer against the impact of negative experiences on outcomes, and this association is tested statistically using moderation analysis. Moderation analysis, therefore, is a pertinent statistical tool for investigating the impact of social engagement (a moderating variable) on the strength or direction of the relationship between the negative impact of motor symptoms (predictor) on wellbeing (outcome; Hayes, 2022).

Overall, to achieve the research aims, a regression analysis was firstly conducted to investigate whether social engagement with friends and family predicted the wellbeing of pwP during the COVID-19 pandemic when controlling for illness-related variables and demographics. Then, a second analysis of the same dataset investigated whether social engagement with friends and family moderated the established relationship between motor symptom worsening and psychological wellbeing (Cusso et al., 2016; Sagna et al., 2014). The adoption of multiple regression and moderation analysis facilitated a more nuanced understanding of the predictors of psychological wellbeing outcomes than was established by the simple analyses adopted by the studies investigated in the review (chapter three).

2.4.3 Study 3: Northern Ireland study

The NI study, broadly speaking, sought to understand Parkinson's-related healthcare experiences in NI before, during and after the COVID-19 pandemic. The choice to research NI was, in part, informed by the experience of Parkinson's UK who acknowledged a reduced quality of care (compared to mainland UK) in the region. Moreover, it was apparent that individuals from NI were insufficiently represented in UK (quantitative and qualitative) research (see chapter four). Importantly, pertinent differences are acknowledged between NI and the UK (e.g., a history of sectarian conflict, separate governance) that limit the application of insight from the UK/English context to a NI one. Consequently, given the suitability of qualitative research to attending to context (e.g., sociocultural, historical, political; Creswell & Poth, 2016), a qualitative study was undertaken to gain an in-depth insight into the experience of Parkinson's-related healthcare in the region.

Though the choice of analysis was limited by the strong experiential component of the research aim, it was acknowledged there exist other relevant methodologies including other phenomenological approaches (e.g., Giorgi, 2009) and narrative enquiry (Clandin, 2022). Narrative enquiry was suitable for the investigation of lived experience over time, which was an important component of the research. However, recent advancements in IPA methodology acknowledge the importance of understanding how experiences are shaped by sense-making through time (i.e., through past experiences and consideration of future experience; Smith, 2024).

Ultimately, IPA was preferred due to the greater relevance of understanding participants sense making of their lived experience, the comprehensiveness of the guidance, its prominence as a methodology in health and illness research, and its focus on the psychological entailments of experience and meaning making (Biggerstaff & Thompson, 2008; Pietkiewicz & Smith, 2014).

IPA is well suited to research that seeks to understand how individuals attach meaning to their lived experience of a given phenomenon (phenomenology). The (double) hermeneutic focus (i.e., the researcher's interpretation of the participants' interpretations) and encouragement to engage in reflexivity (situating the researcher in the creation of knowledge; see section 2.6; Murray & Holmes, 2014; Smith et al., 2021), among other factors, are consistent with a critical realist research paradigm (Hood, 2016). This is, in part, because of the compatibility between placing the researcher and participants in an active role in the knowledge that is gained through the analysis with an epistemologically relativist stance regarding how knowledge is obtained.

It was anticipated there would be difficulty recruiting participants in NI, evidenced by the minimal representation in the data presented in chapter four and feedback from Parkinson's UK. As such, recruitment was primarily (though not entirely) carried out using the infrastructure established by Parkinson's UK, who acted as gatekeepers. The resultant potential for selection bias (Vinkenburg, 2017) was reduced by asking staff members to advertise the study at local events and on social media and by allowing direct contact between potential participants and the researcher.

Finally, phone and video interviews were used to enable access to a broader number of participants by reducing the geographical barriers to in-person interviews (Keen et al., 2022). This was done with acknowledgement of the debate between the benefits and disadvantages of using these methods of data collection with regard to the richness and quality of the data collection (Roberts et al., 2025). In recognition of potential impact of using phone and video interviews on rapport (Carr & Worth, 2001), I actively sought to engage in rapport building to enhance participants' willingness to engage (De Villiers et al., 2022).

2.4.4 Study 4: Telemedicine study

The final study sought to understand experiences of telemedicine in UK Parkinson's-related healthcare. As with the NI study, it was, in part, supported by the guidance of a collaborator at Parkinson's UK, who noted that its use was a contentious and salient topic for many pwP. Research suggests that the use of telemedicine, though in use before the pandemic, became more prominent in an effort to provide continued care during lockdown measures (Nittari et al., 2022). However, in chapter five, it was found that pwP in NI had contrasting experiences with and opinions about the use of telemedicine in Parkinson's-related healthcare. To elucidate this complex picture, qualitative research methods were apt because of their ability to develop understanding about emerging topics of interest (Creswell & Poth, 2016; Jamshed, 2014).

In congruence with the research aims, thematic analysis was selected as the most suitable method of analysis. IPA was also a viable consideration because of its phenomenological focus and consideration of context. However, this method was deemed less suitable to the research topic because it was anticipated that the provision of healthcare through telemedicine would not be an emotionally salient experience for HCPs. The research aims were not well suited to a methodology with a strong phenomenological focus or where homogeneity of participants is a central component, as with IPA (Smith et al., 2021).

Though various 'types' of and approaches to thematic analysis exist (Braun & Clarke, 2021b; Wiltshire, G., & Ronkainen, 2021), Braun and Clarke's (2021b) reflexive thematic analysis is argued to be especially congruent with the adopted critical realist philosophical stance (see section 2.2.3). Reflexive thematic analysis was selected rather than the critical realist thematic analysis method developed by Fryer (2022) because the research aim was fundamentally exploratory (i.e., sought to describe experiences with telemedicine) rather than explanatory (i.e., sought to explain experiences with telemedicine). Though it should be noted that, in line with the critical realist approach, explanation of the causes of experiences is evident in the themes as well as the discussion section. Overall, the adoption of Braun and Clarke's (2021b) thematic analysis provided a comprehensive and well-

respected guide, that encouraged consideration of the role of the research through engagement with reflexivity and enabled the flexibility to engage with the data in an explanatory way where relevant.

With regards to recruitment, both HCPs and pwP were included in the analysis to facilitate a more balanced insight into the use of telemedicine. This decision was consistent with a critical realist paradigm as multiple perspectives may facilitate a more detailed understanding of the layered reality (Given, 2012). As with the NI study, and with the same rationale (e.g., reducing geographic limitations, stimulating open ended conversation; see section 2.4.3), the technology study used semi-structured, open-ended interviews using video or telephone calls.

2.5 Purpose and timing

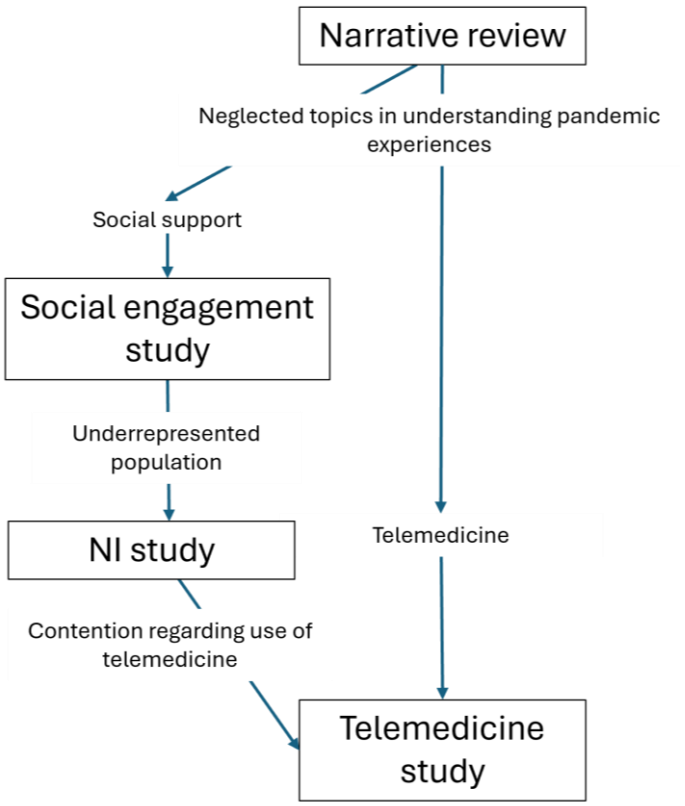
Returning to Greene et al.'s (1989) categories of the purposes of mixed methods research, the relationships between the studies will now be outlined (see Figure 2 for an overview).

The systematic review (chapter three) identified not only those at risk of worsened wellbeing but also highlighted key gaps in literature. Specifically, a lack of research into the impact of technology, the unsatisfactory investigation of the impact of psychosocial factors on wellbeing, and no investigation of positive psychological wellbeing measures. Additionally, the review highlighted the adoption of simplistic statistical techniques, such as bivariate correlations, which limited the insight that could be gained from the findings and potentially contributed to some of the inconsistent findings regarding the significance of predictors. In line with these findings, the purpose of progression to the social engagement study (chapter four) was both expansion (to extend the breadth/range of inquiry using different methods) and development (using the results of one analysis to inform the use of another). Similarly, the psychological wellbeing review (chapter three) influenced the telemedicine study with the rationale of development, to investigate in-depth experiences with telemedicine. Additionally, though not the primary focus of the analysis, the NI study (chapter five) provided anecdotal evidence regarding the dissatisfaction that some pwP had with the use of telemedicine in healthcare. As

such, the NI study informed the telemedicine study (chapter six) with the rationale of complementarity and with the goal of seeking elaboration about telemedicine in the healthcare experiences of pwP. With regard to the timing at which the different methods were employed, the thesis took a sequential approach as the studies were conducted one after the other.

Figure 2

Sequence of studies



2.6 Methodological rigour in quantitative and qualitative research

Throughout the research, consideration was given to rigour. Importantly, concepts fundamental to consideration of rigour vary between quantitative and qualitative research. Quantitative research commonly considers validity, reliability and generalisability, in congruence with the aim of reducing bias and identifying findings that can be generalised to broader contexts (Heale & Twycross, 2015; Vu,

2021). In chapters three and four, relevant considerations included, for example, the reliability and validity of measures, sampling techniques, and the generalisability of findings when considering key characteristics of the sample (e.g., age of the sample, representation of ethnicities).

However, such considerations are less suitable to the assumptions underpinning qualitative research (Leung, 2015; Yardley, 2000). For both qualitative studies (chapters five and six), consideration of rigour was firstly guided by general qualitative indicators (Yardley, 2000). Congruently, supporting files are provided in the appendices (see sections 5.2.6 and 6.2.6 for an overview) to demonstrate the audit trail that was kept and enable critique on the rigour of the approach (Yardley, 2000; Smith et al., 2021). Additionally, the incorporation of participant quotes, although common practice in both IPA and TA, provide transparency (Yardley, 2000) by showing how the interpretative elements of the analysis were derived from the data. Moreover, the Consolidated Criteria for Reporting Qualitative Research (Tong et al., 2007) was considered (see sections 5.2.2 and 6.2.2 for an overview).

With regards to the thematic analysis (chapter six) the adoption of Braun & Clarke's (2021b) thematic analysis made relevant the consideration of their tool for evaluating quality of thematic analysis research (Braun & Clarke, 2021a). The checklist broadly considers the suitability and explanation of methods and methodology and the development and justification of the analysis. Finally, in the NI study (chapter five), Nizza et al.'s (2021) four markers of high-quality IPA research were given consideration. Firstly, the construction of the narrative, both within and across themes, was achieved through a purposeful progression of the analysis supported by carefully selected quotes. In line with the recommendation that a good analysis involves 'developing a vigorous experiential and/or existential account', attention was paid to grounding the coding of the interviews in the participants' experience by, for example, incorporating the participants' own phrasing. This additionally supported the close analytic reading of participants' words. Finally, the analysis attended to both convergence and divergence in participant experiences.

2.6.1 Reflexivity and positionality

An important component of quality in qualitative or mixed methods research is consideration of the researcher's positionality and engagement with reflexivity. Positionality relates to an individual's 'worldview' with regards to ontological and epistemological assumptions as well as assumptions about human nature and agency (Holmes, 2020). Assumptions about human nature and agency can impact, for example, how research is approached and how the results are generated or interpreted. Consequently, it is important to consider how the research may be impacted by 'fixed' aspects of the researcher such as gender or nationality as well as more fluid and contextual aspects such as personal life history or political views (Chiseri-Strater, 1996; Bourke, 2014). Consideration of positionality can be achieved through reflexivity, which is the engagement and critical self-reflection of the broad impact of the researcher on the research (Finlay, 2002).

In the context of the present thesis, reflexivity is not only consistent with the adoption of a critical realist stance (Alderson, 2021) but also central to both IPA and thematic analysis (Braun & Clarke, 2021b; Smith et al., 2021). In reflexive thematic analysis, the researcher is seen as critical to the generation of knowledge. As such, it is encouraged to engage reflexively, through reflexive journalling, about the impact of knowledge and assumptions (Braun & Clarke, 2021b). Contrastingly, reflexivity in IPA is not a central theoretical component. However, IPA is theoretically underpinned by the concept of the 'double hermeneutic', that is, researcher interpretations of participants' interpretations of their life experiences (Smith et al., 2021). Because of this, engaging reflexively about assumptions has been specifically encouraged as doing so may support the hermeneutic process (Murray & Holmes, 2014; Shaw, 2010; Smith et al., 2021).

To consider my impact on the research I conducted, I engaged with reflexivity at various stages during the development of the thesis. Firstly, the explicit outlining of my 'world view' has been substantially addressed in section 2.2. Below, in section 2.6.2, I incorporated a personal statement that outlined salient aspects of my background. Additionally, throughout the IPA and thematic analysis studies, I kept a reflexive journal. Some of the reflections I believe are especially important to the

NI and telemedicine studies can be found in the methods sections of these chapters (see sections 5.2.3 and 6.2.3, respectively). Finally, I carried out further reflection in the discussion chapter (section 7.5).

2.6.2 Reflexive statement

In my undergraduate and postgraduate degrees, I received formal training in only quantitative research methods. My experience in healthcare came from working for a committee member of a hospital consortium in Germany on a project that looked to understand the causes of the incongruence between knowledge about post-operative delirium and its actual handling across the decentralised healthcare system. Although the research was somewhat curtailed by the pandemic, which became the primary focus of the hospitals, nursing homes, and insurance companies with which we engaged, the project nonetheless piqued my interest in the psychological, cultural, political and economic factors that underpinned the structure and functioning of healthcare systems. Because of this experience, I choose to pursue a PhD in Health Research, which I knew would, most likely, feature strongly qualitative research. I saw this an opportunity to expand my skill set and open my mind to new ways of thinking about the world and research. Nonetheless, I knew that my lack of foundational knowledge about qualitative research would be a challenging experience that would require additional effort to achieve the aims of the research.

Additionally, given my educational background, it is perhaps unsurprising that, as my education progressed, I became aware of a previously unacknowledged bias towards positivist and biomedical thinking. That is, I realised I construed research hypotheses in quantitative terms and understood health conditions such as Parkinson's as primarily physical. To challenge these assumptions and understand how they impacted my research, I engaged with thinking about research philosophy and dominant forces in western medicine. Congruently, transparency with regards to the adoption of a critical realist research paradigm and the adoption of a biopsychosocial theoretical lens were provided in sections 2.2.3 and 2.3.1 respectively.

2.7 Ethical considerations

Throughout the thesis, ethical considerations were an important part of the research. For each study (chapters four, five, and six), ethical approval was received from Lancaster University's Faculty of Health and Medicine Research Ethics Committee. These applications broadly aligned with the American Psychological Association's (2017; APA) ethical guidance. This was preferred to the British Psychological Society's (2021) guidance for consistency as the thesis adheres to American Psychological Association (2020) reporting guidelines and because of the greater depth of guidance. Full details of the ethical considerations and how these were embedded in the research process can be found in the ethics applications of each study (see sections 4.2, 5.2.2 and 6.2.2). However, some important considerations, as outlined by the American Psychological Association (2017), will now be discussed in relation to the research reported in this thesis.

For the studies that collected primary data, informed consent (i.e., the voluntary confirmation of willingness to participate in research after being informed and considering all aspects of the study; Nijhawan et al., 2013) was achieved by providing participants with an information sheet. This document outlined, for example, the aims of the study, what taking part would involve, and how data would be used and stored. In consideration of the potential (though not anticipated) distress that taking part could cause, participants were reassured they could withdraw at any point of the study and up to two weeks after. Additionally, contact details for support services were provided. To protect participants' privacy and confidentiality (Cacciattolo, 2015), verbal consent was received and stored in Lancaster University's OneDrive and, as per Lancaster University guidance, general data protection regulations (Lancaster University, n.d.) was adhered to. Moreover, transcripts were anonymised, and identifiable information was removed following American Psychological Association (2020) recommendations. A plan was made for the data retention of ethical approval and (anonymised) written transcripts whereby they would be stored on Lancaster University's PURE system for 10 years with JS as data custodian. Beyond these general ethical considerations, the specific needs of pwP were also considered. In

acknowledgement of the difficulties associated with living with Parkinson's, participants in the interview studies were informed that the interview could be stopped at any time and arrangements made to continue at a later date. Finally, in study three, which analysed secondary data, ethical considerations specific to secondary data analysis were considered (Tripathy, 2013). Of note, the analysed database was anonymised prior to its receipt by this researcher.

2.8 Chapter Summary

This chapter justified the rationale for adopting a mixed methods approach to achieving the research aims, which was situated within the adoption of a critical realist research paradigm. The role of theory in the thesis was outlined and the rationale and implications for adopting the biopsychosocial model as a theoretical lens were noted. The synopsis of studies then noted methodological considerations for each study and outlined how these decisions were consistent with a critical realist paradigm (where relevant). Next, theories of mixed methods integration were applied to explain the progression of research in the present thesis and the consideration of quality and ethics were outlined. Finally, consistent with a critical realist approach, engagement with positionality and reflexivity was noted.

Chapter 3: A Systematic Review of the Factors Associated with the Psychological Wellbeing of People with Parkinson's in the COVID-19 Pandemic

This chapter draws on material published in:

Gotheridge, H., Eccles, F. J. R., Murray, C., Henderson, R., & Simpson, J. (2025). A systematic review of the factors associated with the psychological wellbeing of people with Parkinson's in the COVID-19 pandemic. *Disability and Rehabilitation*, *47*(9), 2234-2245. https://doi.org/10.1080/09638288.2024.2395460

3.1 Introduction

In line with the primary aim of the thesis, to understand the experience of living with Parkinson's during and in the aftermath of the pandemic, it was useful to understand previous research that investigated the psychological wellbeing (see section 1.4.1) during the COVID-19 pandemic. Because of the established corpus of literature that investigated *quantitative* risk factors (see section 2.4.1), a systematic review could provide a nuanced understanding of existing knowledge and identify research gaps through the consideration of inconsistent findings and the heterogeneity of study design (Gagnier et al., 2012; Higgins et al., 2002). As such, this study sought to review the risk factors of poor psychological wellbeing outcomes during the COVID-19 pandemic.

With regards to the focus on psychological wellbeing, the generally negative impact of the COVID-19 pandemic was a particular concern. This was, in part, because the difficulty of living with Parkinson's during the pandemic (e.g., Simpson et al., 2022b) was compounded by the documented, pre-existing vulnerability to poor anxiety and depression (Broen et al., 2016; Lieberman, 2006). Indeed, 'mental health' in Parkinson's pandemic research was identified as a key theme in literature (Brooks et al., 2021), and a systematic review of 28 studies worldwide concluded an overall reduction in the quality of life of pwP compared to people living with other neurological conditions and control groups (Mai et al., 2022).

Identifying risk factors of poor psychological wellbeing is pertinent to understanding the difficulties of supporting pwP in the aftermath of the pandemic given the suggested long-term consequences of the pandemic on psychological (and physical) wellbeing (Rafizadeh et al., 2025). For example, a qualitative analysis of accounts of living with Parkinson's in the UK during the pandemic noted that participants reported the need to rebuild their (physical and psychological) health after lockdown ended (Murray et al., 2024). Addressing the extension of such difficulties beyond the pandemic should be a key aim of post-COVID health and social care services. The direction of such support could be facilitated by the identification of the subgroups that experienced worsened psychological

wellbeing during the pandemic. Additionally, although not the specific aim of the present thesis, such insight could advance understanding of circumstances with comparable characteristics (e.g., yearly flu outbreaks, economic uncertainty) as well as inform public health strategies in future pandemics (Gouglas et al., 2023). As such, the investigation of risk factors could yield useful academic, policy-oriented and clinical insights.

Notably, previous research has been conducted that, broadly speaking, reviewed literature pertaining to the wellbeing of pwP during the pandemic. However, unlike Mai et al. (2022), which identified a small number of risk factors of physical and mental wellbeing during the pandemic (e.g., biological sex, socioeconomic status), no limitation with regard to the type of risk factors included in the review was imposed. This approach was chosen given the novel research context where significant risk factors may diverge from those identified in a pre-pandemic context and where previously unresearched pandemic-specific factors may be influential.

Additionally, the review also focused on psychological wellbeing and therefore has a narrower focus compared to Mai et al. (2022), which concentrated on physical and psychological wellbeing. The theoretical foundation of psychological wellbeing lies in eudaimonia[5] (living well and actualising one's human potential; Deci & Ryan, 2008). However, variance in modern theories of different 'types' of wellbeing (e.g., subjective, psychological, social) and their overlapping conceptual boundaries causes a high level of variability in conceptualisations and thus, operationalisations (Carter & Anderson, 2020; Jarden & Roache, 2023; Zhang et al., 2024). For the purpose of the review, psychological wellbeing was broadly defined as "feeling good and functioning effectively" (Huppert, 2009: p137), with a focus on both what promotes a state of wellbeing and what hinders it. The boundaries of its operationalisation are outlined in section 3.2.3.

To review quantitative literature (see section 2.4.1 for a discussion of the exclusion of qualitative literature) that investigated the factors associated with the

[5] The other major historical tradition of though regarding wellbeing is hedonia - the pursuit of pleasure and avoidance of pain.

psychological wellbeing of pwP in the pandemic, a narrative synthesis was employed following the guidelines provided by Popay et al. (2006). This approach to synthesis was selected because the narrative synthesis enabled the inclusion of diverse research designs and thus the inclusion of the most amount of data from the relatively small corpus of literature. Additionally, the synthesis method was suitable given the breadth of outcome variables that constitute 'psychological wellbeing' (see section 3.2.3).

3.2 Materials and methods

The review was registered on PROSPERO on the 30th of January 2023 (CRD42023391029).

3.2.1 Research question

The review question was: what are the factors associated with the psychological wellbeing of pwP during the COVID-19 pandemic?

3.2.2 Description of systematic search process

The PCC framework (population, concept, context; Pollock et al., 2023) was used to identify the main concepts for the review which were: Parkinson's, psychological wellbeing, and the COVID-19 pandemic. Given the considerable variability in the operationalisation of 'psychological wellbeing', the search focused only on Parkinson's and the COVID-19 pandemic. After completion of this process, retrieved papers that investigated psychological wellbeing were then manually selected. This was judged to be viable owing to the relatively small corpus of literature relating to Parkinson's and the COVID-19 pandemic.

Following consultation with an academic librarian, the PsycINFO, MEDLINE, Embase, CINAHL and Web of Science databases were selected to identify literature, and the final search took place in April 2024[6]. The search terms "COVID-19" OR covid* OR coronavirus OR "sars-cov-2" AND parkinson* were used in every

[6] A previous literature search was conducted, but to enable the inclusion of the more recent literature, this was updated when the research was submitted for publication.

database. Key terms were also identified and incorporated in databases that allowed this functionality (see Appendix A).

Figure 3 is a PRISMA flowchart (Page et al., 2021) of the screening process. The articles identified were uploaded to Endnote (*N* = 7745) and duplicates were removed (*n* = 1675). Articles were then excluded by title (*n* = 5700), abstract (n = 265) or after reading the full text (*n* = 82) according to the inclusion and exclusion criteria listed below. Finally, reference lists of the articles included after all rounds of the exclusion process (*n* = 23) were searched to identify further relevant articles (*n* = 0). The systematic search process was carried out and decisions that required additional input were discussed with supervisors until a consensus was reached. For ease of referencing, the studies were allotted a number (see Table 1) and are referred to by that number.

3.2.3 The operationalisation of psychological wellbeing

In the review, both positive (e.g., general wellbeing and quality of life measures) and negative (e.g., depression, anxiety, stress) measures of psychological wellbeing were identified. To prevent conceptual confound (i.e., overlap between constructs), pragmatic considerations were made regarding the inclusion (or exclusion) of variables that constituted psychological wellbeing. Congruently, while psychotic difficulties such as hallucinations and delusions were included, cognitive difficulties such as forgetfulness were not.

3.2.4 Inclusion and exclusion criteria

To ensure the included studies met the scope and aims of the review, the following inclusion and exclusion criteria were set.

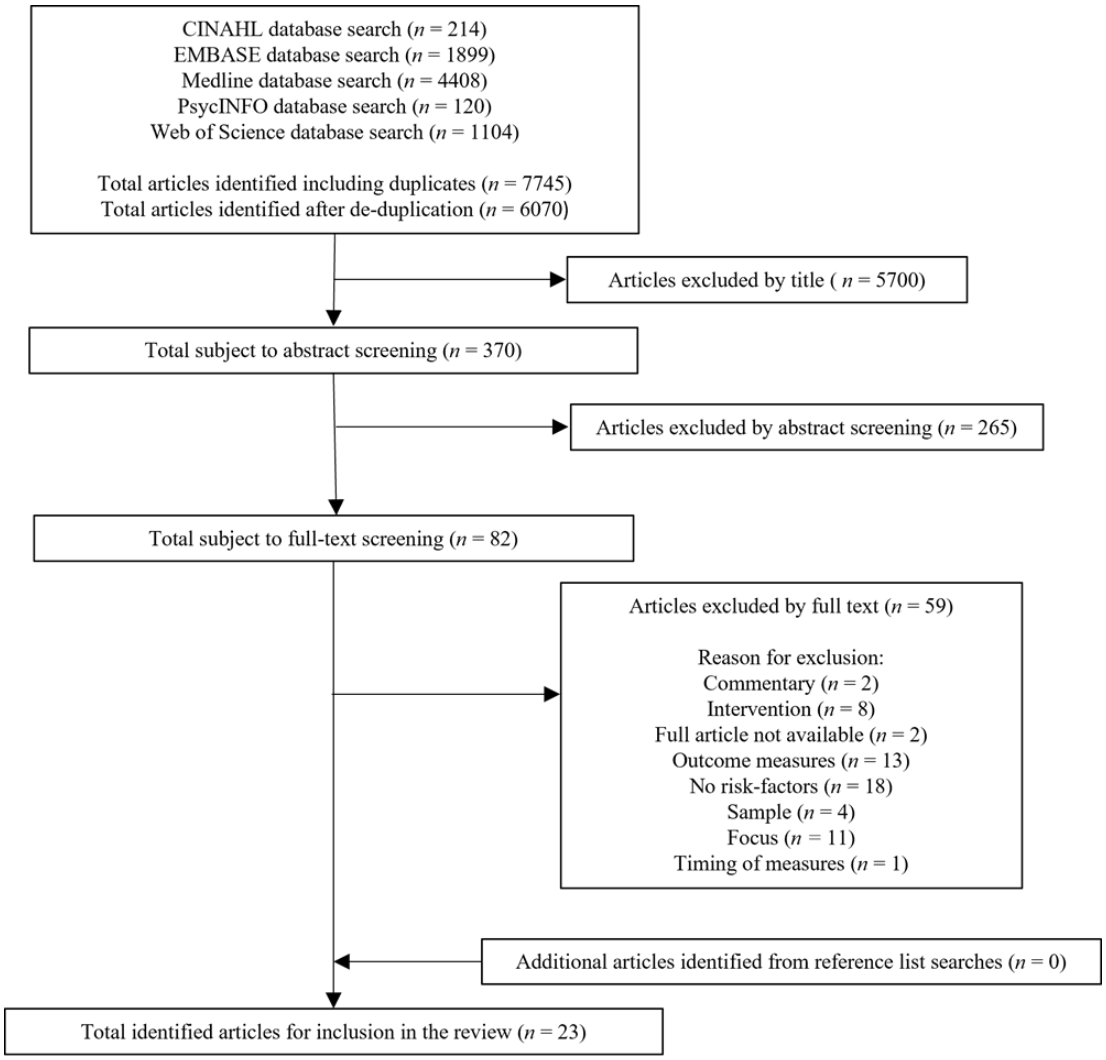
3.2.4.1 Inclusion criteria

- Studies that collected at least one data set during the acute stage of the pandemic (when lockdown restrictions were intermittently imposed between January 2020 and December 2022) or after restrictions began to ease (e.g., studies investigating the impact of lockdown restrictions after their conclusion).

- Participants who were adults (18 or over) with a confirmed diagnosis of Parkinson's or where a diagnosis of Parkinson's could be reasonably assumed.
- Studies reporting quantitative measurements of positive or negative psychological wellbeing (as outlined in section 3.2.3).
- Studies reporting risk factors (predictors and/or correlations) of psychological wellbeing variables.
- Separate studies investigating the same participants if novel analyses are reported.

Figure 3

PRISMA flowchart



3.2.4.2 Exclusion criteria

- Studies where the collection of data during the acute stage of the pandemic or after restrictions began to ease cannot be reasonably assumed.
- Studies that included people with Parkinson's as part of a larger analysis (e.g., movement disorders or members of a household) but which did not analyse or report their data separately.
- Studies exclusively investigating the outcomes of participants who were diagnosed with COVID-19.
- Studies investigating psychological wellbeing with unvalidated scales or where reporting of the scales was insufficient to judge their validity.
- Studies investigating the impact of interventions (e.g., dance therapy, mobile phone applications to facilitate social activity).
- Qualitative studies, conference abstracts, or other reviews.

3.2.5 Appraisal of methodological quality

After consideration of alternatives, Kmet et al.'s (2004) quality appraisal tool, an established tool in health research (e.g., Lebel et al., 2020; van Munster et al., 2024; Vescovelli et al., 2018) was selected. In addition to enabling the appraisal of studies with different designs (cross-sectional, case-control, longitudinal), unlike other tools, the appraisal questions were applied homogenously enabling direct comparison. While this was also possible using the Mixed-Methods Appraisal Tool (MMAT; Hong et al., 2018), the greater breadth of consideration and depth of guidance in Kmet et al.'s (2004) tool was ultimately preferred. The tool comprised 11 questions applied to all study designs to consider factors such as the reporting of participant characteristics, the description and justification of analytical methods and the reporting of results. A score (ranging from zero to two) was attributed to each of the questions and combined to provide an overall score of methodological quality ranging from 0 to 22 (see Table 1). A sample of 20% (five studies) was appraised by a second researcher (RH/JS); discrepancies were minor, and final ratings were agreed upon by both researchers.

Table 1

Study Characteristics

No.	Study	Country	Participants	Design	Pandemic Context	Psychological Wellbeing Measures	Quality Rating
1	Banerjee et al. (2022) **not peer reviewed*	India	55 pwP (78% male)	Longitudinal	Baseline data taken from a routine check-up before the pandemic and a telephone follow-up interview taken May to June 2020	Non-motor symptoms Questionnaire (NMSQuest)	14
2	Blakemore et al. (2021)	New Zealand	134 pwP (mean age = 72)	Cross-sectional	Taken during alert levels 3 (slightly loosened but vulnerable people still advised to self-isolate where possible) and 4 (strict lockdown unless providing an essential service) from April 17th to May 14th, 2020)	Perceived Stress Scale (PSS-10).	19
3	De Micco et al. (2021)	Italy	94 pwP (mean age = 65.5, 66% male)	Cross-sectional	Taken after a mean of 40 days of lockdown	Impact of Event Scale - Revised (IES-R), Kessler Psychological Distress Scale (K-10)	19
4	Dommershuijsen et al. (2021)	Netherlands	844 pwP (mean age = 70.3, 62% male)	Cross-sectional	Taken between April 14th 2020 and February 25th 2021	Beck Depression Inventory (BDI), State-trait Anxiety Inventory (STAI),	21
5	El Otmani et al. (2021)	Morocco	50 (mean age = 60.4, 48% male)	Longitudinal	Taken before and after 6 weeks of lockdown	Hospital Anxiety and Depression Scale (HADS)	12

No.	Study	Country	Participants	Design	Pandemic Context	Psychological Wellbeing Measures	Quality Rating
6	Erro et al. (2022) **not peer reviewed*	Italy	50 pwP (mean age = 72.1, 68% male)	Cross-sectional	Taken after lockdown restrictions were lifted	A modified version of the Trauma Screening Questionnaire (TSQ), EuroQoL-5 dimensions (EQ-5D)	15
7	Falla et al. (2021)	Italy	14 pwP (mean age = 64.9, 50% male)	Cross-sectional	Taken during the last week of lockdown from April 24th to May 1st 2020	12-item Parkinson Anxiety Scale (OR-PAS), 30-item Geriatric Depression Scale (GDS), Apathy Evaluation Scale (AES)	18
8	Haas et al. (2022)	Brazil	156 pwP (mean age = 64, 50% male)	Cross-sectional	Taken during self-isolation	Mental health symptoms (feeling anxious, depressive, fear, and thoughts of death) on a 5-point Likert scale *Validation reported	20
9	Hero et al. (2022)	Croatia	87 pwP (mean age = 72.9, 41.4% male)	Cross sectional.	Taken between 15th November 2020 and 15th February 2021	Hamilton Anxiety Rating Scale (HAM-A), Hamilton Depression Rating Scale (HAM-D)	17

No.	Study	Country	Participants	Design	Pandemic Context	Psychological Wellbeing Measures	Quality Rating
10	Kinger et al. (2023)	US	111 pwP (mean age = 67.2, 45.05% male)	Longitudinal	Taken once before the pandemic (June 2017 to December 2018) and once during the pandemic (from March to June 2021).	Apathy Scale (AS), Beck Depression Inventory-II (BDI -II), Parkinson's Anxiety Scale (PAS)	19
11	Kitani-Morii et al. (2021)	Japan	39 pwP (mean age = 72.3, 65% male) and 32 controls	Cross-sectional	Taken between April 7th to May 22nd, 2020, during the state of emergency	9-item Patient Health Questionnaire (PHQ-9), Generalized Anxiety Disorder (GAD-7)	21
12	Knapik et al. (2021)	Poland	30 pwP (mean age = 69.7, 60% male)	Cross-sectional	Taken after 90 days of social distancing	Hospital Anxiety and Depression Scale (HADS)	15
13	Montanaro et al. (2020)	Italy	100 pwP (mean age = 62.4, 60% male) and 60 caregivers	Longitudinal	Taken once during lockdown and once after lockdown	Hospital Anxiety and Depression Scale (HADS)	17
14	Conradsson et al. (2024)	Sweden	63 pwP (mean age – 71, 59% male)	Longitudinal	Taken during the first wave of the pandemic (June to July 2020) and during the third wave of the pandemic (June to July 2021)	Hospital Anxiety and Depression Scale (HADS)	20

No.	Study	Country	Participants	Design	Pandemic Context	Psychological Wellbeing Measures	Quality Rating
15	Oppo et al. (2020) **not peer reviewed*	Italy	32 pwP and 32 caregivers	Cross-sectional	Taken at the end of lockdown	Questionnaire for Impulsive-Compulsive Disorders in Parkinson's Disease–Rating Scale (QUIP-RS), Hospital Anxiety and Depression Scale (HADS).	18
16	Rábano-Suárez et al. (2021)	Spain	114 pwP (mean age = 72, 57% male)	Longitudinal	Measures taken after four months of strict lockdown during the pandemic were compared to a control group of matched participants measured before the pandemic	Impulse control disorder screening	19
17	Salari et al. (2020) **not peer reviewed*	Iran	137 pwP (mean age = 55, 34.3% male), 95 caregivers, and 442 controls	Cross-sectional	Unknown	Beck Anxiety Inventory II–Persian	15
18	Shalash et al. (2020)	Egypt	38 pwP (mean age = 55.6, 76.3% male) and 20 controls	Cross-sectional	Taken during the pandemic	Depression, Anxiety, and Stress Scale-21 (DASS-21)	19
19	Simieli et al. (2022)	Brazil	97 pwP (mean age = 67, 52.6% male), 56 MS	Cross-sectional	May 21st to June 13th 2020	Hospital Anxiety and Depression Scale (HADS)	17

No.	Study	Country	Participants	Design	Pandemic Context	Psychological Wellbeing Measures	Quality Rating
20	Suzuki et al. (2021)	Japan	100 pwP (mean age = 72.2, 45% male) and 100 caregivers	Cross-sectional	Taken between June and December 2020	Short form (SF)-8	20
21	Van der Heide et al. (2020)	Netherlands	358 pwP (mean age = 52.8, 61.5% male)	Cross-sectional	Taken after several weeks of a request to stay at home	Perceived Stress Scale (PSS)	18
22	Van der Heide et al. (2024) *Used the same data as Van der Heide et al. (2020)	Netherlands	350 pwP (mean age = 62.7, 61.6% male)	Longitudinal	Taken at 11 timepoints over a six-month period (April to October 2020) during the pandemic	Beck Depression Inventory (BDI), State-Trait Anxiety Index (STAI)	21
23	Xia et al. (2020)	China	119 pwP (mean age = 68.2, 51% male) and 169 controls	Cross-sectional	Taken shortly after the conclusion of lockdown	Hospital Anxiety and Depression Scale (HADS)	20

3.3 Results

Four of the studies (1, 6, 15, 17) were submitted as letters and were, therefore, not necessarily subject to the same degree of peer review as the standard articles. However, they were still included given the relative scarcity of international data, although care was taken not to base overall conclusions solely on these studies. Moreover, these studies scored an average rating of 15.5, above the recommended inclusion threshold of the appraisal tool (see quality appraisal section, below).

3.3.1 Study characteristics

An overview of the studies including basic demographic data is provided in Table 1. Twenty-three research articles from 22 separate studies were identified which analysed data from a total of 2822 pwP. Studies were carried out across the world in 15 countries, specifically Italy (*n* = 5), Brazil (*n* = 2), the Netherlands (*n* = 2), Japan (*n* = 2), China (*n* = 1), Croatia (*n* = 1), Egypt (*n* = 1), India (*n* = 1), Iran (*n* = 1), Morocco (*n* = 1), New Zealand (*n* = 1), Poland (*n* = 1), Spain (*n* = 1), Sweden (*n* = 1) and the US (*n* = 1). The majority of the studies employed a cross-sectional design (*n* = 16) although longitudinal designs were also used (*n* = 7). Of the longitudinal studies, six (1, 5, 10, 13, 14, 22) collected within-participant data while one (16) matched participant characteristics between the data sets and all but study 21 (which collected data at 11 points in time during and prior to the pandemic) collected data at two points in time. Notably, the reported study design refers to the overall design of the included studies rather than the data extracted for inclusion in the present review, which sometimes differed. Reports of the severity of lockdown that the participants were experiencing in each study were inconsistent, but all extractable data are presented in Table 1.

3.3.2 Psychological wellbeing variables

The psychological wellbeing measures investigated in the studies were anxiety, depression, apathy, fear, impulse control disorders, psychological distress, loss of interest, stress, thoughts of death, trauma, the mood dimension of a quality of life (QoL) measure, the mental health summary of a health-related QoL measure, and the hyperarousal, avoidance, and intrusion subscales of a post-traumatic stress

disorder questionnaire. All studies, therefore, investigated negative aspects of psychological wellbeing, with no study assessing positive constructs such as happiness or flourishing. The majority of studies used pre-established and validated (sub-sections of) measures. Six studies used the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), three used the Beck Depression Inventory (Beck et al., 1996), two used the State-trait Anxiety Index (Spielberger et al., 1971), and two used the Perceived Stress Scale (Cohen et al., 1983). All other scales were used in a single study. Finally, one study measured the number of individuals diagnosed with impulse control disorders through clinical assessment (16) and one study designed a bespoke, validated questionnaire to investigate mental health symptoms (8).

3.3.3 Quality appraisal

Although no strict cut-off of the quality of the studies is provided by Kmet et al. (2004), the authors suggest a conservative threshold of 75% (a score of 16.5) and a liberal threshold of 55% (a score of 12.1). The studies had a mean rating of 18 out of 22 and a range of 12 to 21. Study 5 scored below the liberal threshold and studies 1, 6, 12, and 17 scored below the conservative threshold. All studies were included because the narrative synthesis method enabled the quality of the study to be considered in the present review without skewing results. A breakdown of the score for each item is provided in Appendix B.

3.3.4 Main findings

3.3.4.1 Illness-related risk factors

Seventeen articles investigated illness-related factors associated with psychological wellbeing. Disease duration (*n* = 10) was the most frequently investigated, followed by motor symptoms (*n* = 8), Hoehn and Yahr (H&Y) stage (*n* = 5), age of onset (*n* = 4), comorbidity (*n* = 2), treatment (*n* = 1), and Parkinson's type (*n* = 1). A summary table of the relationships between these risk factors and psychological wellbeing measures is presented in Appendix C.

Disease duration

Five (3, 9, 10, 11, 20) of the ten studies that investigated the relationship between disease duration and psychological wellbeing (1, 3, 7, 9, 10, 11, 15, 17, 18, 20) reported significant associations, all of which reported that longer disease duration was associated with worse psychological wellbeing. However, study 11 reported that this association was no longer significant when both disease duration and the motor complications component of a symptom assessment scale were entered in a multivariate regression model. Similarly, while disease duration was associated with psychological distress in a bivariate analysis, it was not significant when motor complications (as well as anxiety and QoL) were entered into a multivariate regression analysis (3). Disease duration was also associated with the mental component summary of a health-related QoL measure in the single study that investigated this association (20). Only two (9, 10) of eight studies that investigated anxiety reported a significant association.

Motor symptoms

Of the eight studies investigating the relationship between motor symptoms and psychological wellbeing (2, 3, 9, 11, 18, 19, 20, 21), all but three (15, 18, 21) reported worse psychological wellbeing for individuals experiencing more severe motor symptoms. Four (9, 11, 18, 19) studies investigated both anxiety and depression and reported significant correlations with the worsening of symptoms (9, 19), the motor experiences of daily living section of a symptom assessment scale (11) and a motor examination during 'off' time (when Levodopa treatment had worn off; 18). Study 11 additionally reported the association was significant in a multivariate regression analysis when controlling for age, gender, disease duration and H&Y stage. Notably, study 18 reported no correlation with anxiety and depression when Levodopa treatment was working (during 'on' time). As well as investigating overall motor symptom worsening, study 19 investigated individual symptoms and reported that while self-reports of overall motor symptom worsening as well as worsening of tremor, balance, and bradykinesia were correlated with both depression and anxiety, worsening of freezing and body sensation were not. Of the three studies which investigated stress, two studies (18

and 21) reported no correlation with cross-sectional measurements of motor symptoms. However, study 2 reported significantly greater stress in participants reporting retrospective worsening of symptoms during lockdown than those who did not. Finally, higher motor complications scores (indicating more complications) of a symptom assessment measure predicted greater scores on the intrusion, avoidance, and hyperarousal subscales of a post-traumatic stress disorder measure indicating worse psychological wellbeing (3).

Hoehn and Yahr stage

Five studies investigated the relationship between the H&Y stage (see description in section 1.2.4.3) and psychological wellbeing (1, 3, 5, 11,18), of which only one (18) reported a significant association. Although three studies reported no correlation between H&Y stage and both anxiety and depression (1, 5, 11) significant positive correlations were reported by study 18 when Levodopa medication (used to control motor symptoms) had worn off.

Age of onset

Of the four studies that investigated the relationship between age of onset and psychological wellbeing (3, 7, 16, 18), two reported significant associations (3, 16). Firstly, participants who developed impulse control disorders during lockdown had a significantly younger age of onset than those who did not (16). Additionally, younger age of onset was associated with greater scores on the avoidance subscale of a post-traumatic stress disorder measure. However, this relationship was no longer significant when all significant associations were entered into a multivariate regression analysis with only the motor complications section of a symptom assessment scale and anxiety remaining significant (3).

Comorbidity

Two studies reported a significant association between the number of other comorbid medical conditions and anxiety (9, 17), both of which indicated that the presence of more comorbid medical conditions was associated with greater anxiety. No association was reported with depression (9).

Treatment and medication

Study 13 investigated the relationship between types of Parkinson's treatments and both anxiety and depression. The treatment groups investigated were deep brain stimulation, levodopa/carbidopa intestinal gel infusion and standard medical treatment. While treatment group did not predict depression either during or after lockdown, significant associations were reported for anxiety. Specifically, participants in the deep brain stimulation group had significantly less anxiety than those in the levodopa-carbidopa intestinal gel and standard medical treatment groups during lockdown but no significant difference was reported between the levodopa-carbidopa intestinal gel and standard medical treatment group. After lockdown, the only significant difference in anxiety was reported between the deep brain stimulation and levodopa-carbidopa intestinal gel groups with lower anxiety reported by the former. Additionally, study 3 reported that levodopa equivalent daily dose was associated with the intrusion subscale of a post-traumatic stress disorder measure and psychological distress.

Parkinson's type

No significant difference in depression, anxiety or apathy was reported between participants with bradykinetic/rigid or tremor dominant Parkinson's (7).

3.3.4.2 Demographic risk factors

Fifteen articles investigated demographic risk factors of psychological wellbeing. Age (n = 12) was the most commonly investigated risk factor, followed by gender (n = 9), education (n = 4), and living arrangement (n = 2). A summary table of the relationships between these risk factors and psychological wellbeing is presented in appendix D.

Age

Of the 12 articles that investigated the relationship between age and psychological wellbeing (1, 3, 5, 7, 9, 10, 11, 15, 16, 18, 19, 21) only three reported significant findings (1, 5, 16). Firstly, the increase in the number of participants experiencing loss of interest in the pandemic (compared to a baseline taken before the pandemic) was significantly associated with age and worse psychological

wellbeing was experienced by younger individuals (1). Additionally, individuals who developed impulse control disorders during lockdown were significantly younger than those who did not (16). Finally, younger age was associated with higher scores on the avoidance subscale of a post-traumatic stress disorder measure (indicating greater avoidance), although this was no longer significant when all significant associations were entered into a multiple regression analysis with only the motor complications section of a symptom assessment scale and anxiety remaining significant (3). Notably, non-significant associations were reported between age and both anxiety and depression in a total of 19 analyses reported in 9 studies (1, 5, 7, 9, 10, 11, 15, 18, 19).

Gender

Nine articles investigated the relationship between gender and psychological wellbeing (1, 3, 5, 7, 9, 11, 20, 21, 23) of which three reported significantly worse psychological wellbeing for females (3, 20, 23). Five (1, 5, 7, 9, 11) of the six studies investigating the association with anxiety and depression reported non-significant associations. Of note, study 1 reported no association with the worsening of these variables compared to a baseline taken before the pandemic. However, study 23 investigated the anxiety and depression scores classified as moderate clinical diagnoses and reported that significantly more females than males experienced these moderate symptoms. Analysis of the mental component summary of a health-related QoL measure suggested that female gender (as well as disease duration, anxiety, depression, and stress) was a significant risk factor in a stepwise linear regression (20). Finally, study 3 reported that female gender was associated with higher scores (indicating worse psychological wellbeing) on the avoidance and intrusion subscales of a post-traumatic stress disorder measure and psychological distress. However, these relationships did not remain significant in a multivariate regression analysis investigating all the significant associations identified in the study, where motor complications, anxiety, and lockdown hours per day remained significant (3).

Education

Of the four studies that investigated education (7, 9, 10, 18), only one reported a significant finding (9). Study 9 reported a non-linear association between education (grouped into four ascending levels) and anxiety scores and those with secondary education reported the highest scores. This may explain the non-significant linear associations reported by studies 7, 10 and 18. Finally, education was consistently not associated with depression (7, 9, 18).

Living arrangement

Two studies investigated living arrangement as a risk factor (9, 12). Study 9 reported that participants who lived alone during the pandemic had significantly higher anxiety scores than those who lived with a partner or family member. This finding was not confirmed by study 12 which reported no difference; however, this study scored below the conservative quality threshold (predominantly due to a lack of concise reporting) and the conclusions of this study should be viewed with some caution. Neither study controlled for potentially confounding variables such as the severity of motor symptoms.

3.3.4.3 Pandemic-related risk factors

Ten articles investigated pandemic-related risk factors for poor psychological wellbeing. Lockdown-related stressors (*n* = 8) were the most commonly investigated risk factors followed by physical activity (*n* = 6). A summary table of the relationships between these risk factors and psychological wellbeing is presented in Appendix E.

Lockdown-related stressors

Eight studies investigated the relationship between lockdown-related stressors and psychological wellbeing (3, 4, 7, 10, 12, 17, 19, 21) of which six reported significant findings (3, 4, 7, 17, 21). Study 10 investigated the overall impact of the pandemic using a bespoke scale that assessed various aspects of the pandemic including family income/employment, medical healthcare access and access to extended social support. The study reported a positive correlation (i.e., greater pandemic impacts were associated with worse psychological wellbeing) between

the impact of the pandemic and both anxiety and depression. Study 4 reported that care stressors (problems accessing care, medication, and nursing) predicted more anxiety and depression. Supporting this, study 17 reported that concern about drug availability as well as being infected with COVID-19 were associated with greater anxiety. Study 4 also reported that social stressors (loss of social contacts, social events cancelled, tension or conflict at home) were associated with greater depression and anxiety. Again, this was supported by study 21 which found that more perceived social support was associated with less stress. Study 3 reported that the number of hours in lockdown per day was positively correlated with the intrusion subscale of a post-traumatic stress disorder measure and the time since the participant was last visited was positively correlated with psychological distress. Most notable of the non-significant findings, the number of days of lockdown, hours of lockdown per day, and having a caregiver present at home were not correlated with psychological distress (3). Finally, the use of technology to continue access to healthcare in the pandemic was associated with a significant improvement in depression and a borderline significant improvement in anxiety between a baseline taken before lockdown and a follow-up during lockdown (7).

Physical activity

Of the six studies investigating the relationship between physical activity and measures of psychological wellbeing (8, 12, 14, 15, 19, 21), four reported that increased activity was associated with better psychological wellbeing (1, 15, 19, 21). Four studies (8, 12, 15, 19) investigated both anxiety and depression with mixed findings. Study 19 reported a significant negative correlation between physical activity and both anxiety and depression (more physical activity was associated with lower anxiety) in a measure that encompassed exercise and activity built into day-to-day living. The association with anxiety (non-significant findings were reported when depression was investigated) is supported by study 15 which reported that participants practising 45 minutes of physical activity per day had significantly lower anxiety than those who did not when controlling for age, disease duration, levodopa dosage, motor symptoms, non-motor symptoms, QoL

and impulse control disorders. Study 12 conducted a regression analysis and reported that only physical fitness remained a significant risk factor for anxiety and depression when also factoring in physical activity, staying at home, and leaving home. However, the operationalisation of 'physical fitness' used in the study was similar to a measure of instrumental activities of daily living, potentially explaining this finding. Contrastingly, study 8 suggested a lack of association between physical activity and both depression and anxiety, although this measure was a single item question asking participants' subjective, qualitative perception of their physical activity levels on a scale from sedentary (1) to very active (4). Finally, study 8 reported that a lower physical activity level during the pandemic was associated with an increased probability of thoughts of death in a logistic regression analysis.

3.3.4.4 Psychological traits

A summary table of the relationships between psychological traits and psychological wellbeing is presented in Appendix F. Three studies investigated the relationship between psychological traits and psychological wellbeing (6, 21, 22). Participants with lower resilience (the maintenance of mental health during or after periods of adversity; Kalisch et al., 2017) scores had poorer anxiety, depression, and trauma than those with higher resilience scores (6). Similarly, study 22 reported that stressor-reactivity (a variable indicating how strongly an individual's mental health reacted to COVID-19 stressors) was associated with increased depression and anxiety during the pandemic (22). Study 21 also reported that trait resilience was associated with lower stress. Additionally, the study reported that optimism and positive appraisal style were negatively correlated with stress whereas neuroticism was positively associated with stress. Finally, behavioural coping style (e.g., problem focused coping, emotion focused coping) was not associated with stress.

3.4 Discussion

This review sought to investigate the factors associated with the psychological wellbeing of pwP during the COVID-19 pandemic and a total of 23 studies were included. After conducting a systematic review with narrative synthesis it was

found that illness-related, demographic, pandemic-specific variables and psychological traits have been investigated. Worsening of motor symptoms, poor motor-related daily living experiences, and motor symptoms when symptom-controlling medication has worn off, as well as less physical activity, emerged as the most consistent risk factors for worse psychological wellbeing. Psychosocial variables, such as more social support and higher resilience, were also suggested to be associated with better psychological wellbeing although the limited number of analyses restricts the conclusions that can be drawn.

One of the review's most striking findings was the high number of non-significant associations reported. This may be related to the novel and exploratory research context as well as the fact that the data extracted for the review were often tangential to the overall research aims of a given study; indeed, many studies were not informed by theory or to test a specific hypothesis. These opportunistic analyses may also account for varied reports regarding the significance of risk factors as analyses did not sufficiently control for potentially confounding variables. Indeed, this was highlighted as an area of weakness in the quality appraisal (see Appendix B). This includes both confounders that are traditionally controlled for in such analyses, such as motor symptom severity, as well as those unique to the pandemic context, such as the duration of home confinement, which was reportedly a significant risk factor for poorer psychological wellbeing in its own right (Kumar et al., 2020).

Additionally, lack of statistical power (Baguley, 2004) could explain some of the non-significant findings, particularly where relationships have been identified in pre-pandemic research (i.e., age and gender; Lutz et al., 2016; Wee et al., 2016). Only two studies (11, 12) reported *a priori* power calculations and only one of these (11) recruited the required number of participants. Most studies did not report the effect sizes of insignificant findings and insufficient reporting generally meant it was not possible to calculate effect sizes and undertake *post hoc* power calculations (e.g., 7, 9). Moreover, although study 11 reported no differences in anxiety or depression depending on age or gender, it must be noted that these analyses (comparisons of anxiety and depression between genders and age

groups in pwP) were not in the purview of the power calculation, which was calculated for a comparative study between pwP and a control group. Thus, lack of power may still explain these unexpected results.

An alternate explanation for the deviation from pre-pandemic reports of psychological wellbeing risk factors is that key stressors such as lack of access to medication or difficulty maintaining social support did not discriminate along demographic lines and the basic statistical analyses neither captured nor illuminated the complexity of such interactions. With regards to age, the investigation of non-linear relationships where the division of age groups is informed by hypotheses concerning the potentially differing impact of the pandemic across these groups may provide useful insights. For example, the experience of technology to maintain social contact may have been experienced differently by older and younger pwP. Finally, both age and age of onset appear to be associated with less commonly investigated measures of psychological wellbeing such as the development of impulse control disorders, loss of interest, and avoidance (1, 3, 16). Thus, developing hypotheses concerning these less used psychological wellbeing measures, but which may be more specific to pwP (Den Brok et al., 2015; Weintraub et al., 2015), may also advance understanding.

More generally, the relationship between risk factors and psychological wellbeing was likely impacted by variability in the severity and nature of lockdown regulations between and sometimes within (e.g., state-level regulations) countries. This is due to the varying impact of the different levels of severity of lockdown measures on the ability to engage in normal health management practices. An attempt was made to account for this in the current analysis using the Stringency Index of the COVID-19 Government Response Tracker developed by Oxford University (Mathieu et al., 2020) which attributed an overall score of the severity of lockdown restrictions to each country from the beginning of the pandemic to the end of 2022. However, included studies' insufficient reporting of the dates of data collection (meaning the severity could not be identified and compared between studies) as well as heterogeneity in the severity of lockdown conditions within

studies during data collection (meaning a singular lockdown severity could not be attributed) meant this was not feasible.

Despite the challenges faced by researchers designing and carrying out research during the pandemic both motor symptoms and physical activity emerged as the most consistent risk factors of worsened psychological wellbeing. These findings are consistent with pre-pandemic investigations of risk factors (Cusso et al., 2016; Sagna et al., 2014) and suggest their continued association with the psychological wellbeing of pwP in the context of the pandemic. Notably, significant associations were identified where symptom management may have become challenging (e.g., motor complications and symptoms when medication had worn off) rather than the overall progression and severity of the symptoms. This may relate to the uncertainty of managing such unpredictability during the pandemic (Mishel, 1990) or a lack of available support because of social distancing regulations (Mathieu et al., 2020; The Health Foundation, 2021) and the strain on healthcare services (Filip et al., 2022; British Medical Association, 2022). More generally, the identification of both motor symptoms and physical activity is unsurprising given that it is likely bidirectional as physical activity is thought to aid the maintenance of physical functioning (Xu et al., 2019) and the extent of motor symptoms naturally impacts the ability to engage in physical activity (Amara et al., 2019; Bryant et al., 2016). However, given the cross-sectional design of the majority of research, it is not possible to infer either causality or a uni-directional, potentially causal, relation. Additionally, variations in the conceptualisation of physical activity and overlap with physical limitations due to Parkinson's symptomology, as well as concerns with the validity of operationalisations (single item and subjective assessment), limit the conclusions that can be drawn with regard to this risk factor.

Given the significance of motor symptoms as a risk factor of psychological wellbeing, it was surprising that analyses investigating the H&Y scale as a risk factor were generally non-significant as the measure quantifies the progression of Parkinson's (albeit with limited variability due to the small number of stages). However, study 18, which reported that H&Y stage predicted psychological wellbeing when Levodopa medication has worn off, provides a useful insight.

Specifically, accounting for fluctuations in the experience of motor symptoms may be an important distinguishing factor when considering the relationship between motor symptoms and psychological wellbeing. Moreover, the nature of the motor symptoms also appears to be important with tremor, balance, and bradykinesia individually associated with both anxiety and depression (19). Overall, this suggests that it is the severity of motor symptoms (rather than the overall progression of the disease) that is associated with psychological wellbeing, and some motor symptoms represent a greater psychological burden than others.

Some studies investigated pandemic-related risk factors and psychological traits (3, 4, 6, 7, 8, 12, 15, 17, 19, 21), although these were minimal in comparison to the investigation of illness-related and demographic risk factors. Due to this limited investigation, no overarching themes emerged in the research. While some insight can be gained from specific findings, these must be viewed with appropriate caution. Most notably, care and social stressors such as difficulty accessing medication and lack of social support (3, 4, 17, 21) were associated with anxiety and depression. The use of technology to continue healthcare access was associated with reduced anxiety in the pandemic (7), although varying results were reported depending on the nature of the technology use and the association with psychological wellbeing was not always positive (Kumar et al., 2020). Although psychosocial variables were investigated (6, 21, 22), the general lack of investigation of such factors reflects the state of literature prior to the pandemic (Garlovsky et al., 2016). The findings of these studies suggest that these variables could indicate useful adaptive behaviours during challenging and uncertain times.

Finally, the majority of studies used a cross-sectional design and without the use of longitudinal data that incorporates baseline values, optimally pre-pandemic, of risk factors and/or psychological wellbeing measures, it is more challenging to infer the specific impact of the pandemic. While some studies attempted to overcome this by creating new questionnaires that investigated perceived worsening in psychological wellbeing as a result of the pandemic (Brown et al., 2020; de Rus Jacquet et al., 2021; Feeney et al., 2021; Helvaci Yilmaz et al., 2022; Hermanowicz et al., 2022; Krzysztoń et al., 2021; Kumar et al., 2020; Silva-Batista

et al., 2021; Zipprich et al., 2020), these were almost entirely excluded from the current review as tests assessing the questionnaires' reliability and validity were not conducted or reported.

3.4.1 Implications and recommendations

The findings suggest that motor symptoms and physical activity were particularly important in the psychological wellbeing of pwP during COVID, suggesting the maintenance of physical health should be a priority during times of difficulty. This could be supported by the provision of sufficient and accurate information regarding the nature and impact of the pandemic on healthcare access (which was associated with a psychological burden; 4, 7) and changes to daily living, to facilitate perceived control. Indeed, pre-pandemic research suggests the importance of the provision of information in facilitating perceived control and, ultimately, the successful adaptation to changing circumstances (Eccles et al., 2011). While the reported significance of resilience as a risk factor of psychological wellbeing was likely, in part, the result of conceptual confound, targeting psychological traits such as this to improve psychological wellbeing outcomes has been previously recommended (Liu et al., 2020). Although certainly not a replacement for ensuring adequate access to healthcare services and information, individual levels of resilience could form part of a holistic approach to ensure the best outcomes for pwP in future challenging and uncertain circumstances (Ovaska-Stafford et al., 2021). Finally, modifiable behaviours such as the use of technology may be a useful tool to counteract the impact of social isolation through facilitating social connectedness (Chen et al., 2021) as well as enabling continued access to healthcare both in the pandemic and more generally with regard to isolated persons.

The included studies revealed a lack of focus on some psychosocial factors, such as coping and perceived control, despite the reported significance of such factors in predicting wellbeing in similar pre-pandemic assessments of risk factors (Garlovsky et al., 2016). However, the studies that investigated such risk factors in the context of the pandemic (6, 21) reported significant findings. Additionally, although the review sought to identify risk factors of both negative and positive

psychological wellbeing, no single study investigated risk factors for positive indicators of psychological wellbeing (e.g., Barak & Achiron, 2009). Again, this reflects pre-pandemic research in the Parkinson's population and such investigations are carried out notably less than in other chronic conditions such as multiple sclerosis (Vescovelli et al., 2018). Further research on psychosocial factors and positive wellbeing measures through either the re-analysis of previously collected data or in new investigations of the lingering impact of the pandemic would strengthen the corpus of literature.

Moreover, the lack of applied theory in both the design and interpretation of the studies was notable. The application of theory would facilitate a more in-depth understanding of the findings in studies as well as aid in directing further research. Illness uncertainty (Mishel, 1990) is particularly relevant given the unprecedented nature of the pandemic and other theories, such as the self-regulation model of illness perceptions (Leventhal et al., 1992), coping theory (Lazarus & Folkman, 1984) and the health theory of coping (Stallman, 2020), could also be used to direct hypotheses. Indeed, broader research has begun to apply such theories to better understand the experience of pwP during this time (e.g., Murray et al., 2024; Simpson et al., 2022b). While the identification of risk factors is a necessary and useful starting point, the application of theory to understand why these risk factors were associated with psychological wellbeing is necessary to progress these academic findings to practical outputs and aid with prediction in similar contexts in the future.

Finally, with reference to the thesis aim, it can be inferred from the findings that individuals who experienced difficulty with motor symptoms may be particularly in need of support to rebuild both their physical and psychological health. Within the UK, efforts are being made to account for the backlog in care services that was exacerbated by the pandemic (British Medical Association, 2022). However, the addressing of mental health in Parkinson's healthcare is hampered by, for example, difficulty establishing successful MDT care and the dominance of biomedical conceptualisations of Parkinson's (see sections 1.2.4). This is despite the finding that psychological difficulties have been identified as consistent

predictors of QoL and health-related QoL in pwP (e.g., Soh et al., 2011). As such, improving psychological health support in the NHS should be a key aim for the improvement of healthcare services, both to better reflect the preferences of pwP and to improve the QoL of the Parkinson's population in the aftermath of the pandemic.

3.5 Conclusion

This review identified worsening of motor symptoms, poor motor-related daily living experiences, and motor symptoms when symptom controlling medication has worn off, as well as less physical activity, as the most consistent risk factors of poor psychological wellbeing. However, notable omissions were obvious in the investigation of predictors including psychosocial variables and predictors relevant to the pandemic context such as difficulty accessing healthcare or the use of telemedicine to facilitate continued care. Moreover, there was a notable omission of positive indicators of psychological wellbeing (e.g., general wellbeing measures). Finally, the predominant use of simple exploratory statistical analyses could be strengthened through the theory driven application of more complex statistical techniques. As previously detailed in section 2.5, these considerations informed the research conducted in the following chapters.

Chapter 4: Exploring social engagement and the wellbeing of people with Parkinson's during the COVID-19 pandemic - a hierarchical regression and moderation analysis

4.1 Introduction

Chapter three investigated the risk factors associated with the worsened psychological wellbeing of pwP during the COVID-19 pandemic. Consistent with pre-pandemic findings (Cusso et al., 2016; Sagna et al., 2014), the review of 23 international studies concluded that the experience of more and/or worsening of motor symptoms, poor motor-related daily living experiences and motor symptoms during 'off time' (when symptom suppressing medication has worn off; compared to 'on' time) were consistently associated with poor wellbeing outcomes. Additionally, the review highlighted two major aspects of the pandemic research that should be addressed to strengthen understanding in this area. Firstly, psychosocial predictors of wellbeing outcomes such as social support, perceived control, and coping style were not widely investigated in the context despite prior research suggesting their relevance (Garlovsky et al., 2016). Secondly, the majority of research employed simple statistical techniques (e.g., bivariate correlation) that limited the understanding of the interplay between variables. These methodological observations informed the development of the present study which, broadly speaking, sought to investigate the role of psychosocial variables in the psychological wellbeing outcomes of pwP during the COVID-19 pandemic using more sophisticated statistical models.

Though many pertinent psychosocial variables have been identified as predictors of wellbeing in pwP (Garlovsky et al., 2016), social interaction (broadly construed) is important given the role of family and friends in the maintenance of the physical and psychological health of pwP, as discussed in section 1.3.1.3. Indeed, social interaction has been consistently associated with more positive health and wellbeing outcomes in various populations including pwP, older adults and those with chronic illness (Barnes et al., 2022; Joyce et al., 2022; Leigh-Hunt et al., 2017; Ling et al., 2022; Subramanian et al., 2020). In chapter three, it was concluded that reduced access to social support (Kinger et al., 2023) and increased social stressors such as loss of social contacts or social events being cancelled (Dommershuijsen et al., 2021) were significantly associated with increased anxiety and depression during the pandemic. Moreover, higher perceived social support

was associated with lower stress (Van der Heide et al., 2020). However, the simple statistical tests employed in these studies (predominantly bivariate correlations) did not provide insight into the interactions between the different predictors of wellbeing outcomes, and, as such, limited the depth of insight that could be gained. Congruently, the present research will further investigate the prediction of wellbeing by social engagement, informed by the conclusions reported in chapter three regarding the limitations of existing pandemic research.

In research investigating social engagement a high degree of conceptual and methodological diversity is evident (Monteiro et al., 2024). To ground the research and interpretation of findings theoretically (i.e., to clarify the nature of social engagement and its pertinent dimensions and facilitate consistency with other academic research), the present study adopted Lydon et al.'s (2022) integrative framework. Broadly speaking, this framework posits that social engagement encompasses the constructs of social activity and social network which consist of structural and functional components. Structural components relate to, for example, format (e.g., in-person versus remote/virtual social activity) and size (i.e., the number of connections in a social network). Functional components consist of, for example, purpose (e.g., social activities that encourage belonging, enjoyment) and the quality of interactions (e.g., level of support, positive or negative interactions in a social network). This framework, developed through a review of literature investigating social engagement in older people, offers a comprehensive overview of the construct of social engagement and its components that aligns with the current field of research.

Notably, Lydon et al.'s (2022) social engagement framework suggests an overlap with social support (see section 1.3.1.3 for an overview of social support theory). In Lydon et al.'s (2022) framework, the authors posit that research investigating social support is relevant to understanding the 'quality' of interactions (a functional component of social networks). Building on this, Monteiro et al. (2024) argues that social support is a mechanism through which the association between social engagement and wellbeing can be understood. Indeed, consistent with the buffering effect of social support (see section 1.3.1.3), the buffering effect of social

engagement on the deterioration of wellbeing has also been evidenced in literature (Nimrod & Shira, 2016; Sharifian & Grühn, 2019). The overlap between social engagement and support highlights the relevance of applying social support theory to better understand the association between 'quality' social engagement and wellbeing. Congruently, both social engagement and social support theory will be referenced, where relevant.

As established by Eccles et al. (2023a; see section 2.4.2), social engagement independently predicted wellbeing in pwP during the pandemic when controlling for loneliness, worsening physical symptoms, age, gender, and disease duration. However, research investigating the impact of the pandemic suggests that social engagement with different groups of individuals (e.g., family, friends) was differentially impacted by social distancing and, as such, should be better understood as distinct constructs. During the pandemic, in-person engagement with family, particularly partners or spouses, was more likely to persist (compared to friends) because of cohabitation. Although pwP in the UK could have made support bubbles with friends (the merging of two households without the need to socially distance or quarantine; Department of Health and Social Care, 2021), accounts of the public's reasoning for making these (e.g., supporting family members with illness; Roberts, 2021; Hinde, 2020) suggests these bubbles were also more likely to involve family members. Consistently, Zipprich et al. (2020) found that 86.9% of participants reduced social contact with friends and distant relatives. As such, the social distancing measures during the pandemic likely reduced in-person contact with friends more than family.

However, rather than cancelling or postponing social engagement with friends, research suggests that pwP increased their usage of online forms of social contact (e.g., Feeney et al., 2021; Zipprich et al., 2020). This is important because modes of social contact (in-person versus online) have been suggested to have differential associations with wellbeing. Specifically, although online social contact has been reported to have a direct positive effect on wellbeing outcomes in older populations (Sen et al., 2022; Yu et al., 2016), its use as a *replacement* for in-person contact may lessen the positive impact. For example, a study of older

people during the pandemic reported that decreased in-person contact was associated with increased depression and loneliness, and that increased online social contact had no significant effect (Hawkley et al., 2021). This suggests that replacing in-person contact with online contact did not mitigate the loss (with regard to worsened wellbeing) of in-person contact. This finding could be understood through the work of Trepte et al. (2015), who applied social support theory to investigate how different 'types' of support were experienced online versus in-person. Of particular note, the study found that emotional and instrumental support were perceived more greatly in relation to in-person engagement compared to online. This is important because emotional support has been evidenced to be especially important in dealing with uncontrollable events (Uchino, 2009) such as the pandemic (Simpson et al., 2022b). This suggests that, particularly when considering the (emotional) support needed during the pandemic, the predominantly in-person contact with family may have been of greater 'quality' and, therefore, more beneficial to wellbeing than the predominantly online contact with friends.

Consequently, building on the work previously conducted on the same dataset by Eccles et al. (2023a; see section 2.4.2), the present study sought to investigate the impact on the wellbeing of pwP of social engagement with family and friends (as separate constructs) during the pandemic. The distinction between family and friends was important given the differential impact of social distancing measures on the ability to engage in-person with family and friends, which likely affected the 'quality' of interactions. In congruence with the importance of continued social contact on wellbeing, a hierarchical regression analysis (see section 2.4.2 for justification of this statistical design) was carried out to test the independent prediction of wellbeing by social engagement with family and friends (as separate constructs) when controlling for demographic and symptom-related variables. It was hypothesised that social engagement with family and friends would *independently* predict wellbeing when controlling all other variables. Then, the study investigated the moderating effect (see section 2.4.2 for a justification of this statistical design) of social engagement with family and friends on the association

between motor symptom worsening and poorer wellbeing. In line with the above research, which suggested social engagement can buffer against negative impacts on wellbeing, it was hypothesised that social engagement with family would moderate the relationship between motor symptom worsening and wellbeing. That is, the negative impact of motor symptom worsening on wellbeing would be less severe for participants with (continued) higher social engagement with family. Then, it was hypothesised that social engagement with friends would not moderate the relationship between motor symptom worsening and wellbeing during the pandemic. Specifically, it was predicted that the disruption to in-person social engagement with friends reduced the quality of social support, which limited the buffering capabilities of engagement with regards to the negative impact of motor symptom worsening on wellbeing.

4.2 Materials and Methods

The analysis was carried out on quantitative data (previously described in section 2.4.2) collected by Parkinson's UK between August and September 2021 as the UK reopened after a period of lockdown (Simpson et al., 2020; Simpson et al., 2022a). The survey, distributed online by Parkinson's UK to members of the charity, collected demographic data and investigated changes to medical care during the pandemic (e.g., appointment cancellations, experiences of hospital admissions and stays), motor symptoms, and physical activity. It also included validated scales of wellbeing (Warwick-Edinburgh Mental Wellbeing Scale; Tennant et al., 2007), loneliness (UCLA 3-item Loneliness Scale; Hughes et al., 2004) and social engagement (Lubben Social Network Scale; Lubben et al., 2006). The present study focused on the wellbeing and social engagement scales as well as the symptom data and demographics. Ethical approval to carry out secondary data was granted by the Lancaster University Faculty of Health and Medicine Research Ethics Committee (Ref: FHM-2023-3250-RECR-1; see Appendix G). An overview of ethical considerations is presented in section 2.7.

4.2.1 Design

The questionnaire consisted of cross-sectional data collected at a single time period. The data were analysed via hierarchical multiple regression to investigate whether social engagement with family and friends predicted wellbeing when controlling for illness-related variables and demographic factors. Finally, two moderation analyses were carried out to investigate the potential moderating effect of social engagement with family and friends (in two separate analyses) on the association between motor symptom worsening and wellbeing using model one (one independent predictor; see Figure 4 and Figure 5) of Hayes PROCESS macro (Hayes, 2022).

Figure 4

Moderation analysis with social engagement with family as the moderator

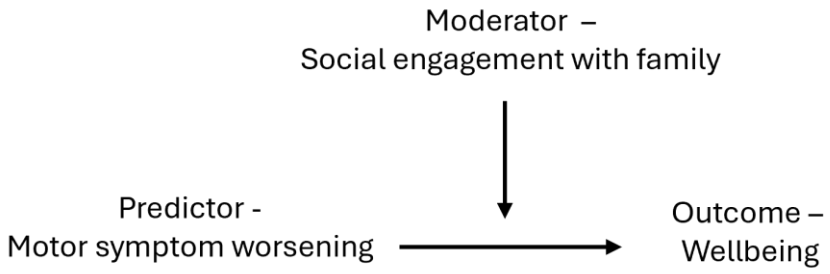
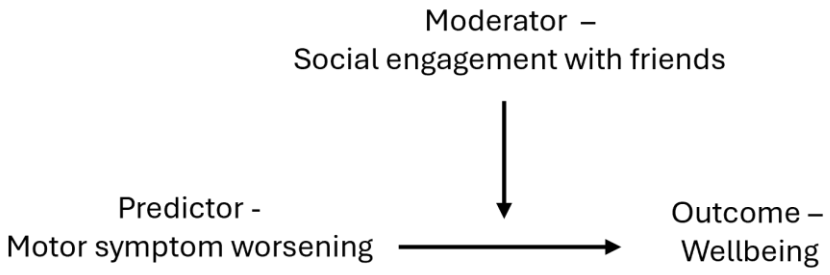


Figure 5

Moderation analysis with social engagement with friends as the moderator



4.2.2 Participants

Two power analyses (for the multiple regression and the moderation) were calculated using G*power (Faul et al., 2007). The first analysis indicated that, to conduct a multiple regression analysis, a minimum sample of 68 was required to detect the increase in the variance explained by two predictors in a model already

accounting for four predictors with a minimum statistical power of 0.8 assuming a medium effect size (0.15; Cohen, 1988; Field, 2017) using a probability value of 0.05. The second analysis indicated that, to conduct the moderation analysis, a minimum sample of 395 participants was required to achieve a minimum statistical power of 0.8 assuming a small effect size (0.02) and using a probability value of 0.05. However, the effect sizes of moderation analyses are typically smaller than those of regression analyses (Aguinis et al., 2005). Nonetheless, previous studies that investigated the moderating effect of social support, social engagement and social interaction (using the social engagement measure adopted in the present study; see section 4.2.3.2) reported significant findings with smaller sample sizes (as low as 287; e.g., Arslan, 2018; McKibbin et al., 2016; Uchida et al., 2022).

In the data collected by Parkinson's UK (see section 2.4.2), 622 people submitted a questionnaire online and indicated they had Parkinson's. Participants who did not explicitly state they resided in the UK (n = 14) were excluded to ensure a homogeneous sample with regard to the lockdown regulations which varied between countries (Mathieu et al., 2020). Additionally, 195 participants were excluded due to missing data on variables relevant to the hierarchical regression analysis (age, gender, disease duration, motor symptom worsening, social engagement with friends and family, wellbeing; see section 4.2.4). After these exclusions, 413 participants were included in the regression analysis. As the moderation analyses did not include the age, gender and disease duration variables, eight more participants had full data. As such, 421 participants were included in the moderation analyses. Therefore, the aforementioned power analyses and precedence in literature suggested that, after these exclusions, there were sufficient participants for the intended analyses.

4.2.3 Measures

4.2.3.1 Motor symptom worsening

Motor symptom worsening was measured by a composite of individual questions assessing the deterioration of symptoms during the pandemic on a scale of one to

five, with higher scores indicating greater symptom deterioration. The data investigated tremor, slowed movement, stiffness, freezing, muscle cramps, falls/dizziness, pain, eating problems, drinking problems, talking problems, sleep problems, fatigue, memory problems, hallucinations, dementia, anxiety, and depression. The selection of relevant motor symptom variables was carried out with the rationale of meaningful grouping (the combination of variables guided by the science of the field; Song et al., 2013) and was informed by the categorisation of Parkinson's symptoms outlined by Chaudhuri et al. (2006). As previously noted in section 1.2.1, pain, eating problems, drinking problems, talking problems, sleep problems, fatigue, memory problems, hallucinations, dementia, anxiety, and depression were not considered motor symptoms and were removed from the analysis. Thus, the composite motor symptom measure included the six symptoms of tremor, slowed movement, stiffness, falls/dizziness, freezing, and muscle cramp. The measure, therefore, consisted of a total motor symptom worsening score ranging from six to 30.

To assess further the coherence of the grouping, Pearson correlation coefficients[7] were calculated to test the correlations between the individual symptom variables. Following the guidance of Cohen (2013) medium correlations (interpreted as a correlation coefficient of roughly 0.30) were found between all variables except tremor, which was weakly correlated (interpreted as a correlation coefficient of roughly 0.10) with the other motor symptom variables. The coherence of including tremor in the composite motor symptom measure was therefore considered.

To decide whether or not to include tremor in the composite motor symptom worsening measure, a number of considerations were taken. Firstly, the internal consistency of the measure with and without tremor was investigated. Including tremor resulted in a Cronbach's alpha of .74 compared to a Cronbach's alpha of .77 when tremor was not included in the scale. This suggests that the inclusion of

[7] In acknowledgement of the debate regarding the correct classification of Likert scales (i.e., scale or ordinal; Carifio & Perla, 2007; Jamieson, 2004), the correlations were also tested using Spearman's rank correlation and the findings were not notably different.

tremor only marginally decreased the internal consistency, which, regardless, fell within the acceptable range of 0.70 (above which indicates internal consistency) and 0.90, defined by DeVellis & Thorpe (2021) and Streiner et al. (2024). Two Pearson correlation coefficients (as the data passed the assumptions for this test) were then calculated to assess the association with wellbeing when including ($r(413) = -.420$, $p < .001$) and excluding, ($r(413) = -.428$, $p < .001$) tremor and no notable difference in the strength of the relationship was found. Consequently, to prevent the unnecessary loss of information (Song et al., 2013) and align with the theory of symptom categorisation and precedence set in relevant academic literature (e.g., Chaudhuri et al., 2006), tremor was included in the composite measure.

4.2.3.2 The Lubben social network scale (LSNS-6)

Social engagement was operationalised using the Lubben Social Networks Scale-6 (LSNS-6; Lubben et al., 2006). The LSNS-6 is divided into two subscales consisting of the same three questions to investigate social engagement with family (LSNS-Family) and friends (LSNS-Friends). The items are self-reports of social engagement that investigate the number of social contacts i) that are seen/heard from at least once a month, ii) that they feel closeness with such that they could call them for help, and iii) that they feel at ease with such that they could talk about private matters. Each item is measured on a scale ranging from zero (none) to five (nine or more). Total subscale scores, therefore, range from zero to 15, with higher scores indicative of greater social engagement, and scores of less than six suggestive of social isolation.

In terms of theoretical underpinning, the scale investigates the quantity of social engagement which, as previously noted, is typical of such measures as the size of social networks is an important structural component of social networks (Lydon et al., 2022). With regards to the focus of the items, item one of the LSNS-6 investigates the quantity of social interactions within a given timeframe. The second and third items investigate the quantity of social contacts whom participants feel they could ask for support. As such, these items investigate the *quantity* of *quality* social engagement. More specifically, these items investigate

the quality of social engagement with regard to social support, which is argued to be a mechanism through which the association between social engagement and wellbeing occurs (Monteiro et al., 2024). With reference to social support theory (see section 1.3.1.3), consideration in item two of the number of individuals that 'could be asked for help' is indicative of instrumental (practical assistance) social support. Additionally, the consideration in item three of the number of individuals with whom participants 'could talk about private matters with' it indicative of emotional (empathy, love) social support.

The LSNS-6 is an abbreviated version of the 10-item Lubben Social Network Scale (LSNS; Lubben, 1988) that was designed to assess social isolation in older adult populations. The shortened version has since been validated and used internationally for such purposes and has repeatedly shown satisfactory psychometric properties including internal consistency, construct validity and model reliability (Buckley et al., 2022; Chan et al., 2023; Chang et al., 2018; Crooks et al., 2008; Gray et al., 2016; Hayashi et al., 2020; Lubben et al., 2006; Vilar-Compte et al., 2018). It has also been used in studies with people with neurodegenerative conditions such as Alzheimer's and Parkinson's (Balouch et al., 2019; Dyer et al., 2021; YuanRong et al., 2023). The Cronbach's alpha of the LSNS-6 in the original validation study was .83 (Lubben et al., 2006), and in the present study it was 0.85 which is within the acceptable range (DeVellis & Thorpe, 2021; Streiner et al., 2024). Additionally, the Cronbach's alpha of the family and friends subscales were .86 and .89, respectively.

For ease of reference, the overall measure (LSNS-6) will be referred to as the social engagement measure. The original validation study describes that higher scores indicate less social isolation. That is, social isolation is suggested by self-reports of engagement with a small number of individuals across the items aforementioned. However, referencing high/low 'social engagement' rather than high/low 'social isolation' is less open to misunderstanding and arguably more accurately reflects the content of the measure. Congruently, the LSNS-Family and LSNS-Friends subscales will be referred to as measuring social engagement with family and social engagement with friends, respectively.

4.2.3.3 Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)

The WEMWBS (Tennant et al., 2007) is a 14-item scale that measures subjective wellbeing. The measure was designed to assess a wide conception of wellbeing through the investigation of affective-emotional aspects, cognitive-evaluative dimensions and psychological functioning. As such, it focuses on the positive aspect of wellbeing rather than negative factors such as the presence of depression or anxiety. Each item is scored from one (none of the time) to five (all of the time). Thus, total scores range from 14 to 70, where higher scores indicate greater wellbeing and scores below 40 are indicative of probable clinical depression (Tennant et al., 2007). A Cronbach's alpha of 0.91 was reported in the original validation study (Tennant et al., 2007) and in the present study it was .95. Thus, both the present use of and the original validation of the measure indicate satisfactory reliability (DeVellis & Thorpe, 2021; Streiner et al., 2024). The WEMWBS has been used previously with pwP (Hadley et al., 2020; Pandya, 2024) and satisfactory psychometric properties have been reported in a variety of populations (Koushede et al., 2019; Perera et al., 2022; Taggart et al., 2013; Trousselard et al., 2016). A scoping review of the use of online wellbeing measures identified it as the most commonly used with regards to the measurement of subjective wellbeing (Ong et al., 2021).

4.2.3.4 Single-item variables

Age and disease duration (the length of time since being diagnosed with Parkinson's) were scale variables measured in years. Gender was coded as a binary variable, where 0 corresponded to male and 1 corresponded to female.

4.2.4 Missing data

The nature of the missing data was explored to inform the appropriateness of potential approaches to dealing with it. Little's MCAR (Little, 1988) was calculated, and the non-significant result suggested the missing data were missing completely at random. That is, the cause of the missingness was not related to the data, allowing flexibility with regard to how to deal with the missing data. The benefits and disadvantages of the different approaches (e.g., imputation, proration,

deletion) to missing data were considered. Despite potential downsides such as the reduction of variability in the data, the proration (i.e., the replacement of missing values with the mean of completed values in the scale) of missing scale items was deemed appropriate. This decision was taken, in part, because of the aforementioned high internal consistency of both the scale items and, thus, the cogency of replacing missing values based on the participants' responses to other items in the scale. Additionally, it offered a computationally efficient way of including as much data as possible. Finally, the proration of missing values was consistent with the guidance of the measure. Specifically, WEMWBS (wellbeing) guidance suggests that prorating more than three missing items (roughly 20%) would likely result in a measure that is no longer robust (Tennant et al., 2007). Given the lack of guidance provided for the social engagement measure, a similar rationale was employed to this as well as the bespoke motor symptom worsening measure. As such, one missing item for the motor symptom worsening measure and no missing items for the social engagement measures were allowed.

Using this 20% criterion, 41 participants were included who had missing wellbeing (n = 26) and motor symptom worsening (n = 15) items. To investigate the impact of prorating the missing items a sensitivity analysis was carried out by conducting the moderation and regression analyses with only participants who provided full data and comparing this to the results reported in section 4.3. No change in the pattern of results was found and it was concluded that prorating the missing data did not meaningfully impact the analysis.

With regards to the single item variables age (n = 3), gender (n = 0) and disease duration (n = 5), a total of eight participants had missing data. Given the data were missing completely at random and the amount was negligible, listwise deletion was used as it did not meaningfully reduce the sample size or introduce bias. This process of exclusion culminated in the sample sizes reported in section 4.2.2.

Finally, to test the potential systematic exclusion of participants as a result of missing data, the demographic data of included and excluded participants (for both the regression and moderation analyses) were compared. Of note, excluded participants had a significantly longer disease duration than those who were

included. This potentially relates to the degenerative nature of Parkinson's where cognitive difficulties and motor symptoms worsen with time (Sveinbjornsdottir, 2016; Weintraub et al., 2022). This deterioration may have impacted the ability to complete the questionnaire successfully. Although disease duration is not necessarily a proxy for symptom severity, people with a longer disease duration are more likely to have more advanced symptoms and consequently experience greater difficulty in completing the questionnaire. No other statistically significant differences between included and excluded participants were identified.

4.2.5 Data analysis

The data were first explored by tabulating demographics, calculating descriptive statistics and investigating the correlations between wellbeing and the other variables used in the regression and moderation analyses (motor symptom worsening, social engagement with friends, social engagement with family, disease duration, age and gender).

Then, correlation analyses were conducted to explore the relationship between wellbeing and all other variables investigated in the analysis (motor symptom worsening, social engagement with friends, social engagement with family, disease duration, age and gender). As the data met parametric assumptions, the associations between wellbeing with motor symptoms worsening, social engagement with family, social engagement with friends, and age were investigated using Pearson's correlation. Gender was investigated using the point biserial correlation as it can be conceived as a dichotomous variable.

The relevant assumptions of the regression model were assessed by investigating linearity, homoscedasticity, independent errors, normality of residuals, multicollinearity, and outliers (see Appendix H). Notably, two outliers were identified outside of the values expected in a normal distribution. However, further assessment using Cook's distance suggested they did not exert undue influence over the model (Cook, 1977) and no further action was thought necessary. The hierarchical regression analysis was carried out with three blocks of variables (demographic data, illness-related variables, and social engagement with family

and friends). Following the guidance of Cohen et al. (2013), the order of entry was decided based on temporally and logically determined priority. As demographic variables precede all other variables, these (age, gender) were entered first. Previous research suggests that illness-related variables (motor symptom worsening, disease duration) are consistently associated with wellbeing (chapter three; Ahn et al., 2022; Cusso et al., 2016; Sagna et al., 2014) so these were entered in the second step. The social engagement variables (social engagement with family and social engagement with friends) were those of novel interest and were, therefore, entered last. The variables within each of these three steps were entered into the model using the enter method.

The assumptions of the moderation analysis were also met (see Appendix H). The Hayes PROCESS macro (Hayes, 2022) was used to carry out two moderation analyses (using mean centred variables). Model one was used to analyse the moderating effect of one independent moderator on the relationship between a predictor and outcome. The moderating variable in the first analysis was social engagement with family and in the second analysis it was social engagement with friends. The predictor (motor symptom worsening) and outcome variable (wellbeing) were the same in both analyses. Significant results were probed using the Johnson-Neyman output which identifies statistically significant transition points. That is, it finds the values of the moderator (social engagement) at which the effect of the predictor (motor symptom worsening) on the outcome (wellbeing) is no longer significant. Finally, visualisation of any significant associations was made to facilitate understanding of the association.

4.3 Results

4.3.1 Demographics

Participants' demographic details can be seen in Table 2. The mean (*SD*) age of the 413 participants in the regression sample was 67.3 (8.9) years and 64.7 (8.94) for the 421 participants in the moderation sample. For both the regression and moderation analysis samples, the mean number of years participants had been living with Parkinson's was 7.1 (5.2), 53% of the sample was female, and the

respondents were generally white (80%), retired (76%) and living with a partner or spouse (80%) in England (82%).

4.3.2 Descriptive statistics

The means, standard deviations and ranges of the measures used in the regression and moderation analysis samples are reported in Table 3. WEMWBS guidance suggests that wellbeing scores of 40 or below are indicative of probable clinical depression (Tennant et al., 2007) and 39.5% of the regression analysis sample and 39.9% of the moderation analysis sample reported such scores. Similarly, social engagement scores of six or below are indicative of social isolation (Lubben et al., 2006). In the regression analysis sample, 29.5% of participants reported social isolation from family and 44.3% reported social isolation from friends during the pandemic. This is comparable to reports of social isolation in the moderation analysis sample, where 29.7% of participants reported social isolation from family and 43.9% reported social isolation from friends. Finally, as it is a bespoke measure, no guidance exists about threshold values for motor symptom worsening. However, values of 24 and over would be reported by participants who stated all (six) symptoms worsened 'quite a lot' during the pandemic and is therefore indicative of widespread symptom worsening. In the regression analysis sample, 7.7% of participants reported symptom worsening equal to or above this threshold, as did 7.8% of the moderation analysis sample.

4.3.3 Correlations with wellbeing

In the regression analysis sample, wellbeing during the pandemic was strongly negatively correlated with motor symptom worsening, $r\,(413) = -.414$, $p = <.001$, and strongly positively correlated with social engagement with family, $r(413) = .406$, $p = <.001$, and social engagement with friends, $r(413) = .494$, $p = <.001$ and moderately positively with disease duration $r\,(413) = -.239$, $p = <.001$. Additionally, wellbeing was weakly correlated with gender, $r_{pb}(413) = .099$, $p = .045$ and not significantly correlated with age $r\,(413) = -.088$, $p = <.001$. Thus, higher wellbeing scores during the pandemic were associated with less motor symptom worsening,

lower disease duration, higher social engagement with family and friends, and (weakly) with lower age and female gender.

Table 2

Demographic characteristics

	Regression analysis			Moderation analyses		
	M (SD)	Range	*N* (% of sample)	*M (SD)*	Range	*N* (% of sample)
Age (years)	67.38 (8.9)	37-90		67.47 (8.94)	37-90	
Disease duration (years)	7.12 (5.19)	1-31		7.13 (5.18)	1-31	
Gender						
Female			218 (52.8%)			223 (53%)
Male			195 (47.2%)			198 (47%)
Ethnicity						
White			330 (79.9%)			338 (80.3%)
Asian			1 (.2%)			1 (.2%)
Black			1 (.2%)			1 (.2%)
Mixed			1 (.2%)			1 (.2%)
Missing			80 (19.3%)			80 (19%)
Employment						
Key worker			31 (7.5%)			31 (7.4%)
Not a key worker			31 (7.5%)			31 (7.4%)
Unemployed			7 (1.7%)			7 (1.7%)
Retired			315 (76.3%)			323 (76.7%)
Missing			29 (7%)			29 (6.9%)
Living situation						
Partner			333 (80.6%)			339 (80.5%)
Friends/family			8 (1.9%)			8 (1.9%)
In a care home			3 (.7%)			3 (.7%)
On my own			68 (16.5%)			70 (16.6%)
Missing			1 (.2%)			1 (.2%)
Country living in						
England			341 (82.6%)			347 (82.4%)
Scotland			34 (8.2%)			34 (8.1%)
Wales			29 (7%)			30 (7.1%)
Northern Ireland			9 (2.2%)			10 (2.4%)

A similar pattern of findings was identified in the moderation analysis sample, where wellbeing during the pandemic was strongly negatively correlated with motor symptom worsening, r (421) = -.415, p = <.001, and strongly positively correlated with social engagement with family, r(421) = .403, p = <.001, and social engagement with friends, r(421) = .492, p = <.001, moderately negatively correlated with disease duration r(416) = -.239, p = <.001, and weakly correlated with (female) gender and age r(418) = -.097, p = <.001.

Table 3

Means and standard deviations of scale variables from regression and moderation samples

	Regression analysis		Moderation analysis	
Variable	*M (SD)*	Range	*M (SD)*	Range
Wellbeing	43.47 (10.61)	14-70	43.36 (10.58)	14-70
Motor symptom deterioration	16.86 (4.05)	7-28	16.91 (4.03)	7-28
Social engagement with family	7.99 (3.19)	0-15	8 (3.2)	0-15
Social engagement with friends	6.95 (3.76)	0-15	6.95 (3.76)	0-15

4.3.4 Regression analysis

The results of the hierarchical regression analysis to predict wellbeing during the pandemic from demographic, illness-related and social engagement variables are presented in Table 4. In the present sample, the first model (demographics) accounted for 1.6% of the variance in wellbeing and was not significant. The second model (demographics and illness-related variables) was significant and accounted for 20.1% of the variance in wellbeing. The additional step (adding illness-related variables) was significant and accounted for a further 18.6% of the variance in wellbeing. Finally, the third model (demographics, illness-related variables, social engagement) was significant and accounted for 40.3% of the variance in wellbeing. The step (adding in social engagement with both family and friends) was significant and accounted for an additional 20.1% of variance in wellbeing during the pandemic. In this final model, disease duration (b = -0.17, p = .039) and motor symptom worsening (b = -0.82, p < .001) were independent negative predictors of wellbeing and social support from family (b = 0.61, p < .001) and friends (b = 1.02, p < .001) were independent positive predictors of wellbeing.

4.3.5 Moderation analysis

Two moderation analyses were performed to investigate the potential moderation of the association between motor symptom deterioration and wellbeing during the pandemic by i) social engagement with family and ii) social engagement with friends (see Table 5). While social engagement with family did not significantly moderate the relationship between motor symptoms worsening and wellbeing (*p* =.682), social engagement with friends did (*p* .011).

A visualisation of the moderation analysis of social engagement with friends is presented in Figure 6. Contrary to the hypothesis, the findings suggest that the negative impact of motor symptoms on wellbeing during the pandemic was greater for participants with higher social engagement than those with lower social engagement. The visualisation additionally shows that across all levels of motor symptom worsening (low, medium, high), those with high social engagement from friends report better pandemic wellbeing than those with low social engagement. Finally, while participants with high social engagement reported wellbeing above the threshold indicative of depression for all levels of motor worsening, participants with medium social engagement and high motor symptom worsening as well as low social engagement and medium to high motor symptom worsening report wellbeing levels indicative of probable depression. Further investigation of the significant moderation by friends using the Johnson-Neyman output identified no statistically significant transition points. That is, there were no values of the moderator (social engagement) at which the effect of the predictor (motor symptom worsening) on the outcome (wellbeing) was no longer significant.

Table 4

Results of hierarchical regression analysis

						Variance explained (adjusted model)				
Model	Predictor	*b*	*b*(SE)	*B* (standardised)	*p*	R^2	Adjusted R^2	R^2 change	F change	*p*
1	(Constant)	48.727	4.099		<.001	.016	.011	.016	3.268	.039
	Age	-.093	.059	-.078	.115					
	Gender	1.902	1.047	.090	.070					
2	(Constant)	62.889	4.089		<.001	.201	.194	.186	47.433	<.001
	Age	-.021	.054	-.018	.696					
	Gender	1.609	.948	.076	.090					
	Disease duration	-.322	.094	-.158	<.001					
	Motor symptom worsening	-.982	.119	-.374	<.001					
3	(Constant)	49.018	3.765		<.001	.403	.394	.202	68.479	<.001
	Age	-.033	.047	-.028	.483					
	Gender	-.346	.839	-.016	.681					
	Disease duration	-.170	.082	-.083	.039					
	Motor symptom worsening	-.823	.105	-.314	<.001					
	Social engagement (family)	.611	.144	.184	<.001					
	Social engagement (friends)	1.016	.122	.360	<.001					

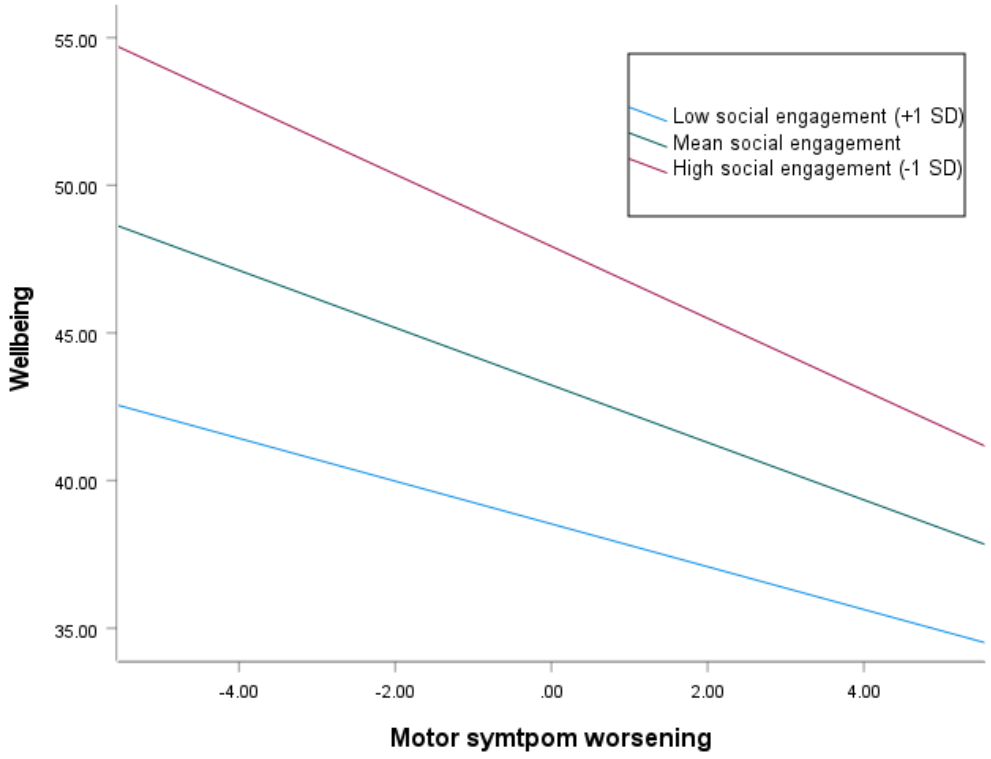
Table 5

Summary of the moderated regression analysis predicting wellbeing

	b[CI]	SE *b*	*t*	*p*
Moderator – Social engagement with family				
Constant	43.33 [42.46, 44.20]	.443	97.785	<.001
Motor symptom worsening (A)	-.94 [-1.15, -.72]	.110	-8.478	<.001
Social engagement (B)	1.14 [.86, 1.41]	.139	8.140	<.001
A*B	-0.02 [-.08, 0.48]	.032	-.485	.682
Moderator – Social engagement with friends				
Constant	42.43 [42.23, 44.04]	.411	105.10	<.001
Motor symptom worsening (A)	-.97 [-1.17, -.77]	.103	-9.417	<.001
Social engagement (B)	1.25 [1.03, 1.47]	.110	11.398	<.001
A*B	-.07 [-.12, -.02]	.025	-2.599	.011

Figure 6

Visualisation of the moderating effect of social engagement with friends



Note. X-axis is mean centred. SD = Standard deviation

4.4 Discussion

This study investigated the association between social engagement with family and friends and the wellbeing of pwP during the COVID-19 pandemic using cross-sectional, quantitative survey data. Firstly, as hypothesised, the multiple regression analysis found that social engagement with both family and friends independently predicted wellbeing when controlling for illness-related and demographic variables. The total model accounted for roughly 40% of the variance in wellbeing, of which around 19% was (significantly) explained by illness-related variables and 20% was uniquely explained by social engagement. Additionally, both social engagement with family and social engagement with friends were independent predictors of wellbeing in the final model. The credibility of this finding was strengthened by the positioning of the two social engagement variables in the final block of predictors, creating a more rigorous test of their predictive power than if they had been added earlier in the model. Secondly, two separate moderation analyses investigated whether social engagement with family and friends moderated the relationship between motor symptom deterioration (predictor) and wellbeing (outcome). However, the findings of both analyses were contrary to the hypotheses. With regard to family, it was predicted that the predominantly in-person contact would maintain the quality of social engagement, meaning social engagement would act as a buffer against the negative impact of motor symptom worsening on wellbeing. However, no significant moderation by social engagement with family was identified. With regard to friends, it was hypothesised that the increased adoption of online engagement would diminish the quality of social engagement, which would, therefore, not buffer against the impact of motor symptom worsening on wellbeing. However, the analysis found that social engagement with friends exacerbated the impact of symptom worsening on wellbeing. That is, the impact of motor symptom worsening on wellbeing was greater for participants with higher social engagement during the pandemic than those with lower social engagement.

The multiple regression analysis highlighted the importance of social engagement with both family and friends (as differentiated constructs) in the wellbeing of pwP

during the pandemic. As previously discussed in section 4.1, social engagement with friends during the pandemic likely took place predominantly online in response to lockdown restrictions. For example, Feeney et al. (2021) reporting that 90.9% of participants in the US replaced in person with online social activities (e.g., exercise classes, support groups, recreational classes). In a theoretical exploration of the mechanisms linking social engagement to (physical and psychological) health outcomes, the direct effect of social engagement on wellbeing was argued to relate to the facilitation of, for example, belonging, self-acceptance and sociability (Thoits, 2011). Although this likely (though not explicitly) pertained to in-person social engagement, the findings of the present study suggests that (predominantly) online engagement in social activities with friends during the pandemic maintained its direct effect on wellbeing despite the change in mode of contact.

With regard to the moderation analysis with friends, although greater social engagement with friends predicted (better) wellbeing outcomes for pwP during the pandemic, it also unexpectedly exacerbated the negative impact of motor symptom worsening on wellbeing. This is contrary to the hypothesis of the moderation analysis, which predicted that social engagement would have no association with the wellbeing of pwP due to the reduced quality (in terms of social support) of online social engagement that became more commonplace during the pandemic. This unexpected finding can be understood through the application of wider social support theory that demonstrates the importance of 'matching' the type (e.g., emotional, instrumental) of support to the contextual needs of the recipient (Uchino, 2009). As previously noted, when events are uncertain or uncontrollable, as was the case during the COVID-19 pandemic (Simpson et al., 2022b), emotional support is especially effective (Cutrona & Russell, 1990). However, during the pandemic, when social contact with friends often took place online, this change in medium likely reduced the perceived quality of emotional support (Trepte et al., 2015). This potential mismatch between the stressor context (the uncertainty of the pandemic) and the support received (reduced quality of emotional support) could negatively impact feelings of esteem and control as well

as health behaviours (e.g., engaging in physical activity), ultimately impacting wellbeing (Uchino, 2009). As those with higher social engagement were more likely to be negatively impacted by this mismatch, this could explain why a greater impact on wellbeing of motor symptom worsening was experienced by people with higher social engagement.

Finally, the finding that social engagement with family did not moderate the relationship between motor symptom worsening and wellbeing during the pandemic could be the result of variability in the quality and focus of support. In a study of the pandemic experiences of pwP in the UK, protecting against COVID-19 became a higher priority than managing Parkinson's symptoms, even when physical deterioration was evident (Murray et al., 2024). Congruently, literature suggests that pwP and their partners took steps to mitigate the risk of infection (e.g., avoiding public spaces, reducing social contact; El Otmani et al., 2021; Feeney et al., 2021; van der Heide et al., 2020). However, perceptions of the risk associated with contracting COVID varied (Brooks et al., 2021) and it is reasonable that the steps taken to mitigate the risk of infection also varied. That is, while some individuals (with lower risk perception) received support from partners that buffered against the impact of motor symptom worsening on wellbeing (e.g., facilitating outdoor activity), others (with higher risk perception) received support that exacerbated this association (e.g., remaining indoors with partners to protect against infection). Additionally, the level of strain experienced by family members during the pandemic varied, which may have differentially impacted their ability to provide meaningful emotional support. In one study, the partner or spouses that provided care to a partner with Parkinson's reported higher levels of anxiety than controls (Salari et al., 2020). Moreover, Oppo et al. (2020) reported that stress was higher for those providing care compared to those living with Parkinson's. However, in a systematic review of pandemic literature, Brooks et al. (2021) reported that this varied depending on the complexity of the needs of pwP. That is, family members of pwP with greater care needs experienced greater psychological difficulty than those with less complex support needs. Collectively, these findings highlight how variability in the quality and focus of social support provided by

family members during the pandemic could have diminished the buffering effect of support on the negative effect of motor symptom worsening on wellbeing. As such, the specific COVID context disrupted the effects of social engagement on wellbeing that would be expected outside such a devastating event.

4.4.1 Limitations

Some limitations should be considered alongside the results of this study. Firstly, the analysis was conducted on secondary data meaning there was no control over the operationalisation (i.e., the choice of measures) of the investigated constructs (social engagement, wellbeing). The use of secondary data additionally meant there was no control over the sampling technique. However, there were no obvious concerns about Parkinson's UK's online advertisement of the study to their members. Although validated scales were employed where possible (i.e., for wellbeing, social engagement), a non-validated measure was used to assess motor symptom worsening. However, the adoption of this measure facilitated an insight into the impact of *worsened* motor symptoms on wellbeing that would otherwise not have been possible to investigate without access to pre-pandemic symptom data. Finally, with regard to the cross-sectional design, the direction of the relationship between social engagement and wellbeing cannot be ascertained (i.e., it is possible that reduced social engagement is the product, rather than cause of low wellbeing). However, designs which would provide more robust evidence of the direction of this relationship were challenging to operationalise for all involved with COVID-related research.

The study also had some limitations to the generalisability of findings. This is because, the average age of participants (M = 67) was younger than the peak incidence (i.e., the rate of new diagnoses) of Parkinson's that occurs between the ages of 70 to 79 (Hirsch et al., 2016). Moreover, the analysis of the demographic data between the included and excluded participants suggested that participants who were excluded had a longer disease duration. This is possibly the result of the cognitive and physical decline associated with this neurodegenerative condition (Sveinbjornsdottir, 2016; Weintraub et al., 2022). Those with more deteriorated symptoms (older, longer disease duration) could have found it more difficult to

complete the questionnaire fully, thus resulting in the submission of incomplete questionnaires or making them less likely to have online access. This was partially mitigated by the inclusion of the explicit option for family members or carers to support pwP in filling out the questionnaire as well as the proration of missing values, which enabled the inclusion of as much data as possible. However, it is likely that individuals with greater symptom severity were not proportionately represented in the analysis. Finally, it should be noted that there was little diversity in the cultural background and ethnicity of the sample. Firstly, the sample were predominantly based in England, and less than 20% of participants were based in Scotland (*n* = 34), Wales (*n* = 29) and NI (*n* = 9). Secondly, there was insufficient representation of ethnicities beyond those self-describing as white. This limits the generalisability of the findings to non-white, non-English populations and highlights the lack of knowledge regarding the diverse experiences of the pandemic.

4.4.2 Future directions and implications

The association between social engagement and the wellbeing of pwP during the pandemic supports the relevance of taking a broad, biopsychosocial approach (compared to the dominant biomedical model of Parkinson's; see section 1.2), where addressing the psychological wellbeing of pwP through social engagement could improve health outcomes (e.g., Subramanian et al., 2021).

Healthcare practice and research commonly focuses on the benefits of support from close family members. However, social contacts should be considered as distinct constructs. While the distinction between family and friends is useful, greater predictive power could be achieved by additionally distinguishing between primary social ties (close family and friends) and secondary social ties (peers with lived experience; Thoits, 2011). Thoits (2011) posits that primary social ties (who do not have personal experience of the unique difficulties faced by pwP) and secondary ties (who have experience of these unique difficulties) provide distinct benefits. For example, secondary ties such as friends at peer support groups can provide validation, normalisation, and the sharing of coping strategies that family and friends without the disease could not. Congruently, future research could

benefit from further distinction between partners/spouses, broader family members, friends, and peers.

The direct effect of social engagement with friends on wellbeing suggests that facilitating social connectedness could, for example, increase physical activity and facilitate the development of coping skills (Collett et al., 2024; Gerritzen et al., 2022; Moya-Galé et al., 2025). As well as reducing the strain on healthcare services by improving physical and psychological wellbeing outcomes, interventions targeting peer support have also been suggested to reduce the difficulties experienced by family members (particularly partners and spouses; Collett et al., 2024).

Finally, future research investigating the importance of social engagement could more explicitly consider social support theory regarding the 'types' of support (i.e., emotional, informational, appraisal and instrumental/tangible; Thoits, 2011) to understand better the relationship between the quality of social networks and wellbeing. Another important consideration of the relationship between social engagement and wellbeing is the mode of social contact (e.g., in-person versus online; Monterio et al., 2024), and this should be more greatly explored given the increasing use of social media and technology in society (e.g., Freedman et al., 2022). Although in-person interaction has traditionally been assumed to be most beneficial, evidence regarding online contact remains mixed (Al-Kandari & Al-Sejari, 2021; Falla et al., 2021; Khosravi et al., 2016; Kumar et al., 2020; Sen et al., 2022). While some studies question its quality compared to face-to-face engagement (Monteiro et al., 2024; Freedman et al., 2022), qualitative findings suggest that digital technologies can be a "saving grace," enabling accessible and meaningful social connection for some pwP (Moya-Galé et al., 2025, p. 286). These contrasting findings highlight the need for systematic investigation into how the quality of online contact shapes wellbeing outcomes, particularly in populations with mobility challenges.

4.5 Conclusion

This study provided novel insight regarding the role of social engagement with family and friends (as separate constructs) in the wellbeing outcomes of pwP during the pandemic. Both constructs uniquely predicted wellbeing outcomes when controlling for symptom-related variables and demographics. However, while social engagement did not buffer against the negative impact of motor symptom worsening on wellbeing, engagement with friends exacerbated the (negative) impact. These findings were understood in relation to the unique impact of the pandemic context on the ability to manage symptoms and the differential nature of support between family and friends. The findings could be applied to enhance approaches to improving the effectiveness of a range of different forms of social support for individuals living with Parkinson's.

Chapter 5: Understanding the lived experience of Parkinson's-related healthcare in Northern Ireland before, during and after the COVID-19 pandemic: An interpretative phenomenological analysis

5.1 Introduction

In the psychological wellbeing study (chapter four), understanding the post-COVID needs of pwP across the UK was constrained by the minimal representation of pwP outside of England. This reflects a broader trend in literature where, especially with regards to qualitative research, studies entirely focused on pwP living in Britain (i.e., England or Wales; Murray et al., 2024; Simpson et al., 2022b; Soilemezi et al., 2023). To partially address this gap, this study sought to understand the in-depth experiences of pwP in NI during the COVID-19 pandemic.

Health and social care in NI, as with Scotland and Wales, is devolved from centralised control by the UK parliament (McGregor & O'Neill, 2014). Devolution supports decision-making pertaining to legislation and administration in accordance with local considerations (Ministry of Housing et al., 2019), which is apt given NI's specific socio-cultural history. This history relates to the religious divide closely associated with the political conflict between pro- (protestant) and anti- (catholic) unionists (the political ideology that favours a political union with Great Britain) that fuelled the political violence known as 'the troubles' between 1969 and 1994 (Beacháin, 2020). In addition to fuelling long-term inequalities based on religious identity (Aunger, 1975; Flaherty & McAuley, 2023), the conflict also shaped the prevalence of sectarianism at both cultural and structural levels (Hayward & McManus, 2021). Recently, this divide contributed to the Assembly (the elected body of ministers that govern the region) not sitting between 2022 and 2024, inhibiting the ability for political reform, the development of new policies, and decision making (e.g., the distribution of funding; McCormack, 2024; Sargeant & Rutter, 2019).

In addition to a unique socio-cultural context, research pertaining to NI has identified concerning gaps in the quality and provision of healthcare. In terms of primary care, an investigation of the quality of such services concluded various unmet needs of service users such as long waiting times and reduced access to care (Connolly et al., 2022). Similar shortfalls were reported in a recent review of neurological care in the region, which highlighted prominent deficits such as

insufficient capacity and staffing (Department of Health, n.d.). However, there remains a notable gap with regard to understanding the in-depth experiences of those using neurological services such as those accessed by pwP. Such understanding provides vital insight into the re-structuring of services in congruence with service users experiences and beliefs (Politis et al., 2010).

Understanding experiences of Parkinson's healthcare in NI is especially important in the context of the COVID-19 pandemic given the denuded healthcare reported worldwide during this time (Fabbri et al., 2021; Martini et al., 2020; Simpson et al., 2020). Difficulty accessing services was associated with negative impacts on physical health and psychological wellbeing (Brooks et al., 2021; Mameli et al., 2022; see chapter three). This finding was reflected in a UK sample where a survey of 1491 pwP identified worsening of motor symptoms, such as slowness of movement, stiffness and tremor, as well as high levels of anxiety and depression (Simpson et al., 2020). These findings have been supported by in-depth qualitative research that has been especially useful in gaining a rich insight into the impact of the pandemic on pwP. For example, Soilemezi et al.'s (2023) study investigating the impact of the pandemic on care management and interactions with healthcare services reported feelings of social isolation and vulnerability as a result of disruptions to daily living. Additionally, Murray et al. (2024) conducted a four timepoint longitudinal interpretative phenomenological analysis (IPA) that explored living with Parkinson's in the COVID-19 pandemic in England. The findings identified the impact of the pandemic on identity, agency and control, the acceleration of symptom worsening as well as the increased consideration given to COVID-19 rather than managing Parkinson's. However, the aforementioned sociopolitical differences limit the transferability of these findings to the NI health and social care context.

Consequently, the present study aimed to understand in-depth, lived experiences of Parkinson's-related healthcare in Northern Ireland before, during and after pandemic restrictions. The broad time period was incorporated to facilitate a more contextually driven insight into Parkinson's-related healthcare in the pandemic

through an understanding of how these informed participants' understanding of present and future healthcare experience.

5.2 Methods

5.2.1 Study design

The study sought to develop an understanding of experiences with Parkinson's-related healthcare in Northern Ireland from the vantage point of pwP. Employing a cross-sectional design, the study investigated participants' experiences with Parkinson's-related healthcare and how these were shaped by sense-making through time (i.e., through past experiences and consideration of future experience; Smith, 2024). Congruently, interpretative phenomenological analysis (IPA; Smith et al., 2021), a qualitative methodology, was used. The approach explores how participants experience and make sense of their world by analysing small, homogenous samples and acknowledging the role of the researcher in the interpretation of these experiences. This is also reflected in the phenomenological (understanding lived experience), idiographic (the detailed examination of individual accounts and identification of convergence and divergence in findings across a sample) and hermeneutic (meaning making) foundations of the approach (Smith et al., 2021). As such, semi-structured, one-to-one interviews are considered the most optimal means to collect data in IPA (Pietkiewicz & Smith, 2014), given the flexibility they provide to probe and clarify participants' accounts.

5.2.2 Ethical considerations

Ethical approval to carry out the study was granted by the Lancaster University Faculty of Health and Medicine Research Ethics Committee (FHM-2022-1043-RECR-3; see Appendix I). An overview of the ethical considerations that were addressed throughout this study is presented in section 2.7.

5.2.3 Quality and reflexivity

Quality and reflexivity, previously discussed in section 2.6, are important considerations when using IPA. With the aim of carrying out quality and rigorous research, qualitative and IPA-specific quality indicators were consulted and a

completed version of the Consolidated Criteria for Reporting Qualitative Research (Tong et al., 2007) can be found in Appendix J. Importantly, the completed guide suggests quality with regard to the (reporting of) considerations taken throughout the research and their description in the present chapter and broader thesis.

To support reflexivity throughout the research process, I kept a reflexive journal. In doing so, I realised that approaching a topic such as Parkinson's, for which I had no academic, personal or professional experience, I understood myself as an outsider with minimal understanding of what it means to live with Parkinson's. Particularly during the first interviews I conducted for the NI study (chapter five), I noticed that my concern about appearing uninformed made me tentative. Moreover, my (at the time) relatively superficial knowledge of Parkinson's healthcare made difficult navigating conversations about Parkinson's healthcare experiences. Reflecting on this, I quickly understood the importance of advancing my knowledge about living with Parkinson's (as well as technical aspects related to Parkinson's healthcare and treatment) to improve the quality of my interviewing with regards to both subject-specific knowledge and confidence. As the interviews progressed, I found the people I interviewed very open. These positive experiences increased my confidence with interviewing and building rapport with participants, which undoubtedly improved the quality of my interviewing skills.

Additionally, of the studies I conducted, my positionality as a young, British researcher was most salient while carrying out the NI study. This was because the study was conducted with a backdrop of political tension between NI and England. More than this, the sectarian divide, fuelled somewhat by this political tension, was directly referenced in the interview guide because of its potential relevance to the research topic. Despite my concern about discomfort of confrontation when discussing such topics, I had only positive experiences with the people I interviewed.

5.2.4 Recruitment

The idiographic focus and labour-intensive analysis of IPA favours the recruitment of small homogenous samples, typically in the region of 4-10 (Murray & Wilde,

2020; Smith et al., 2021). To be included in the study, participants were required to have experienced Parkinson's-related healthcare in Northern Ireland since at least 2018. This timeframe was chosen to ensure participants had experience of accessing healthcare before the pandemic restrictions were implemented in 2020 and could therefore reflect on their impact. Participants were primarily recruited through NI's branch of the Parkinson's UK charity. An advertisement (see Appendix K) was listed on their social media and gatekeepers (key individuals working for the charity) distributed information about the study at events associated with the charity. Interviews were conducted with nine participants. However, one participant was subsequently excluded because difficulties with speech and language meant it was not possible to collect data that supported an in-depth phenomenological interpretation, as is necessary when conducting IPA (Smith et al., 2021). This is important because coherence is needed between data and the method of analysis to ensure analytic validity and thus, methodological quality (Smith, 2011; Yardley, 2000). Therefore, the data of eight individuals were analysed.

5.2.5 Participants

Not including the excluded participant, participants' demographic characteristics are provided in Table 6. The mean age of participants was 60, with a range of 50 to 70. Participants had a mean disease duration and years receiving treatment of 11 years (with a range of 6 to 25). Participants were six males and two females, and self-described as white (*n* = 5) or Caucasian (*n* = 3). With regards to religious identity, Protestant (*n* = 3), Presbyterian (*n* = 2), Catholic (*n* = 2), and Christian (*n* = 1) identities were represented.

5.2.6 Data collection

The interview schedule (see Appendix L) was developed by i) mapping potential questions onto the aims of the research, ii) examining wording to ensure they were open-ended, and iii) framing questions to facilitate responses that concerned lived experience and meaning making, in accordance with the requirements of IPA. The schedule was then reviewed by an expert by experience (a person with Parkinson's

Table 6

Demographic characteristics

Pseudonym (ID)	Age	Gender	Self-described Ethnicity	Disease duration	Duration of treatment	Self-described religious identity
Grace	65	Female	White British	9 years	9 years	Protestant
Cillian	58	Male	White British	11 years	11 years	Presbyterian
Silas	62	Male	Caucasian	10 years	10 years	Catholic
Ronan	62	Male	White British	6 years	6 years	Protestant
Aiden	57	Male	White British	10 years	9 years	Presbyterian
Siobhan	70	Female	Caucasian	25 years	25 years	Catholic
Torin	50	Male	Caucasian	10 years	9 years	Christian
Cian	58	Male	White	8 years	8 years	Protestant

with experience accessing Parkinson's-related healthcare services in NI) who provided feedback on the relevance and wording of the interview questions, and adjustments were made in line with this feedback. The semi-structured interview included open-ended questions and additional prompts wherein the direction of the interview could develop in congruence with the responses of the participants (Karatsareas, 2022). Interviews took place between February and September 2023.

Prior to the interviews, participants were provided with an information sheet (see Appendix M) that detailed what taking part would involve, a summary of included questions, the rationale and goals of the study, how the data would be analysed, and adherence to ethical considerations. The consent process involved audio-recording the reading of a number of statements whereby, after each statement, the participant was asked to indicate their agreement or disagreement (see Appendix N). These statements ensured the participants fully understood the aforementioned information detailed in the information sheet. After all statements were completed, participants were asked to state their name and the date. Six interviews took place via video call and two took place over the phone. Interviews lasted from 37 to 75 minutes (M = 49) and were audio recorded. In congruence with the adopted critical realist research paradigm (see section 2.2.3), there was assumed a close connection between participants' use of language and their

thoughts and experiences (Murray & Wilde, 2020). This is consistent with the guidance of Smith et al. (2021) which suggest interviews should be transcribed verbatim (noting significant pauses in bracketed italics) to provide a semantic record of the words spoken by those present, thus facilitating interpretation of the meaning of the *content* of participants' accounts.

5.2.7 Data analysis

The interpretative element of the analysis was supported through the consideration of pre-existing assumptions while keeping a reflexive journal (see chapter two). Data were analysed following the guidance of Smith et al. (2021) and advice for producing a fully audited analysis by Murray and Wilde (2020). Additionally, as detailed in section 2.6, consideration was given to quality and rigour throughout the analysis.

Given the idiographic focus of IPA, each interview was analysed separately. The analysis of each interview began with repeated reading of the transcript to create familiarisation with both the participant and the data. Interpretive, linguistic and conceptual exploratory notations were then written down on the transcript next to data excerpts to examine semantic content and language use on an exploratory level and facilitate further familiarisation with the data (see Appendix O). These notations were grouped in an iterative process into discrete components (themes) of the participant's experience (personal experiential themes[8]) of the phenomena of interest. For each personal experiential theme, narrative summaries were written, as outlined by Murray and Wilde (2020; see Appendix P). These summaries sought to articulate the key dimensions and variation of the participant's experience in an interpretive manner. This additional step was carried out to facilitate a deeper interpretative engagement with the data as well as to aid the researcher when later merging themes across participants. The narrative summaries were then titled in an informative and explanatory manner to help the

[8] Personal experiential themes and group experiential themes were not abbreviated to PETs and GETs respectively, as often seen in the literature, to ensure accessibility for those without knowledge of updated IPA terminology guidelines.

researcher recall the key components of the participant's experience in future analysis. The process was repeated for each participant. Finally, through a process of iterative synthesis, the experiential themes of each participant were grouped together to form group experiential themes and narrative summaries were written (see appendix Q). This grouping attended to convergences and divergences in experiences and meaning making in relation to experiences of Parkinson's-related healthcare. The key dimensions and variations in these experiences were outlined and data excerpts were incorporated to evidence the analysis. As the analysis was a product of the writing up process (Smith et al., 2021), the themes were developed and refined until the final draft. In congruence with Smith et al. (2011), more than 50% of the sample size were represented in each theme (see Appendix R).

5.3 Results

Three group experiential themes relating to participants' experiences of Parkinson's-related healthcare in Northern Ireland before, during and after the COVID-19 pandemic were developed. These were (1) 'We're at the behest of healthcare': Shaping care expectations around perceived resource limitation; (2) 'If you don't ask you don't get': Protecting healthcare needs; and (3) 'Chuck a few pills at you, do some exercise, you'll be fine': The limited nature of Parkinson's-related healthcare.

Theme 1: 'We're at the behest of healthcare': Shaping care expectations around perceived resource limitation

This theme explores how participants meaning making of healthcare experiences in NI during the pandemic were shaped by the long-term resource strains on regional care services. Participants understanding that the resource limitations they experienced during the pandemic were systemic (and, as such, difficult to change) meant they reduced their expectations of support and reliance on these services.

Resource limitations were prominent in participants' accounts of Parkinson's-related healthcare as far back as the early 2000s. Experienced deficits

in care included long waiting times, difficulty contacting healthcare professionals, and difficulty accessing desired services. These long-term difficulties in accessing healthcare precluded the acute resource strain that was experienced during the pandemic:

> *Basically, I'm supposed to see my consultant every 6 months and recently that's extended, it's taken maybe 18 months between consultations just simply because of the pressures the NHS are under.*
>
> (Aiden)

Participants attributed various systemic causes to their experienced deficits in access to healthcare before, during and in the aftermath of the pandemic. On one hand, participants acknowledged the unique political climate in NI, wherein the elected body responsible for making decisions related to the reform of care services was not fulfilling its role:

> *I think the structure of government being devolved isn't necessarily helping at the moment in the sense that they're not actually doing their job. So, you know the ministers aren't actually in place and aren't able to make ministerial decisions, you know, regarding the funding of healthcare.*
>
> (Silas)

As Aiden expressed, *'[deficits in healthcare are] basically an NHS issue, but in Northern Ireland, it's very closely related to a devolved government issue'*. For Torin, the impact of politics was thought to extend beyond the borders of Northern Ireland, which was portrayed as an *'outlying region'* in the UK, where *'generally, things come to us last'*.

In addition to such political considerations, some participants also noted that long-term and acute (pandemic) resource limitations were, in part, a consequence of misunderstandings about Parkinson's resulted in the reduced allocation of resources to Parkinson's-related healthcare services compared to other conditions:

> *Well, because I've been involved for a few years with Parkinson's UK and lobbying, but I went to two, three meetings and that was the end of it. Nothing was ever done, no changes, although everybody bought into the fact that something that had to be done. But with the pressures the NHS is under, it's not life threatening so it's not top priority.*
>
> (Siobhan)

The systemic (i.e., unchangeable) nature of the perceived causes of resource limitations meant participants found it difficult to locate a concrete cause for their dissatisfaction:

> *…even going back to the consultant and he diagnosed me and said that 'I haven't got time to talk about this, talk to the Parkinson's nurse, don't blame me, blame the NHS' you know, so he said.*
>
> (Cillian)

Congruently, participants' experiential accounts of resource limitations during the pandemic suggested that the resultant deficits in care had to be accepted because '*at the end of the day nobody can make it any different, and that's, just something I've got to put up with'* (Grace). Indeed, Grace vividly described feeling at the *'behest'* of healthcare, suggesting feelings of powerlessness in her healthcare experience. However, this feeling was not shared by all participants. Most prominently, participants with less reliance on healthcare services during the pandemic because, for example, they had not yet experienced much deterioration or had relatively stable symptoms tended to have more positive interpretations of their healthcare experiences.

The perception that resource limitations in NI were an unchangeable aspect of care meant participants often reduced their expectations. This resulted in participants, before, during and in the aftermath of the pandemic, accessing private healthcare services or the accepting the absence of support that should normally be received. When talking about extended waiting times to access support from a neurologist, Grace noted:

> *… [the misdiagnosis of neurological conditions in Northern Ireland[9]] obviously impacted us because it meant that, you know, extra appointments had been made and so our [consultant neurologists] were under pressure to help… and you accept that and just wait*.
>
> (Grace)

Over the years of accessing Parkinson's-related healthcare, participants appeared to recalibrate their expectations of the system in line with beliefs about the extent of resources (i.e., what the system could offer) and their perceived personal needs in comparison to their perceptions of the needs of others (i.e., who needed the support more).

More than accepting a reduced level of care in light of experienced long-term resource deficits, Cian came to understand that healthcare should be accessed by service users '*if you feel like you can't go on or whatever'*. This perception of healthcare was extended to his thoughts on individuals who felt unhappy with the healthcare support they received:

> *I know some people that get to see their consultant every 9 months or so, and other people that say I haven't seen mine in a couple or 3 years or whatever it is. I would say 'well, have you had anything wrong with you?', and they say 'no', and I say 'well, what do you need to see them for?'*.
>
> (Cian)

Overall, the reduced or poor healthcare that was experienced during and in the aftermath of the pandemic reflected participants' experiences prior to the pandemic. The overarchingly systemic causes of resource limitation meant some participants felt at the behest of healthcare services. As a result, participants came to understand that healthcare in NI, in both pandemic and non-pandemic contexts, should be accessed and relinquished at appropriate times.

[9] A consultant neurologist was found to have misdiagnosed people resulting in widespread patient recall and, as such, increased strain on regional neurology services.

Theme 2 – 'If you don't ask you don't get': Protecting healthcare needs

Participants' understanding of their role in healthcare was an especially salient aspect of their healthcare experience before, during and in the aftermath of the COVID-19 pandemic. At times of pressure on the NHS, such as during the COVID-19 pandemic, the provision of services by the NHS did not match participants' perceived need. As such, participants increased their involvement in the management of their care to ensure their needs were met.

Resource limitations during the pandemic (i.e., reductions to the frequency of contact, inability/difficulty contacting consultant neurologists and the reliance on phone calls) meant participants often felt that HCPs were *'not as up to date with changes [in symptoms] as they should be'* (Aiden). For example, Cian was doubtful that the limited contact time with his neurologist was sufficient for the proper assessment of his needs:

> *I used to see my consultant maybe once a year, but I haven't seen him now for maybe a year and a half… you're seeing the consultant, you're seeing him maybe for 10 minutes. It's not an awful lot of time for him to see what's going on with you.*
>
> (Cian)

For Siobhan, this difficulty in accessing contact time with healthcare professionals during the pandemic caused her to feel like *'nobody [healthcare professionals] really knows how I'm progressing'* (Siobhan). For Grace, it left her questioning '*who would I turn to?'* and '*what would happen?'* if her symptoms deteriorated.

Because of the insufficient ability of the healthcare system to support participants' needs during the pandemic, rather than leaving their fate in the hands of the system, participants actively pursued support from healthcare services when they believed it was necessary:

> *The system is that I will eventually get another appointment but if I pushed it because things were going downhill for me then I could see him earlier, no doubt about that. But if you want that you have to push it yourself.*
>
> (Torin)

This self-directed approach was succinctly summarised by Cian as *'if you don't ask you don't get, whoever screams the most gets the most out of it'* (Cian).

However, participants' experiences directing healthcare suggested that, while some were comfortable carrying out a self-directed role, others felt this was beyond their perceived capabilities:

> *I'm not sure I understand, I understand how Parkinson's works. I'm not sure I chose the best I can…*
>
> (Siobhan)

Additionally, it was apparent that some participants were concerned about the morality of requesting 'extra' support from the resource strained healthcare service:

> *…you don't want to be pestering people, but at the same time, I think, I know my body. I know when I needed, or I felt I needed a talk over. And on both occasions, you know, my medication was changed so that said to me I'd done the right thing. And neither times did anybody say I shouldn't have done it.*
>
> (Grace)

In this excerpt, Grace seems uncertain of whether or not she did 'the right thing', which suggests her internalisation of the societal view of the negative connotations associated with accessing 'additional' healthcare. The conflict between this negative perception and believing the support was needed is apparent in Grace's search for reassurance that her request was deemed reasonable by healthcare professionals.

Participants highlighted a number of factors that contributed to the successful self-direction of healthcare. These included knowledge of treatment options, the ability to understand one's physical state, and mastery of the healthcare system. For participants who felt comfortable taking a direct approach, the pursuit of healthcare was the difference between getting their desired treatment or not:

> *I think that the people in Northern Ireland have access to the [deep brain stimulation] treatment in London like I did. Just, the other thing is funding… I think that if I was honest, the reason that I got DBS was I was persistent, I think.*
>
> (Silas)

Overall, participants took an increasingly active role in the management of their treatment during the pandemic. This was generally associated with the need to protect their health from the insufficient support of healthcare services that became especially strained because of the pandemic lockdown restrictions. Participants' preferences regarding the balance of responsibility in making healthcare decisions varied and some appeared more confident and able to fulfil this role.

Theme 3 – 'Chuck a few pills at you, do some exercise, you'll be fine': The limited nature of Parkinson's-related healthcare

The final theme related to participants' experiences of the nature of the healthcare they received before, during and in the aftermath of the pandemic with regard to how this aligned with their perceived needs. Noted gaps included the focus of treatment options, the integration of healthcare with other relevant services (e.g., peer-support) and relationships with HCPs.

Most participants portrayed the healthcare they received prior to the onset of the pandemic as being predominantly focused on the consideration and treatment of physical symptoms. This was portrayed by Cillian as '*chuck a few pills at you, do some exercise, you'll be fine'*. Although participants acknowledged this to be an important aspect of care, several 'gaps' in care were evident between

participants' portrayal of their needs and the predominantly biomedically-oriented support they received. One aspect of this was insufficient consideration of, in healthcare assessment and treatment, the psychological difficulties associated with living with and adjusting to Parkinson's:

> *…the mental health aspect of things is really poor, that's generally across the board, because of lack of supply. But also, blokes being blokes, we don't talk about that sort of thing. It's like a Northern Irish greeting - 'how are you?' doesn't actually mean how are you*.
>
> (Cillian)

Notably, in this excerpt, Cillian suggests that this lack of acknowledgement of mental health issues reflects broader cultural trends in the region. Similarly, Siobhan suggested that attitudes in NI were often '*conservative*' in nature and suggested that society in general might be resistant to change.

Beyond cultural considerations, participants' additionally highlighted that their experiences of 'gaps' in healthcare were associated with funding for treatments:

> *Then I was, um, put in contact with the group, Parkinson's group who met in the gym, and we did exercises and we spent time at the gym and I absolutely loved it. And then that was cut short and stopped eventually, because of COVID and because of um, money, restrictions in the healthcare. And you can only do it now if you're a certain size, or your body mass is a certain level.*
>
> (Grace)

As this excerpt suggests, participants noted that access to such services became increasingly stringent because of the exacerbation of resource strain caused by the pandemic.

In addition to the focus and nature of treatment options, participants highlighted additional factors that were markers of (poor) quality healthcare experience. Most participants felt that peer support was an important aspect of living successfully with Parkinson's. Benefits included sharing *'tips and tricks'*

(Cian) as well as acting as an escape from the diagnosis and providing an outlet to *'[take] my mind away from the illness and keep going'* (Cian). The phrase 'keep going' suggests the existential difficulty he faced because of the diagnosis and therefore the need for peer support in successfully living with Parkinson's.

Moreover, participants additionally discussed the importance of relationships with HCPs. This was especially the case for Parkinson's nurses who, when available, were central to the receipt of personalised care that was achieved through an in-depth understanding of their particular needs. While contrasting with a prior negative experience with a different consultant, Torin highlighted the positive impact on his feelings about his healthcare of a positive working relationship with a consultant neurologist:

> *He [the consultant] was just more personable. He took an interest, he seemed to know what he was talking about more, he explained things better, he, it was just, all round, [I] felt more comfortable with him, you know? It was just his, bedside manner, whatever you call it.*
>
> (Torin)

Personal relationships, especially with Parkinson's nurses, were particularly important. These provided emotional support and helped participants feel confident in the ability of the nurse to provide quality care.

However, for some participants, the use of telemedicine during the pandemic negatively impacted the ability to maintain successful relationships with HCPs:

> *It's, less interactive, less personal. But whether I find that uh, a personal relationship with a healthcare professional is important and valued. I mean uh, rapport, even those little personality traits that work for people or don't work for people. A lot of that is lost by sitting on a telephone.*
>
> (Silas)

In summary, participants' beliefs about what constituted successful Parkinson's healthcare diverged from that which they experienced as the primary focus of healthcare services before, during and in the aftermath of the pandemic.

The cause of this disparity was generally understood to be the result of culture and limited resources. Participants expressed the desire for a broader range of treatment options and the need for healthcare support to acknowledge and address the difficulties of living with Parkinson's beyond motor symptoms.

5.4 Discussion

This was the first qualitative study to explore how pwP in Northern Ireland experienced Parkinson's-related healthcare before, during and after the COVID-19 pandemic. Three experiential themes were identified. The first focused on reduced expectations of healthcare in light of resource limitation, the second on participants' adoption of a more active role in their healthcare to protect their needs, and the third on participants' experiences regarding the focus of healthcare in NI.

One of the most consistent aspects of participants' Parkinson's-related healthcare in Northern Ireland during the pandemic was the resource limitations. A number of deficits in the provision or quality of healthcare were highlighted including extended waiting times between consultations with neurologists, the closure of local healthcare services and difficulty contacting Parkinson's nurses. The most common deficit, which was reported by all participants to varying extents, was the extended waiting times between consultations with neurologists. Most participants reported waiting times of over eighteen months, above the six months recommended by guidelines in the UK (Brock et al., 2019). These were consistent with known deficits in primary, secondary and neurological care services (Department of Health, n.d.; Connolly et al., 2022; Karayiannis et al., 2023; Sutherland & Coyle, 2009).

In their accounts of experienced resource limitations during the pandemic, participants discussed both general (i.e., also experienced outside of Northern Ireland) and Northern Ireland-specific causal factors. Denuded healthcare was reported worldwide during the pandemic and was therefore not unique to Northern Ireland (e.g., Fabbri et al., 2021; Martini et al., 2022; Simpson et al., 2020; Simpson et al., 2022a). Additionally, misunderstandings about the nature of Parkinson's

(and the associated needs of those living with Parkinson's) are widespread (Crooks et al., 2023). However, participants' accounts of resource limitations suggest that the experienced deficits in care, rather than being caused by pandemic strains alone, were an exacerbation of a longstanding regional trend that dated as far back as the 1990s. This highlights an important distinction between NI and the UK more broadly, where such deficits have been understood as consequences of the pandemic (Health and Social Care Committee, 2021). NI-specific challenges, that were apparent both during and prior to the beginning of the pandemic, included the difficulty maintaining healthcare staff in rural regions, efforts to overcome the backlog in neurological services that resulted from the widespread misdiagnosis of neurological conditions (Department of Health, 2022), and the Assembly not being in session to make funding decisions (McKeown, 2020; McCann, 2023; McCormack, 2024).

In addition to the reduced expectations of healthcare services, another experiential theme identified from the data related to participants' understanding of complete and successful healthcare and how well these expectations were met before, during and in the aftermath of the pandemic. Notably, participant accounts suggest that the breadth of their perceived needs (e.g., psychological support) were not well supported at any timepoint. Parkinson's, as with Western healthcare in general, is generally understood from the biomedical model (Rocca & Anjum, 2020a), and this is consistent with the reports in the present study regarding the overwhelming focus on managing physical symptoms. This approach has been criticised for its neurological and pharmacological focus that contributes to the under-recognition of the broader factors that contribute to living successfully with a condition (e.g., the experience of stigma and identity disruption that can impact psychological health; Eccles et al., 2023b; Wieringa et al., 2022). This is despite the evidence suggesting that difficulties other than motor symptoms, such as depression, are the most 'troublesome' for pwP at different stages of the condition (Politis et al., 2010; Port et al., 2021; Soh et al., 2011). Participants acknowledged that the provision of care was constrained by the pandemic restrictions. However, some individuals expressed concern that their healthcare expectations would

continue to be unmet in the aftermath of the pandemic where funding was likely to be increasingly strained. That is, in the event of greater competition for healthcare funding, services that do not support the management of physical symptoms are more at risk of discontinuation.

Participant accounts highlighted that one especially important component of the experience of successful healthcare was positive relationships with healthcare professionals. This is consistent with research that reports an association between positive relationships with healthcare professionals and healthcare outcomes (e.g., psychological health, adherence to treatment; Lee & Lin, 2011; Sutcliffe et al., 2018). Building on this, Rønnestad et al. (2019) suggested that behaviour modification programmes are more effective when the care provider uses their skills to engage with the service users and stay attuned to their needs. Indeed, in the present study, strong (working) relationships, especially with Parkinson's nurses, were seen as an important facilitator of tailored healthcare. Personal relationships have been suggested to enable HCPs to develop a clinical understanding of the varied presentation of Parkinson's (Soundy et al., 2014) and improve person-centred healthcare through an understanding of the particular needs and preferences of services users. The potential impact of telemedicine on the development and maintenance of positive relationships with HCPs is especially pertinent given the increasing use of telemedicine services globally (Nittari et al., 2022).

The final identified theme in experiences of accessing Parkinson's-related healthcare in NI before, during and in the aftermath of the pandemic was the management of healthcare in response to unmet needs. With reference to Lazarus and Folkman's (1984) transactional theory of stress and coping, theme two suggests that participants commonly adopted problem focused coping (i.e., the initiation of coping strategies that address the stressor itself; Biggs et al., 2017) such as increasing self-management (see section 1.3.1.2) and requesting healthcare support. In some instances, participants additionally adopted emotion focused coping (i.e., coping strategies that manage emotions; Biggs et al., 2017) techniques, which may have enabled participants to retain a feeling of control

(McQuillen et al., 2003). Specific examples of this include the philosophical rationalisation of the causes and impact of denuded healthcare and some participants focus on achievable positive healthcare experiences such as fostering positive relationships with healthcare professionals and peers.

The widespread adoption of problem focused coping was particularly interesting given participants generally understood the deficits in healthcare as caused by systemic financial concerns. This is because, when events are appraised as uncontrollable, emotion focused coping has been suggested as most adaptive (Biggs et al., 2017). However, rather than relying on emotion focus coping, participants, to varying extents, identified aspects of their experience they could control (e.g., self-management, fighting for appointments). This could relate to the longstanding threat of resource deprivation in NI that were apparent in participant accounts of healthcare in the region prior to the onset of the pandemic. In this context, emotion focused coping may not be sufficient in the face of longstanding, existential threats to health. The adopted problem focused coping mechanisms were likely well established before the additional stressor of the pandemic occurred. This perhaps explains why participants reported less severe reactions compared to other studies in the pandemic, where, for example, one participant in England described feeling 'abandoned' as a result of the reduced services available (Simpson et al., 2020).

5.4.1 Limitations

Some limitations of the study were identified. Firstly, the interviews took place online which may have impacted the quality of the collected data (e.g., contextual and nonverbal data; Novick, 2008) with regard to the richness of accounts. However, as this interview method enabled access to a distant population (Keen et al., 2022) while COVID-19 was still an active concern, it was felt that the potential negatives were outweighed. Secondly, the age range of the participants included in the analysis was younger (50 -70) than the peak Parkinson's incidence (70-79; Hirsch et al., 2016). This is notable in the present research as older participants may have differing healthcare needs as the condition worsens (see section 1.2.4). As such the transferability of the findings to older pwP should be done with

caution. However, it should be noted that participants in the study reported varying levels of need and dependency on the healthcare system, and the divergence and convergence of such experiences were considered in the narrative. A final limitation of the study was that participants were primarily recruited through Parkinson's UK NI, and these individuals were more likely to be proactive with regard to their approach to healthcare. As such, participants who were less inclined to take an active role in their healthcare may not have been well represented, limiting insight regarding the impact of denuded healthcare services for these people.

5.4.2 Implications and recommendations for future research

This study identified perceived widespread gaps in the provision of Parkinson's-related healthcare in Northern Ireland, before, during, and in the aftermath of the COVID-19 pandemic. Although the emotion focused coping of some participants' likely improved psychological distress (Hurt et al., 2012), the facilitation of problem focused coping skills could be targeted to improve physical health outcomes (e.g., Neumaier et al., 2025). One such approach could be to improve self-management using techniques such as those described by Lawn and Schoo (2010). Self-management is a key aspect of living with Parkinson's and has been associated with better health outcomes in people with chronic health conditions (Pigott et al., 2022). Relatedly, targeting self-efficacy, that is, the belief that a person has the capability to plan and carry out behaviours to manage specific situations (Bandura. 1997), could be particularly beneficial for individuals uncertain of their role in engaging with healthcare services. This could be achieved in a number of ways including peer support (Liang et al., 2021) and validating participants' self-initiation of healthcare support. Additionally, to improve relationships and happiness with roles in managing treatment, a patient-centred approach that emphasises 'autonomy support' and flexibility in the decision-making process that respects individual preferences should be taken (Lee & Lin, 2009).

However, these service user centred changes do not negate the need for widespread reforms in the provision of neurological services in NI (Department of

Health, n.d.). This is important as research suggests that the ability to engage in problem focused coping is associated with cognitive abilities that generally deteriorate as the condition progresses (Hurt et al., 2012; Lieberman et al., 2020). This means that, over time, the ability to combat the deficits in care with problem focused coping is likely to reduce, worsening health outcomes. Increasing the profile of Parkinson's at both a societal and governmental level in NI could increase awareness of the needs of pwP and ultimately healthcare resources.

The present study highlighted the key role of Parkinson's nurses in healthcare and emotional support and these could be targeted as key actors in improving the person-centredness of healthcare services (van Munster et al., 2022). As such, addressing the inconsistency and varied availability of Parkinson's nurses reported by participants should be a key goal for the Northern Ireland healthcare system. People with low self-efficacy, who experience difficulty with self-management and who have experienced poor psychological health, are particularly at risk of having negative experiences with the healthcare system. Psychological health is particularly important at the time of diagnosis (see section 1.2.2) and the measures in place (e.g., signposting to support groups, referrals to mental health support) to support people during this initial phase of adjusting the diagnosis should reflect that.

5.5 Conclusion

This study provided novel understanding of the experiences of Parkinson's-related healthcare in NI. In part through the exploration of experiences prior to the COVID-19 pandemic, the difficulties noted by participants were understood in the broader context of regional healthcare challenges. Three themes were identified, which focused on reduced expectations of healthcare in light of resource limitation, participants' adoption of a more active role in their healthcare to protect their needs, and perceived gaps in the (predominantly biomedical) focus of healthcare in NI. The findings highlighted prominent deficits in the provision of healthcare with regard to the experiences and needs of pwP in the region which should inform the reform of neurological services.

Chapter 6: Experiences with telemedicine in the aftermath of the COVID-19 pandemic: a dual perspective thematic analysis of people with Parkinson's and healthcare professionals

6.1 Introduction

The general acceleration in the adoption of telemedicine during the pandemic (Nittari et al., 2022) was a prominent change in the nature of Parkinson's-related healthcare services. Moreover, the UK government's plan to implement telemedicine across the NHS (Department of Health and Social Care, 2022) highlights its likely prominence in post-COVID health and social care services. In systematic reviews, studies reporting participants' feelings about the use of telemedicine are overwhelmingly quantitative and generally report a generally high level of satisfaction with telemedicine services (Kaur et al., 2022). However, the qualitative NI study (chapter five) identified both positive and negative experiences with and opinions about the use of telemedicine. To understand better the difficulties of living with and supporting individuals with Parkinson's in a post-COVID health and social context, an in-depth exploratory investigation of experiences with telemedicine is a pertinent research focus.

Telemedicine, also known as e-health or telehealth (Fatehi & Wootton, 2012), refers to the delivery of healthcare services at distance using information and communications technology for the diagnosis, treatment and prevention of diseases and injuries, as well as research, evaluation, and the continued education of healthcare professionals (World Health Organization, 2022b). The suitability of telemedicine during the COVID-19 pandemic stemmed from the ability to enable the partial continuation of services (Hincapié et al., 2020) in light of the globally implemented social distancing and lockdown measures (Alfano & Ercolano, 2020). This capability was particularly important for the delivery of services to people with chronic conditions such as Parkinson's (Bitar & Alismail., 2021), who balanced the maintenance of physical and psychological health (Bloem et al., 2021) with the minimisation of the risk of catching COVID as a 'clinically extremely vulnerable' individual (The Health Foundation, 2021).

Since the conclusion of the pandemic, it is important to understand the rapid and reactive change that took place (Valdes et al., 2022). The unprecedented shift in the nature of healthcare and the necessity for widespread integration of

telemedicine into conventional models of care (Smith et al., 2020) contrasts with the more gradual and evidence-based adoption of such services over previous decades (Zanaboni & Wootton, 2012). As noted by Segal et al. (2022), during the early days of the pandemic, little evidence supported the appropriate use of telemedicine in different specialities. Other difficulties included the lack of technological infrastructure for healthcare services and service users, concerns about the quality of care, lack of staff experience and training, technical difficulties, confidentiality, data protection and liability concerns (Appleton et al., 2021; Bouabida et al., 2022; Ftouni et al., 2022; Khoshrounejad et al., 2021; Smith et al., 2020; Solimini et al., 2021).

Though understanding experiences with telemedicine could be approached in a variety of ways, the investigation of service user experiences is well suited to the person-centred approach that underpins this thesis. Indeed, the UK government's planned adoption of telemedicine services (Department of Health and Social Care, 2022) must be informed by the experiences, preferences and needs of those using them (Stewart et al., 2024). However, consideration of the perspective of HCPs could provide additional insights that could strengthen the integration of the findings into clinical practice. Taking a dual-perspective to understanding Parkinson's healthcare has precedence in academic literature (Pigott et al., 2022; Soilemezi et al., 2023) and has been evidenced to facilitate the development of nuanced insights that would not otherwise be possible (McCurdie et al., 2017). In the present research context, the inclusion of HCPs could complement findings regarding the experiences of service users with the clinical and organisational considerations that direct telemedicine use in Parkinson's-related healthcare.

Consequently, the present study sought to understand the post-pandemic context of telemedicine in Parkinson's healthcare in the UK, which was understood to be inextricably framed by the rapid shift that took place during the pandemic. Accordingly, the pre, during and post pandemic experiences with telemedicine of both pwP and HCPs were investigated to gain a dual perspective.

6.2 Method

6.2.1 Study design

The study sought to develop an understanding of the current use of telemedicine in Parkinson's healthcare. More specifically, it explored the developments that took place during the COVID-19 pandemic, the impact of telemedicine from the perspective of HCPs and service user experiences, and feelings and opinions about its current and future use. As such, a qualitative design was employed using one-to-one semi-structured interviews. Two samples (people with Parkinson's and healthcare professionals) were separately recruited and interviewed. However, it was expected that these samples would be integrated into a single analysis and, thus, 'merged' themes would be presented. Braun and Clarke's reflexive thematic analysis (TA; Braun & Clarke, 2021b) was chosen as the most appropriate method for data analysis.

6.2.2 Ethical considerations

Ethical approval to carry out the study was granted by the Lancaster University Faculty of Health and Medicine Research Ethics Committee (FHM-2023-3759-RECR-2; see Appendix S). An overview of the ethical considerations that were addressed throughout this study is presented in section 2.7, to carry out quality and rigorous research, qualitative and IPA-specific quality indicators were consulted. An overview of these considerations is provided in section 2.6. A completed version of the Consolidated Criteria for Reporting Qualitative Research (Tong et al., 2007) can be found in Appendix J. Importantly, the completed guide suggests quality with regards to the (reporting of) considerations taken throughout the research and their description in the present chapter and broader thesis.

6.2.3 Quality and reflexivity

Quality and reflexivity, previously discussed in section 2.6, are important considerations when using TA. With the aim of carrying out quality and rigorous research, consideration was given to quality and rigour throughout the analysis through consideration of both general qualitative and thematic analysis-specific

quality indicators. A completed version of the Consolidated Criteria for Reporting Qualitative Research (Tong et al., 2007) can be found in Appendix J. Importantly, the completed guide suggests quality with regard to the (reporting of) considerations taken throughout the research and their description in the present chapter and broader thesis. Additionally, at each stage of the analysis (coding, initial theme generation, theme development and theme refining), support (feedback, discussions about the data) was received from CM.

To support reflexivity throughout the research process, I kept a reflexive journal. In doing so, I understood that the development of this study stemmed considerably (though not exclusively) from my interpretation of the discussions I had with pwP in the NI study (chapter five) with regards to their experiences with and opinions about the use of telemedicine. This informed the use of an inductive approach to research where divergence and convergence in these experiences could be explored in an in-depth manner. When conducting the interviews, I found, to an extent that I did not expect, that some participants had especially negative and impactful experiences with telemedicine. In one particular interview, I found it emotionally challenging to progress with the interview. Having identified this experience when writing in a reflexive diary, I discussed the experience with my supervisor. This helped me understand why this may have happened, its personal impact, and how this impacted the collected data.

6.2.4 Recruitment

In reflexive thematic analysis (Braun & Clarke, 2021b), no concrete rules exist regarding suitable sample sizes and different approaches and considerations are evident (e.g., Braun & Clarke, 2021c; Malterud et al., 2016). Two approaches to thinking about sample size in thematic analysis, data saturation and information power, are underpinned by epistemological consideration of the nature of knowledge generation. Consistent with the adoption of critical realism (see section 2.2.3), the generation of themes in the present study was understood to be a product of the engagement of the researcher with the data, rather than the themes already existing in the data (as is the case with the concept of data saturation; Braun & Clarke, 2021c). Because of this, information power (i.e., considerations of

the 'richness' of collected data guide decisions regarding sample size; Malterud et al., 2016) was adopted due to its theoretical consistency with critical realism and the perspective of Braun & Clarke (2021b). In congruence with this approach, although initial approximations of sample size are useful, especially when supported by experienced supervisors, these must be revised throughout data collection (Malterud et al., 2016). Potential considerations included the (a) study aim, (b) sample specificity, (c) use of established theory, (d) quality of dialogue, and (e) analysis strategy (Malterud et al., 2016).

Before data collection, a sample size of 15 to 20 was anticipated to be sufficient. This was informed by other studies that employed reflexive thematic analysis (Anestis et al., 2022; Dawson et al., 2025; Lightbourne et al., 2024). The most salient insights that emerged from consideration of sample size during data collection were twofold. Firstly, though I understood myself to be a relative novice with regard to interviewing, I found that I was able to develop rapport with participants which resulted in information power that was greater than initially anticipated. Additionally, it was apparent that the 'quality' of dialogue was generally greater in the interviews with HCPs (compared to pwP) because of their more sustained focus on topics relevant to the research question and the articulateness of their responses. As such, although the recruitment was more heavily weighted towards the Parkinson's group, the relative 'information power' between these groups was considered comparable.

Recruitment was achieved through collaboration with Parkinson's UK, via social media and through snowball sampling. Advertising the study (see Appendix T) through Parkinson's UK's Excellence Network[10] was especially important given the anticipated difficulty with recruiting HCPs (e.g., because of their time constraints; Chen et al., 2025). After registering their interest, participants were given an information sheet (see Appendix U). To be eligible for the study, participants were required to have accessed (pwP) or provided (HCPs) Parkinson's-related

[10] A network of Parkinson's UK staff members and healthcare professionals established to support health and social care professionals in providing better care for people with Parkinson's.

healthcare within the NHS in the UK between 2018 and the date of the interview (which took place between November 2023 and January 2025). This criterion was set to ensure participants had some experience with Parkinson's-related healthcare before the onset of the pandemic. Additionally, it was required that participants had some experience with accessing or providing telemedicine services since 2018. To facilitate the recruitment, potential recruits were (via email) prompted with a list of telemedicine services with which they may have experience. This list included telephone and video consultations, emails and wearable devices, though it was noted that the list was not exhaustive and participants were additionally encouraged to detail healthcare experiences that they believed to be relevant. As such, the study took an inductive approach to understanding the types of telemedicine that were experienced in the UK, which is consistent with Braun and Clarke's (2021b) reflexive thematic analysis. Beyond experience with telemedicine since 2018, no further inclusion or exclusion criteria were set. However, an attempt was made to represent the major HCPs prominent in Parkinson's MDT healthcare. Adopting Bloem et al.'s (2021) outline of the professional disciplines involved in MDT Parkinson's care, the HCP roles that most pwP were expected to have some experience with were specialist (Parkinson's) nurses, speech and language therapists, occupational therapists, physical therapists, psychologists/neuropsychologists, neurologists, geriatricians, psychiatrists, social workers, dieticians and GPs. Consequently, recruitment aimed to gain representation across these disciplines.

6.2.5 Participants

Participants' demographic details and experience with telemedicine are outlined in Table 7. In total, 16 participants were recruited for the Parkinson's (*n* = 10) and HCP groups (*n* = 6), and interviews took place between November 2023 and January 2025. For the Parkinson's group, participants' ages ranged from 40 - 49 to 70 - 79. The modal age bracket was 60 – 69[11] (*n* = 4) and participants were mostly

[11] Age ranges of participants were recorded at the request of the ethics committee that approved this study.

white (90%), female (60%) and had an average of 8.9 years (with a range of 6 - 11) receiving Parkinson's-related treatment. The most common experience with telemedicine was telephone consultations (*n* = 8), followed by video consultations (*n* = 6), the NHS application (*n* = 4), and email (*n* = 3). For the HCP group, ages ranged from 40 - 49 to 60 - 69. The modal age bracket was 40 – 49 (*n* = 3) and participants were mostly white (66%), female (60%) and had a mean of 21 years (with a range of 12 - 31) providing Parkinson's-related healthcare. The most common experience with telemedicine was telephone (*n* = 6) and video consultations (*n* = 6), followed by the Personal KinetiGraph (*n* = 3), email (*n* = 3), mobile applications (*n* = 3), and web-based resources (*n* = 1). Of the six HCPs, two were Parkinson's nurses, one consultant psychologist, one physiotherapist, one speech and language therapist and one consultant physician/geriatrician. Potential participants were given a participant information sheet and consent form prior to scheduling an interview. For clarity, the groups are referred to as 'participants' when spoken about collectively and HCPs or pwP individually.

6.2.6 Data collection

Before taking part in the interview, informed consent was received (see Appendix V). The interview guides (see Appendix W) were shaped by discussions with experts by experience when carrying out the NI study (chapter five) where participants were asked about their experience with telemedicine and their opinions and feelings about its use. The interview guides additionally drew on previous research investigating the care experiences of pwP and HCPs during the pandemic (Soilemezi et al., 2023) which was then adapted to focus on telemedicine. The interviews took a flexible and exploratory approach to gain insight into participants' experiences and were thus adapted as the study progressed. All interviews were conducted remotely. In the Parkinson's group, two interviews were phone calls and eight were video calls. These interviews lasted an average of 44 minutes, with a range of 21 and 80 minutes. In the HCP group, three interviews were phone calls and three were videocalls. These interviews lasted an average of 55 minutes, with a range of 22 and 78 minutes. In congruence with the adopted critical realist research paradigm (see section 2.2.3), there was assumed

a close connection between participants' use of language and their thoughts and experiences (Braun & Clarke, 2021b). Consistently, interviews were recorded and transcribed verbatim into Microsoft Word.

6.2.7 Data analysis

Data analysis followed Braun and Clarke's (2021b) six stages of analysis; familiarisation, data coding, initial theme generation, theme development and review, theme refining/defining/naming, and writing up. The following sections will firstly outline the data handling with regards to the separation and merging of the HCP and Parkinson's groups. Then, a detailed account will be provided of the analysis process, informed by the guidance of Braun and Clarke (2021b).

6.2.7.1 The merging of data between healthcare professionals and people with Parkinson's

The merging of themes was judged to be preferable as this would support the focus on the similarities and differences between the experience of telemedicine use in Parkinson's healthcare between HCPs and pwP. However, the decision about whether or not to present the data as merged or separate (HCP and Parkinson's) themes was deferred to stage three of Braun and Clarke's (2021b) stages, where themes were iteratively explored. Congruently, the first two stages of the analysis (data familiarisation and data coding) for the HCP and Parkinson's groups were carried out at two separate timepoints. This temporal separation firstly supported the inductive development of codes that were a product of the separate familiarisation with the data and distinct between the HCP and Parkinson's groups. Secondly, it provided the opportunity to explore the feasibility of presenting the data as merged themes. After carrying out stage three (initial theme generation), it was judged that the merging of data was possible. Stages three to six (initial theme generation, theme development and review, theme refining/defining/naming, and writing up were therefore carried out with merged data and resulted in merged themes. When developing the merged themes, it was important to capture the experience of both pwP and HCPs within each theme.

6.2.7.2 The six stages of analysis

For each transcript, before conducting the analysis, the researcher became familiarised with the data through multiple readings. The data were first coded in Microsoft Word (see Appendix X) before being extracted to Excel. For each participant, an Excel sheet was created that detailed the specific excerpt in one cell and the code in the adjacent cell. An inductive approach was taken with a focus on semantic content, though latent interpretations (i.e., exploration of meaning at an implicit level) were coded where relevant and to facilitate a deep understanding of experience. The codes were refined through multiple iterations with the goal of creating codes that captured a singular concept but were not overly fine-grained and were easily understood once removed from the raw data (Braun & Clarke, 2021b; see Appendix Y). Attention was given, where possible, to apply previously tagged codes (within but not between the separate HCP and Parkinson's groups) to reduce unnecessary repetition. Given the large amount of data and to ensure as much consistency as possible, a final standardisation of codes (i.e., similar codes were given a final shared code where reasonable) was carried out upon completion of the multiple iterations of coding for each participant group separately. This process resulted in the development of 20 codes in the Parkinson's group and 20 codes in the HCP group.

Once stages one and two, detailed above, were completed, the separate HCP and Parkinson's codes were merged into a single data set. Potential themes were generated by iteratively grouping codes and then exploring potentially viable groups to ascertain the extent to which they were represented by the data and had clear boundaries (in terms of what was and was not relevant). After a second iteration of theme generation and exploration, narrative summaries (see Appendix X) were written and discussed with one of the supervisory team, CM, before being refined. The final grouping of HCP and Parkinson's codes into themes can be found in appendix Z.

Finally, the themes were written up and the theme topics and titles were again refined. Data extracts were selected with consideration of their clarity and

Table 7

Demographic characteristics

Participant	Age	Gender	Ethnicity	Healthcare experience (years)	Profession	Experience with telemedicine
People with Parkinson's						
Par1	70 - 79	Female	White	8	n/a	NHS application, email, video
Par2	60 - 69	Male	White	11	n/a	NHS application, telephone, video
Par3	70 - 79	Female	White	6	n/a	NHS application, telephone, video
Par4	50 - 59	Male	White	10	n/a	Email, telephone
Par5	60 – 69	Female	White	9	n/a	NHS application, telephone, video
Par6	60 - 69	Female	White	11	n/a	Telephone
Par7	80 - 89	Male	White	9	n/a	Email, video
Par8	60 - 69	Female	Asian	9	n/a	Telephone
Par9	50 - 59	Male	White	10	n/a	Telephone, video
Par10	40 - 49	Female	White	6	n/a	Telephone
Healthcare professionals						
HCP1	50 - 59	Female	White	25	Consultant Parkinson's nurse	Telephone, video, PKG
HCP2	50 - 59	Female	White	12	Parkinson's specialist nurse	Email, telephone, video, PKG
HCP3	40 – 49	Male	Other	13	Consultant clinical neuropsychologist	Telephone, video, mobile applications
HCP4	40 - 49	Male	Asian	23	Consultant physician and geriatrician	Telephone, video, online resources, PKG
HCP5	40 - 49	Female	White	24	Specialist speech and language therapist	Email, telephone, video, mobile applications
HCP6	60 - 69	Female	White	31	Specialist physiotherapist	Email, telephone, video, mobile applications

conciseness, the vividness, and the representation of participant experiences (Braun & Clarke, 2021b). As the analysis was a product of the writing up process (Braun & Clarke, 2021b), the themes were developed and refined until the final draft.

6.3 Results

Five themes were constructed from the data: 1) telemedicine is in the early stages of integration into healthcare, 2) the promise (and concern) of telemedicine in a resource strained healthcare environment, 3) phone and video assessments increase the reliance on the reporting of issues by pwP, 4) making the most of telemedicine with the hybrid model, 5) (lack of) freedom of choice in the use of telemedicine. For ease, quotes from HCPs will be represented by 'HCP' and those from pwP will be represented by 'Par'.

Theme 1 – Telemedicine is in the early stages of integration into healthcare

Participants felt the quality of telemedicine increased substantially during the pandemic, before which procedures, infrastructure and guidance were very limited. However, despite improvements, it was also portrayed as being in the early stages of development. HCPs identified specific and general barriers to the implementation of telemedicine across the NHS and pwP noted several areas in need of improvement. Nonetheless, general agreement was apparent between participants that the quality of telemedicine would further improve with time.

When the pandemic began, HCPs believed the healthcare system was '*not ready*' (HCP3) to facilitate the '*incredible speed of change*' (Par2) to telemedicine. Telemedicine was depicted as '*forced upon [them]*' (HCP3) and, as such, an innovation they had to set up '*practically overnight*' (HCP1). Specific examples included the development of technical infrastructure (e.g., ensuring staff had access to technology) and the development/application of protocols and guidance. Consequently, HCPs using telemedicine during the pandemic described having to '*manage as best we could until we were allowed to see them face to face again*' (HCP6) because '*needs must*' (HCP5):

> *…sometimes I was having to ask the relatives 'what's their walking like?', 'are they stiff?' and I would show, demonstrate on myself how to assess rigidity, um, and get the relative to tell me whether they thought they were stiff or rigid. So yeah, I would say, for some, it was great, for others it was not appropriate.*
>
> (HCP2)

This process was characterised as a *'learning curve'* (HCP1) for both HCPs and pwP.

Since the conclusion of the pandemic, HCPs felt that the state of telemedicine was more advanced than it was before and both pwP and HCPs were believed to have emerged from the pandemic more *'tech savvy'* (HCP1, HCP6). Improvements included the development of platforms that were better suited to healthcare goals and the provision of better technological infrastructure across the NHS:

> *From the NHS side of things, [the technical infrastructure is] a lot better [than it was pre-pandemic]. But there are still clinics where I haven't got a camera on my computer or it's somebody else's headphones, or the camera isn't working…so, there're still technical barriers, but it's a lot better, I'd say 90 percent better than it was.*
>
> (HCP4)

However, despite these clear advancements, participants still expressed that significant improvement and change was required. HCPs noted barriers to the integration of telemedicine included high cost, an NHS culture that did not promote innovation and varying financial resources which resulted in inconsistent service provision that *'depends on where it is'* (HCP6). This was additionally reflected in the understanding of some pwP about the services available to them in their socioeconomically deprived locality:

> *…they haven't had the staff or the funding to do anything more, so they've come to telemedicine very late, and I don't really think they know where to go with it, to be honest.*
>
> (Par6)

From the perspective of pwP, participants discussed circumstances where they felt the current use of telemedicine was not yet adequate, purposeful or comprehensive enough. Examples included the need for guidance and (formal/informal) support for pwP on using telemedicine, the need for a more comprehensive and purposeful approach to the integration of telemedicine into current care services, a better understanding of how healthcare goals can (or cannot) be achieved with telemedicine, and the improvement of online platforms:

> *They're [HCPs are] saddled with these systems that don't really work, and don't help them and it don't help us.*
>
> (Par2)

Overall, participants felt that the pandemic rapidly increased the use of telemedicine, which improved services but left the NHS 'catching up' to the developments that took place. Despite the clear need for improvement across a variety of factors, the general sense was that *'I'm sure it will be improved'* (Par1) as technology, procedures and infrastructure become more established over time.

Theme 2 –The promise (and concern) of using telemedicine in a resource strained healthcare environment

Participants believed that telemedicine could bring both benefits and challenges when integrated into a resource strained healthcare environment, as with the NHS. Both pwP and HCPs acknowledged its efficiency with regard to cost and time. However, for pwP, the potential for telemedicine to be used as a cost-effective replacement to in-person care without due consideration for the implications was concerning.

For both HCPs and pwP, the healthcare they provided and received was acknowledged to exist within a resource strained environment. Within this context participants noted the necessity for and potential benefits of telemedicine on improving the efficiency of healthcare services:

> *I think that the number of patients that we're seeing increases, and therefore, I think there will be more online stuff that we will have to manage in the future, yes, absolutely. Because Parkinson's is the fastest growing neurological condition in the world, so we've either got to employ more nurses or we've got to use more technology.*
>
> (HCP2)

From the perspective of HCPs, one of the most promising, though not widely available, ways of improving the efficiency of healthcare was through the application of the Personal KinetiGraph (PKG), which collects remote, 24-hour data about physical symptoms sent to relevant HCPs. Such technology overcomes what Par1 described as the *'pitfall'* of current healthcare assessments of signs and symptoms, which provides HCPs with a *'snapshot'* (HCP1, HCP2) of functioning and is often informed, in part, by subjective and potentially misremembered information provided by the service user:

> *If the decisions are based on inaccurate data, which they may be with the retrospective method of interviewing patients now - 'how long are your 'off' periods?', 'how long are your 'on' periods?' - then it's going to impact me as a patient, of course, because I'm not going to get the correct advice.*
>
> (Par1)

Indeed, HCPs with experience using the PKG believed the breadth and accuracy of the collected data informed the efficient use of resources such as medication and advanced therapies:

> S*ometimes we need to know exactly what's going on with these patients and it's very difficult if we, if we're not with them 24 hours a day, seven days a week… [advanced therapies are] hugely expensive so you want to make*

sure that you're using it on the right patients and that it's benefited the patient.

(HCP1)

In addition to the PKG, mobile and web applications as well as platforms for assessment and/or treatment (in the context of clinical psychology) were felt to facilitate a greater level of assessment while saving time through reduced contact and the automation of processes. Similarly, the use of such applications for (totally or partially self-managed) therapeutic treatment, as with speech and language therapy and physiotherapy, improved outcomes for pwP while reducing resource-intensive contact time:

…if the patients practise [speech and language therapy exercises], we see at least a 10-point improvement on an outcome scale, at least. The more they practise, the better the outcomes. And it massively saves face to face contact time.

(HCP5)

Other examples of the benefits of telemedicine were the use of organisational tools (for pwP) to reduce the waste of healthcare resources, such as forgetting to take medication or missing appointments. Additionally, videocalls were also noted to reduce travel time (with remote meetings) for those involved in MDTs or who provided care in community settings.

Although all pwP acknowledged some benefits of using telemedicine services, some pwP (in particularly resource strained areas) felt the overuse and overreliance on these services negatively impacted care. At the extreme, Par10 reported that in-person contact with specialist HCPs was no longer a notable component of their healthcare support:

I don't think [telemedicine is] enough in itself as it stands, to get a full picture of your health. It was something like three or four years, no, yeah, it was about three years since I actually saw, between seeing somebody face

> *to face, you know. They were all telephone appointments, and I just think that's too long.*
>
> (Par10)

For Par10 and other pwP, the use of telemedicine to cope with resource strain (instead of increasing the quality of care) contributed to negative care experiences. For Par4, the pressure of resource strain on the health services meant the waiting times for in-person were unsatisfactory when considering the perceived urgency of need:

> *… [during the pandemic] you could have had more visits, certainly, you know, face to face visits. Um, once I called her and said 'I've had enough', because of the fact I'd got to that stage, you know, and they said 'what about August?'. Totally gaga.*
>
> (Par4)

In summary, participants felt efficiency of care services was increasingly important in a healthcare context where already strained resources were projected to become more so due to the rising number of individuals diagnosed with Parkinson's. However, for some pwP, the (over)use of cost-effective telemedicine could have negative connotations in specific circumstances, especially in areas with strained resources.

Theme 3 – Phone and video assessments increase the reliance on the reporting of issues by people with Parkinson's

Both participant groups felt phone and video consultations, the most commonly experienced use of telemedicine by pwP, reduced the ability of HCPs to assess pwP and, as such, increased reliance on the ability of pwP to understand, flag and express the challenges they were experiencing. This was especially impactful in 'triaging' interactions where pwP spoke to HCPs about novel issues or where HCPs had to carry out an assessment to decide the appropriate course of action.

A broad consensus was evident between HCPs and pwP that phone and video consultations reduced the transfer of 'information' relevant to assessing pwP. Examples of such 'information' include nonverbal cues, psychological wellbeing, the home environment and movement:

> *...you don't pick up their soft clues [with telemedicine] that you might otherwise have picked up when you see people face to face. You get a lot of additional, um, details about them [in-person]. [With telemedicine] you don't you don't really see, the spouse sitting on the side and rolling their eyes or saying, 'actually that's not true', or they're worried about their memory, you know. You miss a lot on a pure, clinical level.*
>
> (HCP4)

The reduced information and associated impact on the quality and breadth of assessment that could be conducted by HCPs meant that most pwP felt in-person appointments were more 'holistic' as '*they were actually looking at you as a person that they'd met before and assessing how they thought you were doing'* (Par6). Consequently, it was felt that HCPs could not get '*the same in-depth knowledge'* (Par7) of their experience meaning many participants felt that telemedicine was *'just not the same as face to face'* (Par5, HCP1). This was especially apparent for two participants in resource strained areas whose contact with HCPs was limited to the use of telemedicine:

> *I don't think they really get an overall picture of how I am. It's like, they've got a list of questions, they ask them, and then they'll tweak my medication and that's it. And I think, because it's not in person, I don't think they fully appreciate what's going on for me.*
>
> (Par10)

The reduced ability to assess the whole person when using telemedicine meant that, in some circumstances, assessment via telemedicine relied on the reporting of problems by pwP:

> *When they're on the phone, and I think when it's a video, they will deal with, they'll come up with whatever the main issue is, and they'll talk about the main issue, and we'll talk about how we're going to resolve that main issue. When it's face to face, you unearth more by dealing with that main issue…I think the patient deals with what they've got in their head on the phone call, but when it's face to face the therapist has got everything on alert, really, for what they need to know about this patient.*
>
> (HCP6)

Consequently, some pwP felt the burden of responsibility to express the issues they were having and to identify issues as a non-expert. For Par9, this caused concern about the potential for deterioration to be missed by HCPs:

> *…the other aspect of it is that some of the signs and symptoms, obviously I'm very aware of myself, but [other] signs, I might not be. So, deterioration in some of the assessment criteria, that I might not be aware of myself, but somebody looking at me might be very obviously aware.*
>
> (Par9)

In agreement with the idea that telemedicine alters the balance between HCP assessment and reporting by pwP, HCPs responsible for triaging and assessment noted that it was necessary for them to make judgements about '*those who you knew were going to be safe to do videos with and those who you really needed to see'* (HCP2). Factors relevant to this choice included the existence of prior relationships (which were seen to facilitate HCPs' comprehension of the difficulties pwP were having), and whether or not the individuals are *'people who are fit [or] whose Parkinson's is very stable'* (HCP4), the individual could *account for themselves'* (HCP6), and telemedicine was suitable in terms of the specific purpose the healthcare interaction.

In summary, participants felt that telephone and video consultations reduced the ability to carry out assessments to identify or understand the issues pwP were experiencing. As such, the use of phone and video consultations placed reliance on the successful identification and expression of needs and symptoms

on pwP. For pwP, this caused concern about the potential negative consequences of the inappropriate use of such services.

Theme 4 – Making the most of telemedicine with the hybrid model

Participants perceived that the remote nature of telemedicine promoted flexibility and efficiency in care that was not otherwise possible with in-person care, ultimately improving the quality and quantity of care for pwP. As such, but with consideration of the limitations of telemedicine, it was felt best suited to '*augment'* (HCP4) in-person care in a hybrid model.

A general consensus emerged between HCPs and pwP about the benefits of using telemedicine (in a hybrid model) in circumstances such as when illness prevented in-person contact, follow ups, or for service users to feed information back to HCPs:

> *Ideally, I would do a face to face for the first appointment and then determine at that point whether or not they needed to come in person to have some exercises talked to them until they got them right, then to offer them follow up checkups by video call or telephone call, before another follow up appointment face to face after a period of time where they've been doing their exercises at home.*
>
> (HCP6)

> *...it's a very, very useful tool because the patient and the relative can stay at home and not have to travel through public transport and so on where they're at risk of infection. And so it is, it is a very useful tool in certain circumstances.*
>
> (Par8)

Most participants felt that, in some cases, telemedicine provided distinct benefits over in-person care. One of the most notable advantages of the flexibility of telemedicine was that telephone and video consultations enabled greater (remote) access to services in a greater number of situations. Specific benefits included '*being able to have contact with someone*' (Par7) on a more frequent

basis, the prevention of appointment loss (because of e.g., illness or social distancing measures), and the promotion of a flexible lifestyle for service users (e.g., travelling).

For HCPs, the flexibility of telephone and video consultations was considered especially useful for pwP with more impactful physical difficulties, who required a high level of care interactions, who were still of working age (and, therefore, were required to fit care around the working day), or who lived in rural locations:

> *…we would be able to administer it [questionnaires] that way, literally in their homes. That's obviously better for patients with mobility issues or coming from very far away. Or, in Scotland, your hospital might be 90 miles away from where you live and you live in the country with no buses. So, there are various benefits to technology…*

(HCP3)

However, HCPs and pwP agreed that '*it [telemedicine] serves a purpose, but it's not necessarily, maybe, applicable to all*' (Par9). The application of telemedicine in this context was felt to be constrained because, for example, as with a blood test, '*you can't do that by phone*' (HCP6). Exploring the preference for in-person or telemedicine consultations, Par3 considered the circumstances in which she felt the use of telemedicine was acceptable:

> *You see, everybody looks forward to this in-person, like 'oh I'm going to see my neurologist on Tuesday, I'm going to tell him everything', and you come away, and you think 'what was the point of that?'. I did a few toe taps and a couple of pats and he said 'oh you're doing really, really well' and 'off you go'. So basically [using telemedicine for] this sort of thing is fine.*

(Par3)

For Par3 and other participants, benefits such as the convenience of phone and video consultations were balanced with consideration of the fundamental goal of the healthcare interaction. This balance was succinctly captured by HCP5, who

noted '*if you can reach the same end on a video call, that's great, but sometimes you just can't'* (HCP5).

Overall, portrayals of the utility of phone and video consultations varied depending on the specific goal of the interaction (e.g., advice, specific type of assessment or treatment) and the healthcare speciality (e.g., speech and language, physiotherapy). Thus, there was an acceptance between HCPs and pwP that the utility of telephone and video consultations was contextually specific.

Theme 5 – (Lack of) freedom of choice in the use of telemedicine

Both HCPs and pwP acknowledged that freedom of choice for pwP, that is, the ability to use or refuse telemedicine services, was a vital component of successful integration. However, the freedom of choice that HCPs believed they provided was incongruent with the experiences of pwP, who reported various constraints on their ability to pursue the use telephone and video consultations in a self-determined way.

Most HCPs spoke about facilitating the freedom of choice for pwP with regard to whether or not telemedicine was used, which fell under the broad umbrella of *'patient-centred care'* (HCP3) that is central to the ethos of healthcare within the NHS. Contrastingly, however, many pwP felt that the pivot to telemedicine during the pandemic and the perceived need for time and cost-efficient healthcare resulted in a norm of at-distance healthcare. As such, many pwP noted a generalised lack of self-determination in the use of telemedicine:

> *I don't know if you've ever tried to get hold of a doctor for anything, but it is just so difficult. And actually physically seeing somebody face to face is becoming harder and harder. So, therefore, we need to get used to the fact that if you want to see a doctor, you're gonna have to ring, they're gonna ring you back, you're gonna explain how you feel, then they will decide whether you need help or not.*
>
> (Par5)

Congruently, some pwP felt that the motivation behind the continued use of telemedicine was primarily because *'they see it makes massive savings'* (Par9), and that this economic incentive provided a bottom line that they felt outweighed their preferences:

> *I don't think [the use of telemedicine is] shaped around my things at all, I think it's service led. I think, um, they've got a high caseload, I don't think it's individual workers, but I just think they've got high caseload.*
>
> (Par10)

For some pwP, freedom of choice (both for and against telemedicine) was experienced as limited by the idiosyncrasies and sometimes '*highhanded'* (Par2) and '*blinkered'* (Par3) attitudes and beliefs of some specific HCPs with whom they had experience.

In contrast to pwP, who generally noted experiences in which telemedicine was used on occasions where they believed in-person care was necessary or preferable, HCPs felt telemedicine was *'saving the patient coming in'* (HCP6) and in person appointments meant '*dragging them all the way back up to the hospital'* (HCP1). For HCPs, perceived barriers to freedom of choice were those which limited the ability to successfully use telemedicine such as the impact of physical symptoms, technological proficiency, technical infrastructure and support from family and friends. Despite this perception, HCPs generally acknowledged that pwP often, though not always, preferred in-person appointments.

Finally, both pwP and HCPs indicated that effective communication about the use of telemedicine was important in inculcating positive feelings about its use as well as a sense of control for pwP:

> *...you get this letter and it says 'it will be a telephone consultation' in bold letters. Basically 'there is nothing you can do about it'.*
>
> (Par6)

> *I think, with people, if they're given information or they're communicated with, it puts their mind at rest completely. It's when people don't know and there's no communication and they're just left to sit there, and, you know...*
>
> (HCP1)

As can be determined from the above, perceptions about the freedom of choice in the use of telemedicine varied between HCPs and pwP. For pwP, this autonomy was felt to be reduced by resource strain in the healthcare system and the perceived efficiency that telemedicine enables. Contrastingly, for HCPs, telemedicine was seen as a desirable type of appointment and barriers to its adoption were generally seen to relate to the (generational) difficulties of older pwP in using technology.

6.4 Discussion

This study investigated in-depth experiences of pwP and HCPs with telemedicine in Parkinson's-related healthcare before, during and after the COVID-19 pandemic to understand its development, experiences with its use, and feelings and opinions about its future in healthcare. The dual perspective of service users and providers facilitated an understanding of areas of commonality and divergence. From this dual perspective, five shared themes relating to the experience of telemedicine were developed. These focused on the extent of current integration into the NHS, its use in a resource strained environment, its impact on assessment by HCPs, the benefit of the hybrid model and the importance of freedom of choice.

Though the present study was carried out during one, post-pandemic interview, participants nonetheless provided useful insights into the use of telemedicine over time. Previous research suggested that the global adoption of telemedicine during the pandemic was carried out in a challenging environment stemming from the lack of preparedness for the rapid, needs-based transition (Appleton et al., 2021; Bouabida et al., 2022; Ftouni et al., 2022; Khoshrounejad et al., 2021; Murphy et al., 2021; Segal et al., 2022; Smith et al., 2020; Solimini et al., 2021), and the findings of this study suggested a similar experience in the UK NHS. However, it was apparent that services were much improved during the post-COVID era, which

is consistent with Ndwabe et al.'s. (2024) classification of the UK's post-COVID utilisation of telemedicine as 'advanced' with regards to administration, diagnosis, communication and treatment. Importantly, an opinion paper focused on the UK NHS argued that the increased use of telemedicine highlighted several challenges and disparities that need to be addressed regarding accessibility challenges, equity, sustainability, integration and legal/ethical considerations (Jerjes & Harding, 2024). Building on such considerations, in the present study, participants highlighted, for example, the lack of consistent service provision (geographical and socioeconomically) and the need for formal and informal support to use technology.

Reflecting on overarching perceptions of telemedicine, both HCPs and pwP acknowledged the efficiency it enabled. Though specific benefits varied between the types of telemedicine employed, anecdotal beliefs about efficiency included reduced consultation durations, reduced travel times, increased accuracy of assessment (thus a more efficient implementation of resources such as medication and advanced therapies), increased adherence to medication plans and the reduction of missed appointments. Congruently, the perceived efficiency of telemedicine was identified as one of the key facilitators of telemedicine adoption in a global systematic review (Kruse & Heinemann, 2022). This reflects the global perspective of telemedicine in Parkinson's-related healthcare where it is argued to be critical to cope with the rising prevalence of Parkinson's (Dorsey & Bloem, 2018; Feigin et al., 2020; Zhu et al., 2024) and generally resource strained health services (Dorsey et al., 2018). Both in the present study and broader research, the types of telemedicine that were seen to facilitate these benefits most were video and phone consultations for clinical care (Cubo & Delgado-Lopez, 2022), advanced technologies for monitoring such as the PKG (Chaudhuri et al., 2022; Joshi et al., 2019) and self-management tools for pwP (Lakshminarayana et al., 2017).

Given the widespread acknowledgement of its efficiency, it is unsurprising that global efforts are being made to investigate the feasibility of telemedicine for various clinical purposes including rehabilitation, assessment and monitoring

(Bianchini et al., 2022; Chaudhuri et al., 2022; van Westerhuis et al., 2024). Nonetheless, various aspects of the integration process have been argued to need marked improvement within the UK healthcare context (Jerjes & Harding, 2024). Critical issues include the need for standardised criteria, guidance on when and how telemedicine should be used, and clear protocols defining when in-person care is required (Alsaif et al., 2024; Hawley et al., 2020; Qian et al., 2022; Ray & Mash, 2021). Indeed, pwP supported the adoption of regulations regarding in which contexts and how frequently telemedicine should be used.

Congruent with the acknowledged limitations, telemedicine was viewed positively when integrated into a 'hybrid' approach that balanced the benefits, disadvantages and intrinsic limitations of the types of telemedicine. Participants agreed that the ability to continue care when in-person contact was constrained by broader contextual factors such as, but not limited to, the pandemic, was a particular strength of telemedicine, and the utility of telemedicine in this context is reflected in broader telemedicine literature (Smith et al., 2020; Valdes et al., 2022). For the HCPs, the hybrid model of telemedicine improved patient-centred care as it enabled them to provide more flexible service options that pwP could tailor to their personal preferences and needs. However, the current implementation of the hybrid model was suggested to be limited by inconsistent infrastructure (e.g., relevant technology, internal processes), staffing, and the reservations or pwP. In wider literature, a systematic review found that (non-Parkinson's specific) experiences with telemedicine were impacted by system-related, patient-related, socioeconomic factors and the nature of the medical intervention (Pogorzelska & Chlabicz, 2022).

Finally, despite the acknowledged benefits of telemedicine in a hybrid model, a key concern of pwP regarded freedom of choice (for service users) in when and how telemedicine was used. This relates closely to the concepts of decisional autonomy (the ability of service users to decide on a course of action from among a range of options; Arrieta Valero, 2019) and shared decision making (active participation from both patient and professional in the decision-making process; Sandman & Munthe, 2010). Importantly, these are central to patient centred care

(Sandman & Munthe, 2010), a key ethos of the NHS (Department of Health and Social Care, 2023). In the present study, lack of sufficient information regarding options, variance in service provision and the impact of local resource strain were all identified as key barriers to autonomy of decision making with regard to the use of telemedicine. The association between both service provision (e.g., the resources to support telemedicine integration) and local resource strain (e.g., high demand on healthcare services) with local socioeconomic challenges highlights the potential exacerbation of healthcare disparities for pwP residing in such regions.

6.4.1 Limitations

Certain limitations should be considered with the findings of this study. Firstly, although the use of video conferencing appointments gave access to a broader pool of participants, it nonetheless meant participants required some proficiency with technology. Given technology use is generally agreed to decrease with age (e.g., Levine et al., 2016), this may have contributed to a younger, more technologically capable group of participants, thus reducing the transferability of the findings to the broader Parkinson's population. Indeed, the majority of pwP were younger than 69 (n = 7), which is below the peak incidence of Parkinson's between the ages of 70 and 70 (Hirsch et al., 2016). However, it should be additionally noted that older and less technologically capable pwP are less likely to be asked to use telemedicine as they are deemed less 'suitable' or capable (Mao et al., 2022). As such, those who took part may be reflective of individuals currently using telemedicine.

Also related to the transferability of the findings, participants predominantly resided in England (and some in NI), which limits the transferability to other regions in the UK. Additionally, the recruitment of HCPs was especially challenging and the majority of HCPs who took part in the study were associated with Parkinson's UK's Excellence Network and, as such, were leaders in their field. Again, this limits the transferability of the findings as the HCPs involved in the study are likely to have greater knowledge about and experience with telemedicine than other HCPs. However, the impact of this was reduced by the inclusion of the

pwP who provided a different insight into the use of telemedicine in the UK. Finally, it should be noted that no expert by experience was consulted when developing the interview guide. However, the interview guides were informed by previous discussions about telemedicine with pwP during the interviews conducted for the NI study (chapter five).

6.4.2 Implications for future research and clinical practice

In the present study, a critical issue was highlighted regarding the imbalance that the use of phone and video consultations created because of the reduction of 'clinical indicators' that enable HCPs to make judgments (theme three). This is especially notable because the complexity of the psychological and physical difficulties associated with Parkinson's means pwP commonly rely on the expertise of HCPs to identify and address health issues (Bloem et al., 2021). In consideration of this, HCPs, who were experts in their field, noted making clinical judgements about the suitability of using phone and video consultations with service users (e.g., stability of their symptoms or the ability of the individual to 'account for themselves'). To encourage quality care practices as the use of telemedicine becomes widespread, the importance and implications of such considerations should be made explicit in the training of HCPs.

Similarly, the formalisation of a 'hybrid' model (i.e., a context specific clinical guidance document to for the integration of telemedicine into normal care practices) that is specific to Parkinson's could improve the quality of telemedicine use across the NHS as well as improve standardisation between regions. Notably, while a hybrid has been established in some specialities (e.g., Cascella et al., 2023; Chen et al., 2022), the author has found no such outline for Parkinson's care. In the future, Greenhalgh et al's. (2021) 'Planning and Evaluating Remote Consultation Service' could provide a detailed and flexible conceptual framework that could be tailored to MDT Parkinson's healthcare. In the hybrid model, specific attention, in both research and practice, should be given to risk factors for negative healthcare experiences with telemedicine. Those highlighted in the present study include (over)reliance on telemedicine to deal with high demand on services, advanced age, high staff turnover, a lack of relationship/rapport between HCPs

and pwP, and individuals with a preference for not being actively involved in their healthcare management.

While it is important not to challenge freedom of choice, the clear intention of the UK government to encourage the uptake of telemedicine (driven by financial considerations) makes relevant the utility of understanding potential modifiable factors that could increase uptake. Consistent with self-determination theory (Deci & Ryan, 2012), the adequate provision of information about the use of telemedicine, which was highlighted as lacking by many pwP, would go some way to improving feelings of autonomy and increasing overall satisfaction with healthcare. Indeed, communication is a critical aspect of facilitating patient-centred care (Constand et al., 2014). Additionally, given the challenges that older pwP face as well as the general learning curve with new, sometimes idiosyncratic and 'clunky' platforms, informal (e.g., encouraging people to seek support from friends and family) and formal support services (e.g., from third party organisations such as Parkinson's UK) for pwP could improve the overall adoption of and satisfaction with telemedicine. Indeed, both perceived usefulness and perceived ease of use are key components of technology acceptance in the technology acceptance model (TAM; Davis, 1989) and have been evidenced to be important factors in relation to the acceptance of telemedicine (Kruse & Heinemann, 2022; Nazari-Shirkouhi et al., 2023).

6.5 Conclusion

This study provided novel insight into the current use of telemedicine for Parkinson's care in the aftermath of the pandemic. The dual perspective, (pwP and HCPs) enabled the strengths and weaknesses of telemedicine to be understood while acknowledging service user experience and perspective within the broader framework of healthcare centred demands, norms and procedures. A number of benefits and difficulties were acknowledged in relation to the adoption of telemedicine. However, there was a general consensus that telemedicine had certain limitations and, as such, was not sufficient as a singular approach to Parkinson's care. Ultimately, both pwP and HCPs were in broad support of a hybrid

approach to telemedicine, though its application and standardisation across the UK would benefit from formalised guidance.

Chapter 7: Discussion

Having presented the four studies (chapters three to six), this chapter will firstly summarise their key findings. These findings are then integrated with existing literature and theory, and implications regarding Parkinson's-related policy, practice and services will be outlined. Next, the strengths and limitations of the thesis will be reviewed and suggestions for future research will be discussed. I will then reflect on the thesis and my development as an academic researcher. Finally, the chapter will conclude with the novel contributions to knowledge and final conclusions.

7.1 Summary of key findings

The four studies presented in the preceding chapters contributed to an understanding of the experience of living with Parkinson's during and in the aftermath of the COVID-19 pandemic. The research took a mixed methods approach and was carried out within a critical realist research paradigm. Additionally, the topic was understood through a biopsychosocial lens and in congruence with the interests of Parkinson's UK, a key stakeholder. The aims and key findings of the four studies are summarised below. A more detailed account of the purpose of progression between the individual studies can be found in section 2.4.

Study 1: A Systematic Review of the Factors Associated with the Psychological Wellbeing of People with Parkinson's in the COVID-19 Pandemic

The first study sought to identify risk factors of worsened psychological wellbeing of pwP during the pandemic. As such, a systematic review with narrative synthesis was carried out on 23 articles that reported quantitative analyses of the factors associated with the worsened wellbeing of pwP during the acute stage of the pandemic. The analysis identified worsening of motor symptoms, poor motor-related daily living experiences and motor symptoms during 'off time' (when symptom suppressing medication has worn off) as well as less physical activity as the most consistent risk factors of worsened or reduced psychological wellbeing.

Importantly, the review also highlighted the minimal inclusion of variables relating to psychosocial predictors and technology use, as well as the use of basic statistical analyses, limiting the insights that could be gained. These findings informed the investigation of the association between social engagement and the psychological wellbeing of pwP during the pandemic (chapter four) and the qualitative investigation of experiences with telemedicine in Parkinson's-related healthcare (chapter six).

As the literature review was carried out in April 2024, the search was updated in August 2025 to ensure recent research was captured in the thesis. Using the same procedure detailed in section 3.2.2, the search for new literature resulted in 463 articles, of which 455 were excluded through title screening. Of the remaining studies (n = 8), two relevant studies were identified after exclusion through abstract (n = 4) and full text screening (n = 2). Quality appraisal was carried out and the studies received a quality appraisal rating of 20 (Pan et al., 2024) and 13 (Rafizadeh et al., 2025) and thus scored above the conservative and liberal quality thresholds, respectively. Notably, however, unclear reporting in Rafizadeh et al. (2025) made the interpretation of some key findings unreliable.

Using a longitudinal design, the interpretable findings of Rafizadeh et al. (2025) suggested that age was positively associated with greater reductions in the subscales of a QoL measure. That is, that older pwP experienced greater reductions in QoL during the pandemic compared to before the pandemic. The second study carried out a cross-sectional analysis of the predictors of perceived stress and anxiety. Of note, there were significant differences in both anxiety and perceived stress between gender, education level, means of medical payment (self-funded, medical insurance, public expense, other), quality (well, general, poor) and time of sleep and disease duration (<5 years, 5-10 years, >10 years) and occupation. Additionally, stress varied significantly between age brackets (<41, 41-59, 60-79, <79) and differed depending on the nature of transport to a healthcare appointment (online remote medical treatment, driving or taxi, short distance public transport, long distance public transport). Overall, worse anxiety or stress was associated with female gender, higher age, a lower education level, less sleep,

poorer quality sleep and a higher disease duration. No significant changes in anxiety or stress were reported depending on ethnicity or comorbidity. Collectively, these findings did not change the pattern of results and their subsequent interpretation in the literature review (chapter three).

Study 2: Exploring social engagement and the wellbeing of people with Parkinson's during the COVID-19 pandemic - a hierarchical regression and moderation analysis

To better understand the role of psychosocial variables in the psychological wellbeing of pwP during the COVID-19 pandemic (chapter three), the second study explored the relationship between psychological wellbeing and social engagement with family and friends (as separate constructs). To this end, a hierarchical regression analysis (with social engagement with family and friends as predictors) and two moderation analyses (with social engagement with family and friends as moderators) were conducted on data from over 400 participants. With regards to hypotheses, it was predicted that social engagement with family and friends would independently predict wellbeing when controlling for demographic and illness-related variables. Next, it was predicted that the negative impact of motor symptom worsening on wellbeing would be less severe for participants with higher social engagement with family as social engagement would 'buffer' the negative impact of motor symptom worsening on psychological wellbeing. For friends, it was predicted that social engagement would not buffer against the negative impact on wellbeing of worsened motor symptoms because of disruptions to the quality of this social engagement. As predicted, social engagement with family and friends independently predicted wellbeing when controlling for symptom-related and demographic variables. However, the findings of the (two) moderation analyses were contrary to the hypotheses. Firstly, social engagement with family did not moderate the relationship. Secondly, the (negative) impact of motor symptom worsening on wellbeing was worse (i.e., exacerbated rather than buffered) for those with higher social engagement than those with lower social engagement. These unexpected findings were understood through the application of theory relating to the contextual nature of the buffering effect of social support.

Notably, demographic data suggested that pwP residing in NI, Wales and Scotland were not well represented in the data.

Study 3: Understanding the lived experience of Parkinson's-related healthcare in Northern Ireland before, during and after the COVID-19 pandemic: An interpretative phenomenological analysis

The third study was carried out because of the dearth of context-specific literature (and as such knowledge) regarding living with Parkinson's in NI, as highlighted in the social engagement study (chapter four). The importance of conducting the study was further substantiated by Parkinson UK's concerns about the quality of Parkinson's-related healthcare in NI. Given pertinent sociocultural and political differences between NI and England, the research aimed to investigate how pwP in NI experienced and made sense of their Parkinson's-related healthcare. As such, eight semi-structured interviews were conducted and analysed using Smith et al.'s (2021) IPA methodology. From this analysis, three group experiential themes were developed. The findings highlighted the centrality of resource limitations to participants' experiences and understanding of healthcare, the increase of self-management to protect healthcare needs, and participants' perceptions of the predominance of the biomedical approach to the treatment and management of symptoms. Though not the fundamental focus of the study, it was additionally apparent that participants had contrasting experiences with and thoughts about the use of telemedicine.

Study 4: Experiences with telemedicine in the aftermath of the COVID-19 pandemic: a dual perspective thematic analysis of people with Parkinson's and healthcare professionals

The final study built on the findings that telemedicine use predicted better psychological wellbeing outcomes during the pandemic (the literature review/chapter three) and that there exist contrasting opinions about its use (the NI study/chapter five). As UK policy (Department of Health and Social Care, 2022) suggests telemedicine will be increasingly adopted, understanding the impact of its use on healthcare experiences is an important topic. This study, therefore,

sought to understand experiences with the use of telemedicine in Parkinson's-related healthcare prior to, during and after the COVID-19 pandemic from the perspective of those using (pwP) and providing (HCPs) them. Congruently, 16 semi-structured interviews were conducted with pwP (*n* = 10) and HCPs (*n* = 6) and analysed together using reflexive thematic analysis. The five themes that resulted from the analysis focused on the extent of current integration into the NHS, its use in a resource strained environment, its impact on assessment by HCPs, the benefit of the hybrid model and the importance of freedom of choice.

7.2 Integration of findings with existing literature

The following section will integrate the research findings from the four studies (chapters three to six) with existing global and UK literature. In congruence with the aforementioned plan for the integration of mixed methods findings (see section 2.1), conclusions drawn from individual studies will be woven into three themes that run through the thesis and contribute to the overarching research aim of understanding the difficulties of living with and supporting Parkinson's in a post-COVID health and social context. The themes are i) wellbeing in the (post-) COVID era, ii) resource limitation and iii) person-centred healthcare. In keeping with the 'real' layer of critical realism, consideration will be given to the unobservable mechanisms that underpin the experiences of pwP (see section 2.2.3).

7.2.1 Wellbeing in the (post-)COVID era

The findings of the four studies, taken collectively, contributed to a greater understanding of the wellbeing of pwP during and in the aftermath of the COVID-19 pandemic. These integrated findings will now be discussed.

In the psychological wellbeing review, predictors related to the physical symptoms of Parkinson's (e.g., worsening of or more motor symptoms, poor motor-related daily living experience) were the most consistent risk factors of poor psychological wellbeing during the COVID-19 pandemic. Looking to broader literature, the relationship between symptom worsening and poor wellbeing may have been mediated by, for example, reductions in independence, autonomy or stigma. These have documented associations with motor symptom worsening (Macleod et al.,

2016; Maffoni et al., 2017) and are themselves associated with poor psychological wellbeing (Crooks et al., 2025; Vescovelli et al., 2018). This suggestion is supported by the findings of a qualitative pandemic study which reported that, because of symptom deterioration, participants experienced "the encroachment and acceleration of the Parkinson's future" (Murray et al., 2024, p. 155). That is, the experienced deterioration of symptoms (Hero et al., 2022; Murray et al., 2024; Rafizadeh et al., 2025; Simieli et al., 2022) made especially salient their 'Parkinson's future' where they would lose independence and autonomy (Macleod et al., 2016).

The combined findings of the psychological wellbeing review (chapter three) and the social engagement study (chapter four) highlight the importance of not just biomedical but also psychosocial causes of illness in pwP during the COVID-19 pandemic. The insufficient analysis of psychosocial variables is likely related to the strong tradition of biomedical thinking in Western healthcare (see sections 1.2.4 and 2.3.1) which encourages the investigation of biological rather than psychosocial predictors of health (Rocca & Anjum, 2020a). To strengthen understanding of psychosocial predictors of wellbeing, chapter four investigated the importance of social engagement with both friends and family on the psychological wellbeing of pwP when controlling for the impact of symptom-related variables such as symptom worsening as well as demographic variables (see also Eccles et al., 2023a). Drawing on a review of similar pre-pandemic investigations of psychosocial predictors of wellbeing outcomes in pwP, other potentially relevant predictors include perceived control, the strength of an individual's Parkinson's identity (or its influence on their life), and personality types (Garlovsky et al., 2016).

In addition to the psychological wellbeing review (chapter three) and social engagement study (chapter four), the findings of the NI and telemedicine studies (chapters five and six) provided additional insight into the wellbeing of pwP during and in the aftermath of the pandemic. In both studies, the reported experiences of reduced autonomy in aspects of (Parkinson's) healthcare-related decision making negatively impacted outcomes in pwP, perhaps given the importance of control

and related concepts (Rodgers et al., 2008) in coping with illness generally and (psychosocial) wellbeing outcomes (Biggs et al., 2017; Eccles et al., 2011; Pearlin & Schooler, 1978). In the NI study, this was expressed especially well by Grace, who described feeling at the 'behest' of healthcare services, which suggested a (domain specific) lack of control over healthcare access. Similarly, the telemedicine study highlighted that pwP in especially resource limited areas or where the provision of information about available healthcare options was insufficient felt a lack of control over the use of telemedicine services (e.g., phone and video consultations).

Finally, the suggested localisation of the resource limitations identified in the NI and telemedicine studies (chapters five and six) means that regional health disparities could, using positivistic language, be regarded as 'risk factors' for worsened wellbeing outcomes. These included insufficient or inconsistent staffing (i.e., a lack of shared understanding between HCP and service user), a perceived over-reliance on telemedicine due to resource limitation, those with lower health literacy (see section 1.2.4), pwP who had less desire to be actively involved in their care or, conversely, who were perceived by HCPs to be 'suitable' candidates for telemedicine (i.e., younger, stable, capable with technology). The identification of such 'risk factors' through qualitative means are especially useful in research relating to telemedicine given the generally high quantitative reports of satisfaction with telemedicine in the general population and pwP (e.g., Vinadé Chagas et al., 2024; Wilkinson et al., 2016). When using quantitative research methods, important experiences were lost because they were outweighed by more positive experiences (which are thus defined as 'generally' positive) and because the deductive nature of the research did not capture pertinent dimensions of experiences that are not yet understood in theory or practice (Barroga et al., 2023).

7.2.2 Resource limitation

In addition to wellbeing, this thesis advanced understanding of the nature and impact of resource limitations in Parkinson's-related healthcare during and in the aftermath of the COVID-19 pandemic, which will now be outlined. The impact of these on the experience of healthcare highlights the need for healthcare reform.

The NI (chapter five) and telemedicine (chapter six) studies highlighted regional differences in the resource strain that pwP experienced in relation to Parkinson's healthcare services during and in the aftermath of the COVID-19 pandemic. In the telemedicine study (chapter six), which incorporated participants predominantly from England, resource strain was suggested to be caused by the 'backlog' that occurred as a result of the COVID-19 pandemic (Health and Social Care Committee, 2021; Department of Health and Social Care, 2022). This is congruent with the accounts of some pwP in the telemedicine study who suggested that phone and video consultations were being used to improve the efficiency of healthcare provision in light of increased financial strain. Contrastingly, the accounts of pwP in NI, such as historic challenges with care and established coping techniques (i.e., existing prior to the difficulties experienced during the pandemic), suggested longstanding issues with resource deprivation in the region. In this sense, the 'deficits' in healthcare provision that pwP experienced in NI were not novel, but consistent with pre-existing patterns of poor service quality. Such experiences are congruent with the findings of a neurological review (Department of Health, n.d.) that highlighted prominent deficits in neurological care services including, for example, staff shortages and the insufficient capacity of neurological services prior to the onset of the pandemic in 2020.

Within the resource strained healthcare context of NI, the perceptions of Parkinson's in the general public and by HCPs were suggested to impact negatively the quality of care. Siobhan, a participant in the study who had experience of lobbying for Parkinson's, suggested that beliefs about the condition's (lack of) severity, which has been evidenced in global populations (Crooks et al., 2023), meant that the finite resources were allocated to more well known and 'severe' conditions such as Alzheimer's. As discussed in section 1.2.5, insufficient understanding of Parkinson's is a global issue (Crooks et al., 2023) that, despite being more evident in low- and middle-income countries (World Health Organization, 2022a), nonetheless impacts the allocation of resources in high income countries such as the UK. In the Republic of Ireland, the lack of Parkinson's specific knowledge has also been evidenced to be prevalent in HCPs

working with pwP across healthcare settings, with negative impacts on the quality of care (O'Shea et al., 2024). Though vital efforts to improve awareness of Parkinson's in HCPs in NI are underway (e.g. Crooks et al., 2023), sufficient understanding of the needs of pwP is also necessary to encourage decision makers at policy level to improve the allocation of resources. As suggested by Crooks et al. (2023), increasing the condition specific knowledge of the general public could shape public opinion and ultimately influence the decision makers that shape healthcare policy in congruence with these opinions.

In addition to the importance of challenging attitudes and increasing education about Parkinson's, the findings of the telemedicine study suggest that the quality of healthcare services could be additionally improved by the integration of telemedicine into healthcare services. As previously noted, the adoption of telemedicine was outlined in policy as a key approach to addressing the pandemic-induced backlog in healthcare services in England (Health and Social Care Committee, 2021; Department of Health and Social Care, 2022) as well as the deficits noted in NI (Department of Health, n.d.). The need for greater efficiency is consistent with global perspectives on healthcare given the rising cost of services, meaning cost-effectiveness is vital for maintaining and improving the service quality (Berwick et al., 2008; Dorsey et al., 2018). Examples noted in the telemedicine study (chapter six) include the reduction of travel (for some HCPs), quicker check-ups or reviews, and more accurate (thus less wasteful) medication plans and allocation of advanced therapies (through the application of wearable devices that track symptoms). These findings are consistent with broader literature that emphasises the cost-effectiveness of the treatment and management of chronic neurological conditions through phone and video conferencing, digital therapies and wearable devices (Chaudhuri et al., 2022; Maida et al., 2024; Salsabilla et al., 2021).The implementation of cost-saving measures, such as the adoption of telemedicine, are especially pertinent to Parkinson's services globally given the anticipated cost of rising prevalence rates (Dorsey et al., 2018; Zhu et al., 2024). Indeed, in the telemedicine study (chapter six), one HCP, a Parkinson's nurse, suggested that taking advantage of the efficiency of telemedicine was a

necessity given the expected increasing pressure on services that were already felt to be strained.

Importantly, however, the telemedicine study (chapter six) additionally highlighted potential concern regarding the use of telemedicine in especially resource limited localities. Specifically, individuals with experience of healthcare services relying on telemedicine due to resource limitations felt that this prevented HCPs from knowing the 'true' extent of their difficulties. From the HCP perspective, this is likely a result of the reduced number of 'clinical indicators' that are available to HCPs when using telemedicine. The HCPs in the study, who were experts in their field, reported it was necessary to consider the suitability of service users (e.g., pwP who could 'account' for themselves, a pre-existing relationship between HCP and service users, a stable condition and less severe deterioration). However, such insight is predicated on knowledge and experience that cannot always be guaranteed, for example, in regions where training is not sufficient, where the employment of specialist nurses is unsatisfactory, where staff turnover is high, or where staff are required to 'fill in' the roles of others. Moreover, the total reliance on telemedicine is not consistent with the NHS commitment to person-centred care (Department of Health and Social Care, 2023), as service users often feel telemedicine is less accurate and generally not as 'good' as in-person healthcare (Conradsson et al., 2024).

Finally, in addition to highlighting the salience of resource limitation to the healthcare experiences of pwP, the qualitative studies suggest that such limitations may increase dependence on the attributes of service users. This was evident in the telemedicine study (chapter six) where both HCPs and pwP suggested that the reduction of available clinical indicators when carrying out phone and video consultations increased reliance on the ability of pwP to identify and effectively express their difficulties. The potential impact is evident in the NI study (chapter five) where pwP reported increasing self-management to protect their health and wellbeing against insufficient healthcare. In this theme, participants highlighted that, because they were not experts in Parkinson's signs and symptoms, the dependence on their own understanding of the condition

meant it was possible that deterioration would be missed. Health literacy and communication abilities are commonly considered to be social determinants of health (e.g., Nutbeam & Lloyd, 2021; Schillinger, 2020), which are important in considerations of health disparities. As such, the (over) reliance on telemedicine services to address resource strain may exacerbate the impact of such social determinants of health in those with either less ability or desire (Nijhuis et al., 2019; Zizzo et al., 2017) to engage actively in their healthcare. Such disparities should be understood and appropriately addressed when seeking to improve the quality of healthcare in NI and when implementing telemedicine services both in the UK and globally.

7.2.3 Person-centred healthcare

Finally, the findings of the thesis uncovered the preferences of pwP with regard to their healthcare. However, notable gaps were apparent between these preferences and the actual experience of healthcare despite policy-level commitments to person-centred care.

The NI study (chapter five) suggested that HCPs' approaches to health management in the region did not align with the self-described needs and experiences of pwP and, as such, were not sufficiently person-centred. The general approach of healthcare in NI was described by Cillian as 'chuck a few pills at you, do some exercise, you'll be fine'. This participant description depicts a care system that focused on the biomedical aspects of Parkinson's (Santos et al., 2018) and did not consider the broader (bio)psychosocial causes of illness (see section 2.3.1) that are synonymous with a person-centred approach (Moreira et al., 2022; Phelan et al., 2020; Tramonti et al., 2021; Saxena et al., 2022). For example, a meta-ethnography of 37 international studies on living with Parkinson's (Vlaanderen et al., 2019) identified the impact on social identity (e.g., changes to the sense of self, reduced ability to engage in normal activities), psychosocial challenges and adjustment (e.g., social anxiety, stigma, uncertainty about functioning, coming to terms with the diagnosis) and interruptions to life (e.g., unpredictable motor fluctuations, social isolation, concern about burdening others, communication challenges). Such (non-biomedical) causes of illness were

acknowledged in participants' accounts of their health and healthcare. For example, negative impacts on QoL and wellbeing were associated with dealing with their diagnosis, stigma, and changes to their sense of self. These findings suggest that the needs of pwP in NI with regard to the support for the psychosocial aspects of living with Parkinson's are not yet sufficiently met by NI healthcare services.

As well as the incongruence between pwP's (biopsychosocial) perceptions of need and the (biomedical) care received, the NI study (chapter five) additionally suggested insufficient autonomy in the ability of pwP to access preferred services. This preservation of autonomy in decision making is an important aspect of the progression to person-centred care from medical paternalism (see section 1.2.5). Autonomous decision-making has been argued to be necessary for achieving patient empowerment, to encourage self-management and, ultimately, to improve service quality (Aslani, 2013; Kunneman & Montori, 2017). As outlined in the NHS England constitution (Department of Health and Social Care, 2023), the NHS pledges to ensure autonomy by making sure service users can make informed choices (by ensuring accurate information is provided about the range and quality of services) and facilitating service users' involvement in their own care (by being involved in planning, decision making, and having access to information that enables such choices to be made). However, participant reports in the NI study (chapter five) suggest that some pwP in the region experienced difficulties in accessing services outlined in the NICE guidelines (National Institute for Health and Care Excellence, 2017). Regional healthcare services should aim to facilitate autonomy of choice in accessing the services outlined in the Parkinson's NICE guidelines (National Institute for Health and Care Excellence, 2017).

The importance of autonomy in the provision of telemedicine services was additionally highlighted in the telemedicine study (chapter six). For HCPs, telemedicine services were felt to improve the person-centredness of healthcare as it increased the options that pwP could access depending on their personal preferences and needs (e.g., fitting appointments into work schedules, physical difficulty travelling, cost of travelling, perception of needs). However, from the

perspective of pwP, autonomy over when services were received via phone and video consultations was sometimes undermined by insufficient information regarding choice over its usage. The lack of such information may have been caused by the sudden, needs-based changes to the nature of healthcare that took place in response to the pandemic (Valdes et al., 2022). However, given the importance of the provision of accurate and comprehensible information in service user autonomy (Aslani 2013; Kunneman & Montori, 2017), such information is key to ensuring person-centred telemedicine services. As well as a lack of information, pwP in the telemedicine study additionally reported feeling a lack of autonomy because limited resources meant some services were employing telemedicine to address resource strain. Reports that NHS services were facing a 'backlog' because of the pandemic (Health and Social Care Committee, 2021) suggests a potential amelioration as services recover. However, consideration should be given to regions with evidenced health disparities related to pre-pandemic resource deprivation or where the quality of services was previously a cause for concern (Parkinson's Excellence Network, 2022).

7.3 Implications for policy, practice and services

The findings of this thesis highlighted important insights regarding the experience of living with Parkinson's during and in the aftermath of the COVID-19 pandemic. To complement the policy, practice and service recommendations presented in each chapter, the implications of the integrated findings presented in section 7.2 will be explored. Additionally, a summary of the key findings and recommendations is provided in Table 8.

The most prominent finding of the thesis was the centrality of resource limitations in the experience of Parkinson's-related healthcare services (see section 7.3.2). Specific deficits identified in the present thesis include long waiting times that were sometimes felt to impact the ability of HCPs to detect deterioration, insufficient (or inconsistent) staff coverage, and (NI specific) difficulty accessing broader care services that support an MDT/holistic approach to the treatment and understanding of the challenges associated with living with Parkinson's. As

previously noted, the relationship between resource deprivation and Parkinson's care seemingly differed between NI and the broader UK context, with difficulties in NI having existed prior to 2020 and those in England more closely intertwined with the backlog that arose during the pandemic. Nonetheless, addressing resource strained care services is central to the post-pandemic reform of both UK and NI healthcare services, evidenced by the UK Government's outline for dealing with the pandemic 'backlog' (Department of Health and Social Care, 2022) and NI's neurological review (Department of Health, n.d.). The recommendations outlined in these documents provide top-down guidance for addressing resource limitations and the enactment of these recommendations will be vital for improving the experience of accessing post-pandemic Parkinson's-related health and social care services.

In acknowledgement of resource limitations in UK healthcare services, both NI's neurological review (Department of Health, n.d.) and the UK Government's outline for dealing with the pandemic 'backlog' (Department of Health and Social Care, 2022) suggest the integration of telemedicine to improve the financial efficiency of care services. The suitability of implementing such services was highlighted within the telemedicine study where both HCPs and pwP felt that such services could increase the efficiency of, and improve access to, strained care services. However, the telemedicine study (chapter six) additionally highlighted important implications that should be addressed as such services are implemented. These include ensuring service user choice, providing guidelines for when telemedicine is suitable, and ensuring HCPs are sufficiently trained. Consequently, the widespread implementation of telemedicine services would be supported by the adoption of an established framework.

One feasible framework to support the use of telemedicine services by HCPs is PERCS (Planning and Evaluating Remote Consultation Services; Greenhalgh et al., 2021). This framework was developed in response to the increased implementation of technology during the COVID-19 pandemic, which was argued to be characterised by contradiction and tension (Greenhalgh et al., 2021). The seven domains (reason for consulting, the patient, the clinical relationship, the

home and family, technologies, staff, the healthcare organisation, and the wider system) outline key practicalities and considerations relevant to the use of telemedicine, informed by published and ongoing research. Importantly, rather than providing a rigid, formulaic outline, the framework instead supports thinking regarding how best to provide services in different contexts. This flexibility could enable its use across MDT-wide Parkinson's care while also enabling HCPs to apply their clinical judgement based on their experience and understanding of the localised contextual needs. Rather than the trial-and-error implementation of services that was identified in the telemedicine study (chapter six), the adoption of PERCS would encourage a more concerted and consistent effort towards improving the quality of telemedicine services across the NHS. However, it should additionally be noted that there may still exist inequalities in the quality of services depending on the expertise of the HCPs and NHS trust-level differences.

With regards to person-centred care, some participants in the telemedicine study reported that their regional healthcare services over-relied on telemedicine to provide more (cost) efficient healthcare services in light of resource strain. In addition to a general lack of control, these participants reported feeling that the quality of the care they received was negatively impacted. Given the systematic nature of resource deficits, policy level changes are likely required. However, the person-centredness of care could additionally be supported on a service level in a number of ways. Partial amelioration would be supported by implementing the PERCS framework (Greenhalgh et al., 2021) and improving staff training to ensure the clinical implications of telemedicine are sufficiently understood. Additionally, it could be useful to update Parkinson's NICE guidelines (National Institute for Health and Care Excellence, 2017) to, for example, introduce guidance regarding the maximum amount of time (or number of consultations) between which pwP should be seen in-person.

Finally, the results and discussion throughout this thesis have highlighted ways in which post-COVID health and social care services do not meet the current needs of pwP. Most notably, there is a general lack of acknowledgement in research (psychological wellbeing review), practice (NI study) and guidelines (National

Institute for Health and Care Excellence, 2017; Foley & Mobley, 2025) of psychological wellbeing and the related causes of illness. In this respect, the treatment of Parkinson's in healthcare is less advanced than other neurological conditions such as dementia (Gibson, 2017) or epilepsy wherein, for example, non-pharmacological treatments and the importance of providing coordinated care services for mental health issues are made explicit (National Institute for Health and Care Excellence, 2022). The refinement of Parkinson's NICE guidelines would be an important step towards better addressing the importance of wellbeing for pwP, as it would legitimise the increased recognition of the importance of wellbeing at practice level.

However, the updating of NICE guidelines is made difficult by the deep rooted and systemic causes that likely relate to misinformed and stigmatised beliefs about Parkinson's (Crooks et al., 2025) such as those discussed in section 1.2.5. To better address wellbeing in Parkinson's-related healthcare in the short term, a number of service-level changes could be implemented. Currently, the screening of wellbeing by Parkinson's nurses, who are central to the coordination of the Parkinson's MDT in the UK (National Institute for Health and Care Excellence, 2017; Thomas et al., 2024), occurs at their discretion and informed by clinical expertise. To increase the consistency of wellbeing screening across the NHS and support the early recognition of concerns about wellbeing, this screening could be embedded in clinical practice norms. However, the appropriate consideration of wellbeing in Parkinson's is additionally hampered by the cost associated with providing psychological support if concerns about wellbeing are identified. Congruently, NHS services could enhance sign-posting to Parkinson's-specific or general peer support groups or activities. Indeed, a systematic review of the benefits of peer support for pwP concluded that these interactions improved social support and contributed to pwP living a meaningful and satisfying life (Gerritzen et al., 2022).

7.4 Limitations

The following section will note the limitations of the studies specific to the whole thesis (see the discussion sections of chapters three to six for study-specific limitations).

The most consistent limitation across studies relates to the sampling of the Parkinson's population which has implications for the transferability and generalisability of both the qualitative and quantitative findings, respectively. People with Parkinson's in the NI (chapter five; *M* = 62 years) and telemedicine (chapter six; Modal group = 60 – 69 years) studies were younger than the average age of onset of Parkinson's, which peaks between 70 and 79 years (Hirsch et al., 2016). This limits the transferability of the findings to older pwP. In the NI study, the representation of older participants would have generated a more nuanced account of experiences with healthcare in NI given the increased reliance on healthcare services as the condition progresses (Read et al., 2019). Similarly, perspectives of older pwP on telemedicine were not well represented, which is important as age is associated with technology use and acceptance (Alashek & Ali, 2024; Pang et al., 2022). Nevertheless, some insight was gained from HCP accounts of experiences with the use of telemedicine with pwP of all age ranges.

Age was also a limitation of the social engagement study (chapter four). Again, it was found that participants in the regression (*M* = 67.3 years) and moderation (*M* = 64.7 years) analyses were younger than the peak Parkinson's incidence (70-79; Hirsch et al., 2016). Moreover, participants excluded due to missing values have significantly higher disease duration. In acknowledgement of this, where possible, participants' missing data was prorated to enable the inclusion of as much data as possible. Nonetheless, this limitation across all studies is important because the experience of Parkinson's has been suggested to differ with age. For example, research

Table 8

A summary of the relationship between the implications and recommendations, key findings, and the thesis aims

Secondary aim 1 – Understanding the impact of the pandemic on people with Parkinson's	Secondary aim 2 – Understanding the nature of Parkinson's health and social care	Implications/ recommendation
- Some people with Parkinson's experienced worse psychological wellbeing during the pandemic and this likely has long-term health implications	- The post-COVID health and social context will likely experience increased demand on services	-Supporting people with Parkinson's in rebuilding their psychological and physical health should be a key focus of post-COVID health and social care services
- Psychological needs were often not sufficiently supported	-Healthcare guidelines such as NICE do not sufficiently address the range of needs that people with Parkinson's experience - Comprehensive support (e.g., referrals to relevant HCPs and therapies) is undermined by structural and resource limitations	-Embed consideration of psychological outcomes (and relevant treatment) into formal care guidelines such as NICE - Embed consideration of psychological health in screening (e.g., Parkinson's nurses) -Address resource deficits and improve the quality of MDT care
-People with Parkinson's with greater levels of social engagement reported higher wellbeing. However, the impact of social engagement with friends on wellbeing was not always positive	- Health and social care services do not sufficiently acknowledge the impact of social engagement with friends on health outcomes	- The theoretical underpinnings of this engagement should be better understood (e.g., 'types' of social engagement, how these relate to different social actors, and the impact of this in different contexts) - The relevance to improving clinical outcomes should be acknowledged and addressed
-The use of telemedicine exacerbated pre-existing healthcare inequalities for pwP in socioeconomically deprived areas	-The financial efficiency of telemedicine means it is likely to be widely adopted across the UK NHS	-Implement guidelines that account for the limitations of telemedicine in different contexts -When investigating the quality of Parkinson's healthcare services, incorporate nuanced assessment of the use/impact of telemedicine on care - Ensure sufficient staff training alongside the implementation of telemedicine services
-The experiences of denuded healthcare in NI mirrored long-standing deficits	-Post-COVID healthcare services in NI are marred by longstanding resource limitations	-The financial difficulties underpinning denuded healthcare services in NI require structural reform and addressing at a policy level

suggests that younger pwP are more likely to experience psychological distress (e.g., depression) and disruption to life (e.g., loss of employment, disrupted family life; Schrag et al., 2003). In relation to the pandemic, older pwP are more likely to have been impacted by disruption to healthcare services due to their increased reliance (Wolff et al., 2022) in such services. Consequently, the generalisability of findings to older pwP is limited and this should be addressed in future research.

In addition to age, the representation of cultural and ethnic background is minimal across the thesis. This is especially relevant in the context of the pandemic where research suggests that healthcare disparities were exacerbated (Morales & Ali, 2021). For example, pandemic research suggests that people from minority ethnic groups in the UK experienced information barriers, stigma and increased risk of severe outcomes after catching COVID (Germain & Yong, 2020; Siddiq et al., 2023; Winsper et al., 2024). Similar findings were identified with regard to global heath disparities, where, for example, pwP in low- and middle-income countries reported greater difficulties accessing medication than those living in high-income countries (Cheong et al., 2020). Overall, this suggests that the transferability and generalisability of the findings of this thesis may be limited with regards to the cultural and global application of the findings.

Another limitation of the research was its scope with regards to understanding the difficulties of living with and supporting pwP in a post-COVID health and social context. Future research would benefit from a more in-depth understanding of the diverse perspectives of supporting individuals with Parkinson's. A particularly useful line of research could be investigating the impact of difficult healthcare experiences (in relation to healthcare in NI and the use of telemedicine) on the psychological wellbeing of the partners and spouses who support pwP. Such research is important given the documented challenges that family and friends, who commonly provide care and support (McLaughlin et al., 2011), face with regards to the impact on their wellbeing, stress and quality of life (Drutyte et al., 2014; Aamodt et al., 2024; Bhimani, 2014; Macchi et al., 2020; Rosqvist et al., 2022).

Finally, it should be noted the present research was conducted with the ultimate goal of understanding the extent to which post-COVID health and social care services align with service user needs and preferences. Although the research and recommendations were shaped around the UK NHS, the findings of this thesis are likely to be particularly misaligned with paternalistic healthcare services (see section 1.2.5)

7.5 My learning

I began this PhD in October of 2021, when COVID-19 restrictions had reduced, but society had not yet returned to 'normal'. Having lived in Germany through the majority of the pandemic with limited opportunity to return home, the first half of my study was similarly characterised by isolation and minimal in-person contact at university. This context set the scene for the early years of my research, wherein the challenges of PhD study were traversed alongside adjusting back to life both in the UK and after having limited contact with friends, family and colleagues over the previous years.

The PhD that I eagerly accepted was for a project with the pre-determined focus of 'Understanding what it means to live with and support Parkinson's in a post-COVID health and social context'. As I previously noted, though I hold a BSc and MRes in Psychology, health research as an academic discipline was new to me. Although I looked forward to the opportunity to advance my skillset, the breadth of new skills and subject specific knowledge that I was required to gain to research Parkinson's effectively was nonetheless daunting. My overwhelmingly quantitative education meant that I especially enjoyed the prospect of engaging with qualitative research methods. Though, as I am sure my supervisors would agree, the progression from small scale, insulated, quantitative research brought additional challenges with regards to the advancement of thinking about research and the practical skills necessary for 'real world' quantitative research. In addition to methodological knowledge, I also spent time building fundamental subject-specific knowledge related to all aspects of Parkinson's. This experience, in addition to engaging with my insightful supervisors, gave me a feel for the current state of Parkinson's

research, controversies and gaps which lay the foundation for research I conducted as well as the interpretation of findings. This was particularly the case with regards to the pervasiveness of the biomedical model in Parkinson's care and the subsequent adoption of the (bio)psychosocial approach to illness as a theoretical lens.

Developing this knowledge was psychologically challenging, as it involved grappling with being a novice in an area I knew was essential for conducting purposeful and nuanced research. One of the most difficult experiences occurred with the IPA (NI) study (chapter five) which, in hindsight, was a bold choice for a first endeavour into qualitative research. Generally speaking, getting to grips with qualitative research was challenging because of what was, at the time, my positivistic mindset. However, because I chose to conduct a study using IPA, this difficulty was layered with the challenge of getting to grips with the concept of phenomenology and how to apply this to both data collection and analysis given its centrality to the interview guide, data collection and the phenomenologically rooted 'group experiential themes'. Despite the difficulty, the experience of successfully navigating this challenge of becoming acquainted with new fields of study, subject knowledge and (theoretical and practical) methodological skills means I am now more self-assured in my ability to do so successfully in the future.

Reflecting on carrying out a PhD, it was clear that an important aspect of doing so successfully was finding the motivation. A number of things come to mind here. First were the milestones I celebrated along the way which signified clear progression and motivated me to meet the next. One of the most pertinent of these was the gradual (and then very sudden) improvement of my writing skills, which unlocked my ability to express coherently my thoughts and understanding to others. I also found the direct contact I had with pwP during the qualitative interviews especially motivating. In these interviews, I met open individuals who shared their story with me and personalised the impact of (often) challenging healthcare experiences, which reinforced the importance of the work I was doing. This was compounded by personal experience of the practical and emotional consequence of existential healthcare threats and difficulty navigating healthcare

systems when, at the start of my third year of study, my step-father had a near death experience which resulted in a traumatic brain injury.

Overall, carrying out a PhD has fundamentally changed my perspective on research and the world. I began the study with an under-appreciation for qualitative research and a two-dimensional view of research and living with Parkinson's and my academic skillset and subject knowledge have undoubtedly increased. However, more importantly, I now feel capable of approaching future work with an open, systematic and critical mind that will enable me to be effective in the work I carry out after completing the PhD. I look forward to applying my mixed methods skills to a meaningful purpose, hopefully in an interdisciplinary environment.

7.6 Contribution to knowledge

In addition to the research gaps that were filled in each of the studies (see chapters three to six), these findings broadly contributed to an understanding of the difficulties of living with and supporting pwP in a post-COVID health and social context. This was firstly through the generation of knowledge about the post-COVID needs of pwP. Though it has been acknowledged that the pandemic resulted in long-term negative impacts on the psychological and physical health of pwP, the systematic review identified sub-groups that were most at risk of these long-term negative impacts. This research, therefore, is important in understanding the landscape of post-COVID health needs in pwP, which can then inform the allocation of health and social care. More generally, this thesis contributed to an understanding of the extent to which healthcare services during and in the aftermath of the pandemic aligned with the needs and preferences of pwP. The qualitative investigation of experiences with telemedicine provided an especially useful contribution given the preponderance of quantitative literature in the field. In doing so, the research identified clinically important findings that would otherwise have been lost through quantitative investigation. Additionally, to complement existing research that identified gaps in healthcare in NI, study five highlighted the impact of these on the actual healthcare experiences of pwP.

Collectively, this thesis provided novel insight into the impact of the pandemic on pwP, the breadth and impact of resource limitations and the suitability of care services to the post-COVID needs and preferences of pwP.

7.7 Conclusion

This thesis presents a mixed methods investigation of what it means to live with and support Parkinson's in a post-COVID health and social context. At the time of writing, the UK healthcare service is undergoing significant reform to address the backlog that was caused by the pandemic and the increasing financial strain on services. In a time of transition, these studies generated knowledge important for the reform of post-COVID healthcare services in a way that aligns with the needs and preference of pwP. Various deficits were identified in the understanding and treatment of Parkinson's in academic literature and healthcare practice. Those relating to resource limitation require support from decision makers and the more efficient use of currently available resources. More generally, there are gaps between the provision of healthcare services and the actual needs of pwP. Supplementing financial changes, the quality of care for pwP would benefit from greater consideration of (and support from MDTs for) the range of difficulties associated with living with Parkinson's, especially with regards to the impact on psychological wellbeing.

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Appendices

Appendix A. Database key terms/subject headings

Database	Key terms/subject headings	
	Parkinson's	COVID-19
PsycINFO	'Parkinson's Disease' OR Parkinsonism	Coronavirus OR "COVID-19" OR Pandemics
MEDLINE	Parkinsonian Disorders OR Parkinson Disease	SARS-CoV-2 OR COVID-19
Embase	Parkinson disease	Severe acute respiratory syndrome coronavirus OR coronavirus disease 2019
CINAHL	"Parkinson Disease" OR "Parkinsonian Disorders"	"COVID-19" OR "SARS-CoV-2" OR "COVID-19 Pandemic"
Web of Science	n/a	n/a

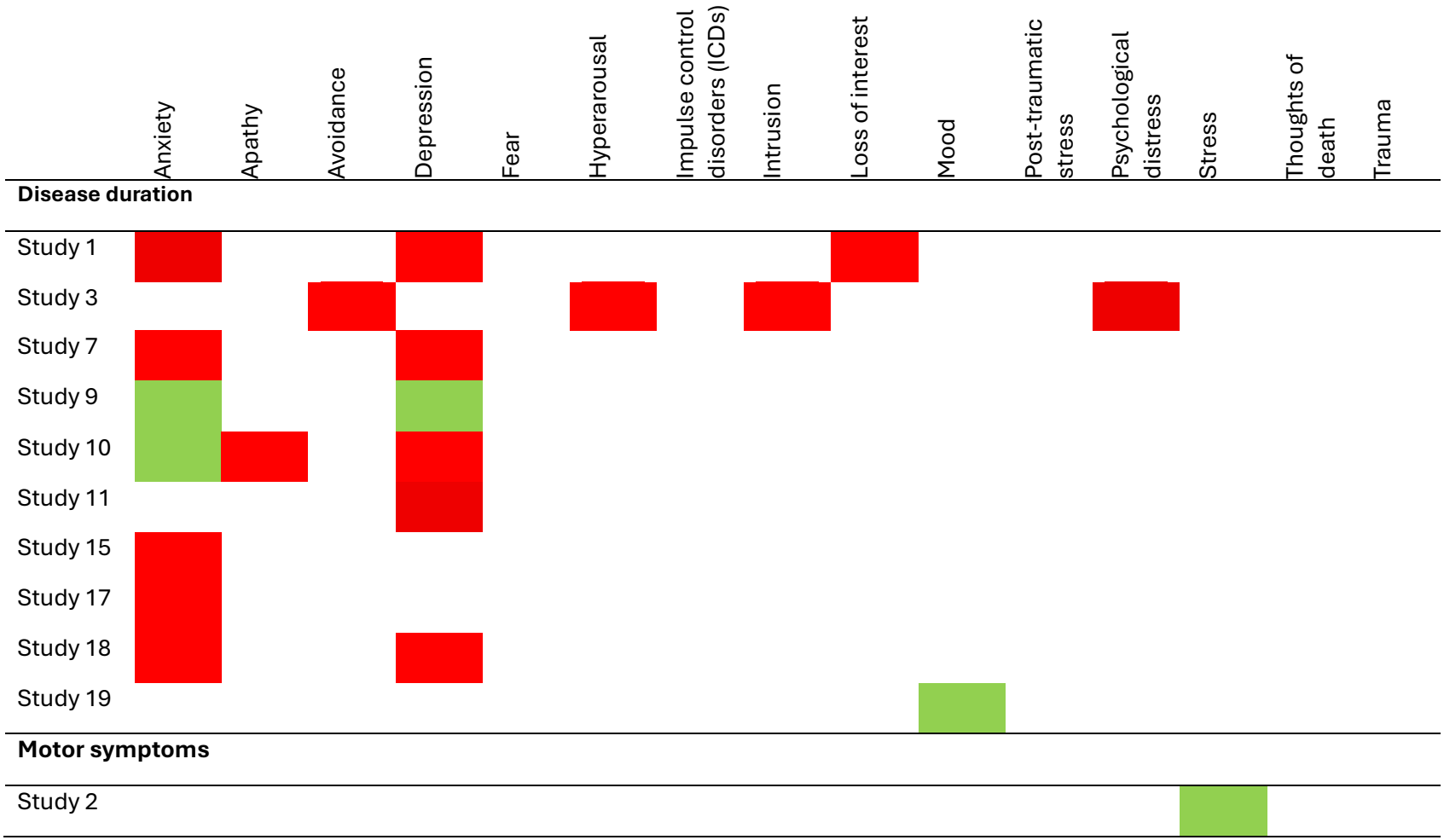
Note. These reflect database functionality at the time of search.

Appendix B. Breakdown of quality appraisal scores

Study number	Q1 Question/objective sufficiently described?	Q2 Study design evident and appropriate?	Q3 Method of participant selection or source of input variables described and appropriate?	Q4 Subject characteristics sufficiently described?	Q8 Outcome and exposure measure(s) well defined and robust to measurement bias?	Q9 Sample size appropriate?	Q10 Analytic methods described/justified and appropriate?	Q11 Some estimate of variance reported for the main results?	Q12 Controlled for confounding?	Q13 Results reported in sufficient detail?	Q14 Conclusions supported by the results?	TOTAL
1	2	2	2	1	1	1	1	1	0	2	1	14
2	2	1	2	1	2	2	2	2	1	2	2	19
3	2	1	2	2	1	1	2	2	2	2	2	19
4	2	2	2	2	1	2	2	2	2	2	2	21
5	2	2	1	1	2	1	2	0	0	0	1	12
6	2	2	1	2	2	1	1	1	1	1	1	15
7	2	2	2	2	2	1	2	0	1	2	2	18
8	2	2	2	1	1	2	2	2	2	2	2	10
9	2	2	2	1	2	1	2	2	0	2	1	17
10	2	0	2	0	2	2	2	2	0	2	2	16
11	2	2	2	2	2	2	2	2	1	2	2	21
12	2	1	1	1	1	1	2	2	0	2	2	7
13	2	1	2	1	2	1	2	1	1	2	2	5
14	2	2	2	0	2	2	2	2	0	2	2	18
15	2	2	1	2	1	2	2	2	1	2	1	18
16	2	2	2	2	2	1	1	1	2	2	2	19
17	2	2	1	2	2	1	1	1	0	2	1	15
18	2	2	2	2	2	1	2	1	1	2	2	19
19	2	2	2	1	1	1	2	1	1	2	2	17
20	2	2	2	2	1	1	2	2	2	2	2	20
21	2	1	2	2	1	1	2	2	1	2	2	18
22	2	2	2	2	2	2	2	2	0	2	2	20
23	2	2	2	2	1	2	2	2	1	2	2	20

Note. Green = 2 points, orange = 1 point, red = 0 points. Questions 5, 6 and 7 were not applicable. Based on Kmet et al's (2004) quality appraisal tool.

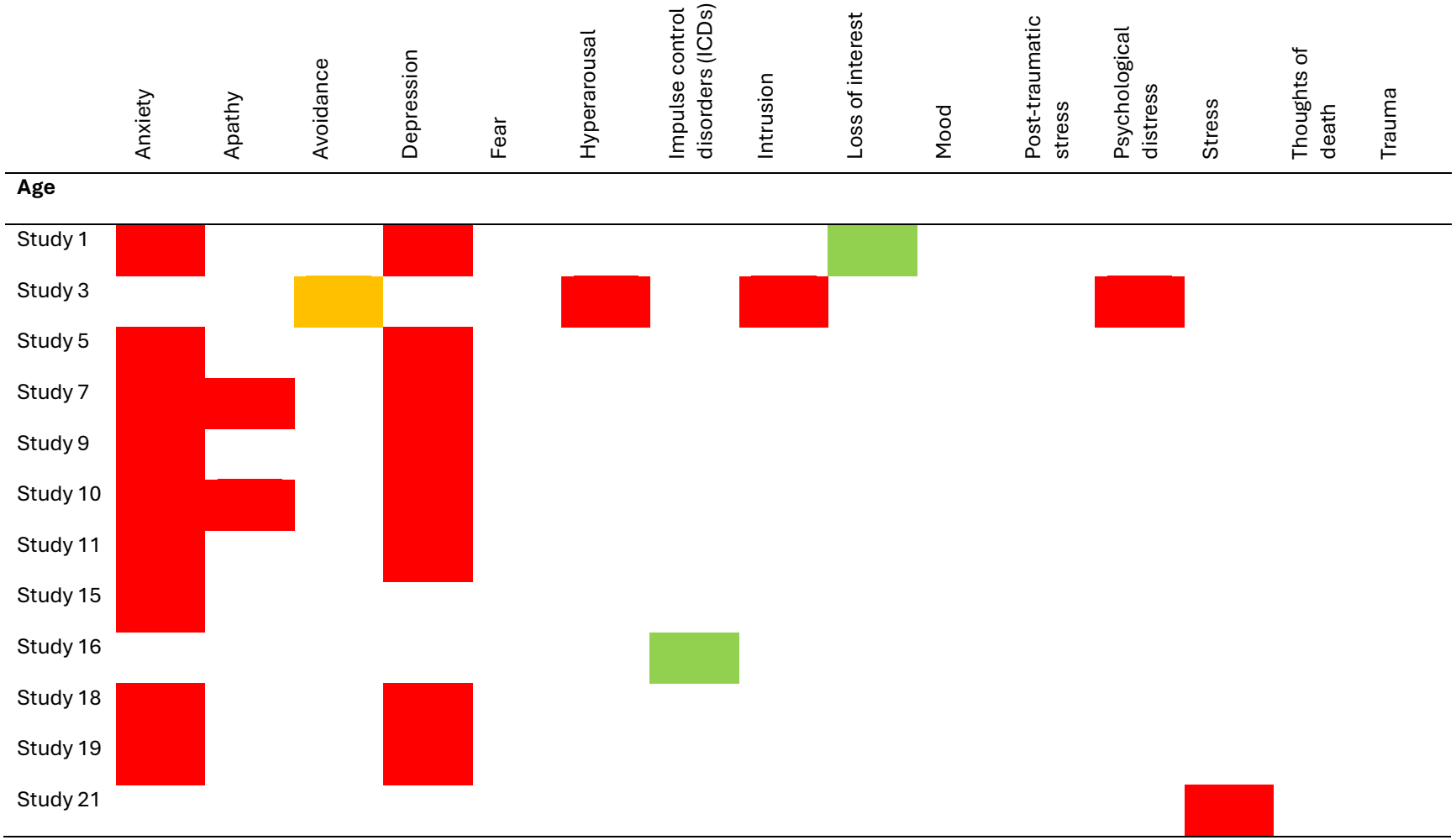
Appendix C. Illness-related predictors stratified by psychological wellbeing




Anxiety
Apathy
Avoidance
Depression
Fear
Hyperarousal
Impulse control disorders (ICDs)
Intrusion
Loss of interest
Mood
Post-traumatic stress
Psychological distress
Stress
Thoughts of death
Trauma
Study 3
Study 9
Study 11
Study 18
Study 19
Study 20
Study 21
Hoehn and Yahr stage
Study 1
Study 3
Study 5
Study 11
Study 18

Note. Green = significant association(s), red = insignificant association(s), orange = one or more analyses with differing results

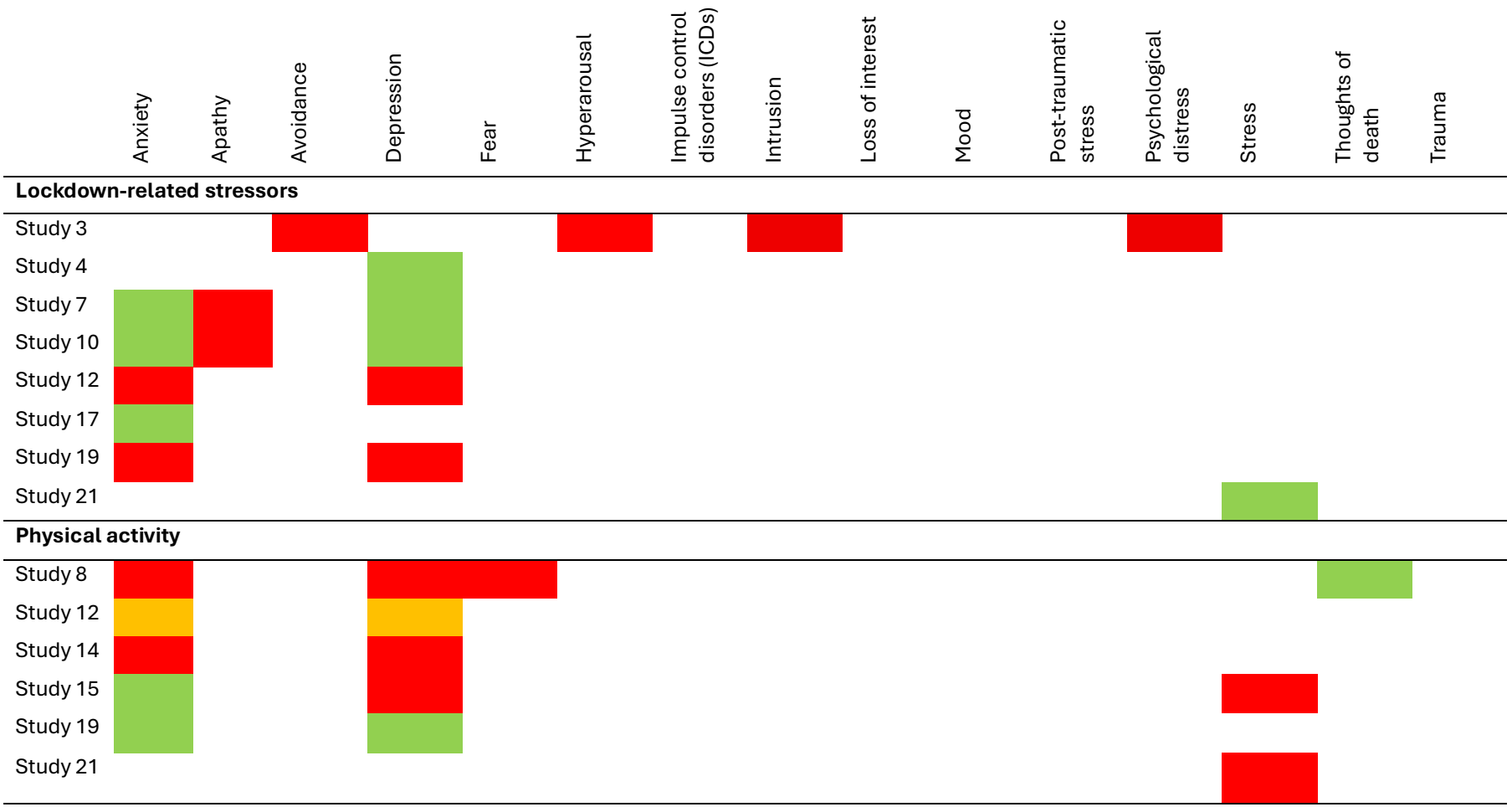
Appendix D. Demographic predictors stratified by psychological wellbeing




Anxiety
Apathy
Avoidance
Depression
Fear
Hyperarousal
Impulse control disorders (ICDs)
Intrusion
Loss of interest
Mood
Post-traumatic stress
Psychological distress
Stress
Thoughts of death
Trauma
Gender
Study 1
Study 3
Study 5
Study 7
Study 9
Study 11
Study 20
Study 21
Study 22
Education
Study 7
Study 9
Study 10

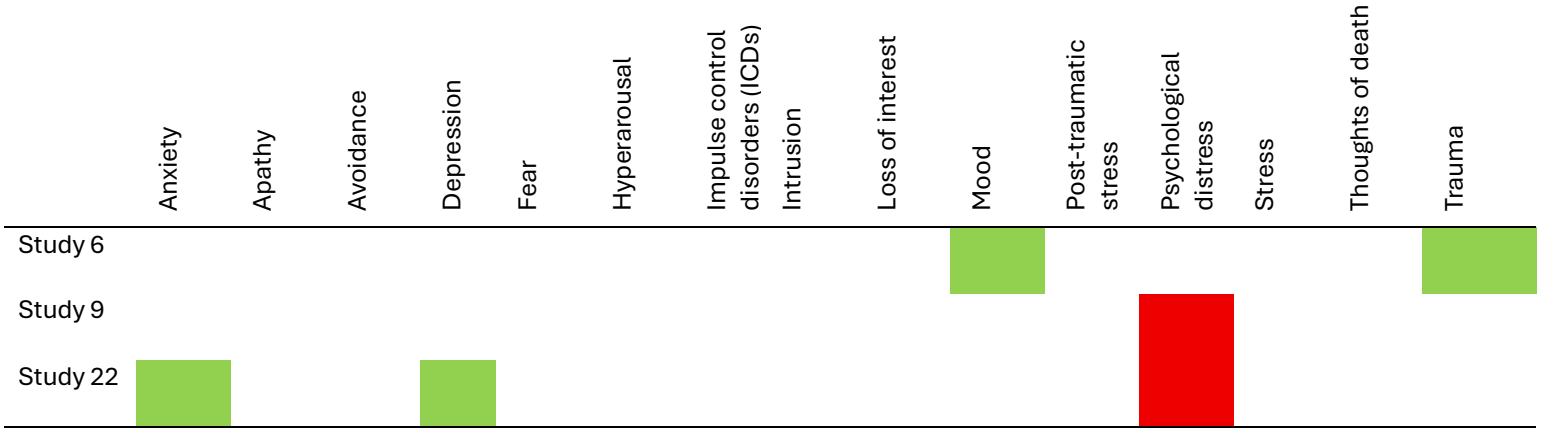
Note. Green = significant association(s), red = insignificant association(s), orange = one or more analyses with differing results

Appendix E. Pandemic-related predictors stratified by psychological wellbeing



Note. Green = significant association(s), red = insignificant association(s), orange = one or more analyses with differing results

Appendix F. Psychological traits stratified by psychological wellbeing



Note. Green = significant association(s), red = insignificant association(s), orange = one or more analyses with differing results

Appendix G. Ethics application (chapter four)

Research Ethics Application Form v1.8.1

Research Ethics Application Form v1.9.5 RECR

A quantitative investigation of the factors affecting the well-being of people with Parkinson's in the pandemic - Pending

Information Regarding this Research Project

Are you conducting a research project?

(for more information on research projects please see our ethics pages)

(•) Yes ( ) No

Does your research only involve animals?

( ) Yes (•) No

Are you undertaking this research as/are you filling this form out as:

( ) Academic/Research Staff
( ) Non Academic Staff
( ) Staff Undertaking a Programme of Study
(•) PhD or DClinPsy student
( ) Undergraduate, Masters, Master by Research, MPhil or other taught postgraduate programme

Which Faculty are you in?

Faculty of Health and Medicine

Which department are you in?

Health Research

Will your project require NHS REC approval? (If you are not sure please read the guidance in the information button)

( ) Yes (•) No

Do you need Health Research Authority (HRA) approval? (Please read the guidance in the information button)

○ Yes ◉ No

Have you already obtained, or will you be applying for ethical approval, from another institution outside of Lancaster University? (For example, an external institution such as: another University's Research Ethics Committee, the NHS or an institution abroad (eg an IRB in the USA)? Please select one of the following:

- ◉ No, I do not need ethical approval from an external institution.
- ○ Yes, I have already received ethical approval from an external institution.
- ○ Yes, I will be applying for ethical approval from an external institution after I have received confirmation of ethical approval from my Faculty Research Ethics Committee (FREC) at Lancaster University, if the FREC grants approval.

Is this an amendment to a project previously approved by Lancaster University?

○ Yes ◉ No

Will your research involve any of the following? (Multiple selections are possible, please see i icon for details)

- ☐ Human Participants
- ☑ Data relating to humans (Secondary/Pre-existing data only)
- ☐ Data collection from online sources such as social media platforms, discussion forums, online chat-rooms
- ☐ Human Tissue
- ☐ None of the above

Project Information

Please confirm/amend the title of this project.

A quantitative investigation of the factors affecting the well-being of people with Parkinson's in the pandemic

Estimated Project Start Date 16/04/2023

Estimated End Date 31/12/2023

Is this a funded Project?

○ Yes ◉ No

Funding Information

Funding information

Please note

Your ACP reference number can be found on your grant application, it will start with an A and be followed by 6 numbers, e.g. A123456 Your Agresso ID is your grant code for expenditure allocated by post-award, e.g. EAA7001.

Research Site(s) Information

Will you be recruiting participants from research sites outside of Lancaster University? *(E.g. Schools, workplaces, etc; please read the guidance in the information button for more information)*

○ Yes ◉ No

Applicant Details

Are you the named Principal Investigator at Lancaster University?

◉ Yes ○ No

Please check your contact details are correct. You can update these fields via the personal details section located in the top right of the screen. Click on your name and email address in the top right to access "Personal details". For more details on how to do this, please read the guidance in the information button.

First Name

Hannah

Surname

Gotheridge

Department

Health Research

Faculty

Faculty of Health and Medicine

Email

h.gotheridge@lancaster.ac.uk

Principal Investigator

You have stated that you are the Principal Investigator for this project.

First Name

Hannah

Surname

Gotheridge

Department

Health Research

Email

h.gotheridge@lancaster.ac.uk

Supervisor Details

Search for your supervisor's name. *If you cannot find your supervisor in the system please contact rso-systems@lancaster.ac.uk to have them added.*

First Name

Jane

Surname

Simpson

Department

Health Research

Faculty

Faculty of Health and Medicine

Email

j.simpson2@lancaster.ac.uk

Do you need to add a second supervisor to sign off on this project?

○ Yes ◉ No

Additional Team Members

Other then those already added, please select which type of team members will be working on this project:

- ☐ I am not working with any other team members.
- ☑ Staff
- ☐ Student
- ☐ External

Search for the names of all other internal staff here:

First Name

Fiona

Surname

Eccles

Department

Health Research

Faculty

Faculty of Health and Medicine

Email

f.eccles@lancaster.ac.uk

Search for the names of all other internal staff here:

First Name

Craig

Surname

Murray

Department

Health Research

Faculty

Faculty of Health and Medicine

Email

c.murray@lancaster.ac.uk

Data Origin

Is the data you will be using in the public domain or from data repositories?

○ Yes ◉ No

Do you intend to use data about humans from online sources such as social media platforms, discussion forums, or online chat rooms?

○ Yes ◉ No

Has consent for the use/reuse of the data for research purposes been obtained?

◉ Yes ○ No ○ I don't know

Will you protect confidentiality and anonymity in your (re)analysis of the data?

◉ Yes ○ No ○ I don't know

Data Analysis

Do you intend to conduct a secondary analysis of existing research data?

◉ Yes ○ No

Was the data ethically obtained and was approval granted from a research ethics committee for its use?

◉ Yes ○ No ○ I don't know

Does the consent obtained from participants cover the proposed re-use of the research data for your current project?

◉ Yes ○ No ○ I don't know

Will you obtain the data in anonymised format?

(•) Yes ( ) No ( ) I don't know

General Queries

Does the funder or any organisations involved in the research have a vested interest in specific research outcomes that would affect the independence of the research?

Yes No I don't know

Does any member of the research team, or their families and friends, have any links to the funder or organisations involved in the research?

Yes No I don't know

Can the research results be freely disseminated?

Yes No I don't know

Will you use data from potentially illicit, illegal, or unethical sources (e.g. pornography, related to terrorism, dark web, leaked information)?

Yes No I don't know

Will you be gathering/working with any special category personal data?

Yes No I don't know

Are there any other ethical considerations which haven't been covered?

Yes No I don't know

REC Review Details

Based on the answers you have given so far you will need to answer some additional questions to allow reviewers to assess your application.

It is recommended that you do not proceed until you have completed **all of the previous questions**.

Please confirm that you have finished answering the previous questions and are happy to proceed.

☑ I confirm that I have answered all of the previous questions, and am happy to proceed with the application.

You have stated that you are research only involves data.

☑ Please confirm that your research will have no direct involvement with human participants.

Questions for REC Review

Summarise your research protocol in lay terms (indicative maximum length 150 words).

Note: The summary of the protocol should concisely but clearly tell the Ethics Committee (in simple terms and in a way which would be understandable to a general audience) what you are broadly planning to do in your study. Your study will be reviewed by colleagues from different disciplines who will not be familiar with your specific field of research and it may also be reviewed by the lay members of the Research Ethics Committee; therefore avoid jargon and use simple terms. A helpful format may include a sentence or two about the background/ "problem" the research is addressing, why it is important, followed by a description of the basic design and target population. Think of it as a snapshot of your study.

For people with Parkinson's, the early pandemic restrictions limited the ability to carry out normal health management practices leading to concerns about the impact on both physical and psychological well-being. Increasing physical symptoms and limited physical activity have been identified as consistent predictors of well-being outcomes both in research carried out before and during the pandemic. However, little is known about potential moderators (i.e., variables which might affect) these relationships in this context. Social support is often seen as a buffering mechanism that can lessen the impact of stressors on wellbeing and will be investigated in this study. Thus, a moderation analysis will be carried out with stressors conceived as the worsening of Parkinson's symptoms and changes to physical activity and psychological well-being will be used as the outcome. Measures indicative of (lack of) social support will be investigated as potential moderators of the relationship between these stressors and outcomes. The investigation of psychosocial factors in relation to well-being is generally understudied in literature and the present research will therefore provide useful insight that could refine understanding.

State the Aims and Objectives of the project in Lay persons' language.

The purpose of the study is to gain a deeper insight into the nature of the impact of motor symptom worsening and changes physical activity on the psychological well-being of people with Parkinson's during the pandemic by investigating the potential moderating effect of psychosocial variables. In particular the study will assess Are changes in exercise associated with wellbeing? Are changes in physical symptoms associated with wellbeing? Does lack of social support moderate (change) the relationship between exercise and wellbeing? Does lack of social support moderate the relationship between physical symptoms and wellbeing? Demographic and other illness related information will used to describe the sample

Information about the Research

Will you be sharing your data with any other organisation?

○ Yes ◉ No

What are your dissemination plans? E.g publishing in PhD thesis, publishing in academic journal, presenting in a conference (talk or poster).

The research will be published in a PhD thesis. It is also planned to publish the research in an academic journal and to disseminate the findings at conferences and other special interest groups although the time frame for this is unknown. Due to the collaboration with and involvement of the Parkinson's UK charity it is also important to disseminate the findings to members and employees of the charity.

Data Origin

You have indicated that the data you will be using is not in the public domain. Please explain how the records will be obtained and indicate the original purpose for which the data was collected.

The data were collected by Parkinson's UK to understand the experience of their members during the pandemic. The analysis of the data by Lancaster University researchers was explicitly mentioned and consent was given for this.

General Queries

You have indicated that you will be gathering/working with special category data. Please confirm here how you will comply with data protection law (GDPR) for use of special category personal data.

Some of the data collected is classed as sensitive personal data, thus must be either encrypted (if stored on a mobile/external storage device) or stored on university Microsoft Office 365 services such as OneDrive. The research data will be retained in accordance with the ethics approval gained by the supervisors including, Dr Fiona Eccles, reference FHMREC19091, who have done previous work on this same dataset. Specifically, the previous application stated, "During the project, data will be stored on the secure university network (the researchers' H drives and One Drive). Once the project is complete, data will be stored on the researchers' H drive or One Drive (or any similar university approved cloud storage) for at least 10 years and will then be destroyed by Fiona Eccles or Jane Simpson." Thus, the dataset used for the current project will be destroyed at the same time as indicated in the previous approval.

Data Storage

How long will you retain the research data?

As above, the research data will be retained in accordance with the ethics approval gained by the supervisors including, Dr Fiona Eccles, reference FHMREC19091, who have done previous work on this same dataset. Specifically, once the project is complete, data will be stored on the researchers' H drive or One Drive (or any similar university approved cloud storage) for at least 10 years and will then be destroyed by Fiona Eccles or Jane Simpson." Thus, the dataset used for the current project will be destroyed at the same time as indicated in the previous approval.

How long and where will you store any personal and/or sensitive data?

As above, the research data will be retained in accordance with the ethics approval gained by the supervisors including, Dr Fiona Eccles, reference FHMREC19091, who have done previous work on this same dataset. Specifically, once the project is complete, data will be stored on the researchers' H drive or One Drive (or any similar university approved cloud storage) for at least 10 years and will then be destroyed by Fiona Eccles or Jane Simpson." Thus, the dataset used for the current project will be destroyed at the same time as indicated in the previous approval.

Please explain when and how you will anonymise data and delete any identifiable record?

The data are already anonymised and therefore no further action is required.

Project Documentation*

Important Notice about uploaded documents:

When your application has been reviewed if you are asked to make any changes to your uploaded documents please highlight the changes on the updated document(s) using the highlighter so that they are easy to see.

In addition to completing this form you must submit all supporting materials.

Please indicate which of the following documents are appropriate for your project:

- ☐ Research Proposal (DClinPsy)
- ☐ Advertising materials (posters, emails)
- ☐ Letters/emails of invitation to participate
- ☐ Consent forms
- ☐ Participant information sheet(s)
- ☐ Interview question guides
- ☐ Focus group scripts
- ☐ Questionnaires, surveys, demographic sheets
- ☐ Workshop guide(s)
- ☐ Debrief sheet(s)
- ☐ Transcription (confidentiality) agreement
- ☐ Other
- ☑ None of the above.

Declaration

Please Note

Research Services monitors projects entered into the online system, and may select projects for quality control.

All research at Lancaster university must comply with the LU data storage and governance guidance as well as the General Data Protection Regulation (GDPR) and the UK Data Protection Act 2018. (Data Protection Guidance webpage)

- ☑ I confirm that I have read and will comply with the LU Data Storage and Governance guidance and that my data use and storage plans comply with the General data Protection Regulation (GDPR) and the UK Data Protection Act 2018.

Have you that you have undertaken a health and safety risk assessment for your project through your departmental process? (Health and Safety Guidance)

☑ I have undertaken a health and safety assesment for your project through my departmental process, and where required will follow the appropriate guidance for the control and management of any foreseeable risks

When you are satisfied that this application has been completed please click "Request" below to send this application to your supervisor for approval.

Signed: This form was signed by Professor Jane Simpson (j.simpson2@lancaster.ac.uk) on 03/04/2023 09:28

Please read the terms and conditions below:

You have read and will abide by Lancaster University's Code of Practice and will ensure that all staff and students involved in the project will also abide by it.
If appropriate a confidentiality agreement will be used.
You will complete a data management plan with the Library if appropriate. Guidance from Library.
You will provide your contact details, as well as those of either your supervisor (for students) or an appropriate person for complaints (such as HoD) to any participants with whom you interact, so they know whom to contact in case of questions or complaints?
That University policy will be followed for secure storage of identifiable data on all portable devices and if necessary you will seek guidance from ISS.
That you have completed the ISS Information Security training and passed the assessment. That you will abide by Lancaster University's lone working policy for field work if appropriate.
On behalf of the institution you accept responsibility for the project in relation to promoting good research practice and the prevention of misconduct (including plagiarism and fabrication or misrepresentation of results).
To the best of your knowledge the information you have provided is correct at the time of submission. If anything changes in your research project you will submit an amendment.

Applicant Only: To complete and submit this application please click "Sign" below:

Signed: This form was signed by Hannah Gotheridge (h.gotheridge@lancaster.ac.uk) on 03/04/2023 12:53

Appendix H. Assumption checks

Appendix H1. Correlation assumption checks

Assumption	Test	Outcome	Implication
Pearson's correlation			
Linear relationship	Scatterplots	Passed	n/a
Normality	Skewness and Kurtosis, histograms, Q-Q plots	Passed	n/a
Outliers	Box plots Scatterplots	Outliers identified in motor symptom worsening, disease duration and age. Outliers were minimal and represented 'real' participants	Visual inspection of scatterplots identified clear outliers. Large sample means the test is relatively robust.
Point biserial correlation			
Homogeneity of variance	Levene's test	Passed	n/a
Normality within groups	Skewness and Kurtosis, histograms, Q-Q plots	Passed	n/a

Note. The Pearson's correlation investigated the assumptions in relation to wellbeing and social engagement with family, social engagement with friends, motor symptom worsening, disease duration and age. The point biserial correlation investigated the assumptions in relation to wellbeing and gender. Assumptions were tested using the moderation analysis data.

Appendix H2. Regression and moderation analysis assumption checks

Assumption	Test	Outcome	Implication
Linearity	Scatterplot, P-P plot	Passed	n/a
Independence of errors	Durbin-Watson	Passed	n/a
Homoscedasticity	Scatterplot	Passed	n/a
Normality of residuals	Histogram, P-P plot	Passed	n/a
Multicollinearity	Correlations between predictors, VIF	Passed	n/a
Outliers	Scatterplot, residual statistics, casewise diagnostics	Some values fall outside of the expected range (roughly -3 to +3)	Further evaluated using Cook's distance which suggested they did not have an undue influence on the model

Note. Assumptions were tested using the regression analysis sample.

Appendix I. Ethics application (chapter five)

Research Ethics Application Form v1.6.1

Research Ethics Application Form v1.8.1 **RECR**

A qualitative study of the experience of people with Parkinson's in Northern Ireland before and during the COVID-19 pandemic - Approved

Information Regarding this Research Project

Are you conducting a research project?

(for more information on research projects please see our ethics pages)

(•) Yes ( ) No

Does your research only involve animals?

( ) Yes (•) No

Are you undertaking this research as/are you filling this form out as:

( ) Academic/Research Staff
( ) Non Academic Staff
( ) Staff Undertaking a Programme of Study
(•) PhD or DClinPsy student
( ) Undergraduate, Masters, Master by Research, MPhil or other taught postgraduate programme

Which Faculty are you in?

Faculty of Health and Medicine

Which department are you in?

Health Research

Will your project require NHS REC approval? (If you are not sure please read the guidance in the information button)

○ Yes ◉ No

Do you need Health Research Authority (HRA) approval? (Please read the guidance in the information button)

○ Yes ◉ No

Have you already obtained, or will you be applying for ethical approval, from another institution outside of Lancaster University? (For example, an external institution such as: another University's Research Ethics Committee, the NHS or an institution abroad (eg an IRB in the USA)? Please select one of the following:

- ◉ No, I do not need ethical approval from an external institution.
- ○ Yes, I have already received ethical approval from an external institution.
- ○ Yes, I will be applying for ethical approval from an external institution after I have received confirmation of ethical approval from my Faculty Research Ethics Committee (FREC) at Lancaster University, if the FREC grants approval.

Is this an amendment to a project previously approved by Lancaster University?

○ Yes ◉ No

Will your research involve any of the following? (Multiple selections are possible, please see i icon for details)

- ☑ Human Participants
- ☐ Data relating to humans (Secondary/Pre-existing data only)
- ☐ Data collection from online sources such as social media platforms, discussion forums, online chat-rooms
- ☐ Human Tissue
- ☐ None of the above

Project Information

Please confirm/amend the title of this project.

A qualitative study of the experience of people with Parkinson's in Northern Ireland before and during the COVID-19 pandemic

Estimated Project Start Date 01/11/2022

Estimated End Date 01/05/2024

Is this a funded Project?

○ Yes ◉ No

Research Site(s) Information

Will you be recruiting participants from research sites outside of Lancaster University? *(E.g. Schools, workplaces, etc; please read the guidance in the information button for more information)*

○ Yes ◉ No

Applicant Details

Are you the named Principal Investigator at Lancaster University?

◉ Yes ○ No

Please check your contact details are correct. You can update these fields via the personal details section located in the top right of the screen. Click on your name and email address in the top right to access "Personal details". For more details on how to do this, please read the guidance in the information button.

First Name

Hannah

Surname

Gotheridge

Department

Health Research

Faculty

Faculty of Health and Medicine

Email

h.gotheridge@lancaster.ac.uk

Principal Investigator

You have stated that you are the Principal Investigator for this project.

First Name

Hannah

Surname

Gotheridge

Department

Health Research

Email

h.gotheridge@lancaster.ac.uk

Supervisor Details

Search for your supervisor's name. *If you cannot find your supervisor in the system please contact rso-systems@lancaster.ac.uk to have them added.*

First Name

Craig

Surname

Murray

Department

Health Research

Faculty

Faculty of Health and Medicine

Email

c.murray@lancaster.ac.uk

Do you need to add a second supervisor to sign off on this project?

○ Yes ◉ No

Additional Team Members

Other then those already added, please select which type of team members will be working on this project:

- ☐ I am not working with any other team members.
- ☑ Staff
- ☐ Student
- ☐ External

Search for the names of all other internal staff here:

First Name

Jane

Surname

Simpson

Department

Health Research

Faculty

Faculty of Health and Medicine

Email

j.simpson2@lancaster.ac.uk

Search for the names of all other internal staff here:

First Name

Fiona

Surname

Eccles

Department

Health Research

Faculty

Faculty of Health and Medicine

Email

f.eccles@lancaster.ac.uk

Details about the participants

As you are conducting research with Human Participants/Tissue you will need to answer the following questions before your application can be reviewed.

If you have any queries about this please contact your Ethics Officer before proceeding.

What's the minimum number of participants needed for this project?

8

What's the maximum number of expected participants?

12

Do you intend to recruit participants from online sources such as social media platforms, discussion forums, or online chat rooms?

(•) Yes ( ) No

Will you get written consent and give a participant information sheet with a written description of your research to all potential participants?

( ) Yes (•) No ( ) I don't know

Will any participants be asked to take part in the study without their consent or knowledge at the time or will deception of any sort be involved?

( ) Yes (•) No ( ) I don't know

Is your research with any vulnerable groups?

(Vulnerable group as defined by Lancaster University Guidelines)

( ) Yes (•) No ( ) I don't know

Is your research with any adults (aged 18 or older)?

(•) Yes ( ) No

Is your research data collected with completely anonymous adult (aged 18 or older) participants, with no contact details or other uniquely identifying information (e.g. date of birth) being recorded?

( ) Yes (•) No

Is your research with adult participants (aged 18 years, or older) in private interactions (for example, one to one interviews, online questionnaires)?

(•) Yes ( ) No

Is your research with any young people (under 18 years old)?

( ) Yes (•) No ( ) I don't know

Does your research involve discussion of personally sensitive subjects which the participant might not be willing to otherwise talk about in public (e.g. medical conditions)?

(•) Yes ( ) No ( ) I don't know

Could the study induce psychological stress or anxiety, or produce humiliation or cause harm or negative consequences beyond the risks encountered in a participant's usual, everyday life?

(•) Yes ( ) No ( ) I don't know

Is there a risk that the nature of the research topic might lead to disclosures from the participant concerning either:

- Their own or others involvement in illegal activities
- Other activities that represent a threat to themselves or others (e.g. sexual activity, drug use, or professional misconduct)?

( ) Yes (•) No ( ) I don't know

Does the study involve any of the following:

- Physically intrusive procedures including touching or attaching equipment to participants
- Administration of substances
- Ultrasound or sources of non-ionising radiation (e.g. lasers)
- Sources of ionising radiation, (e.g. X-rays)
- Collection or use of samples of Human Tissue (e.g. Saliva, skin cells, blood etc.)

( ) Yes (•) No ( ) I don't know

Details about Participant relationships

Do you have a current or prior relationship with potential participants? For example, teaching or assessing students or managing or influencing staff (this list is not exhaustive).

( ) Yes (•) No ( ) I don't know

If you need written permission from a senior manager in an organisation where research will take place (e.g. school, business) will you gain this in advance of undertaking your research?

( ) Yes ( ) No ( ) I don't know (•) N/A

Will you be using audio recordings in outputs (e.g. giving a presentation in a conference, using it for teaching)?

- ○ Yes
- ◉ No

Will you be using portable devices to record participants (e.g. audio, video recorders, mobile phone, etc)?

- ○ No
- ○ Yes, and all portable devices will be encrypted as per the Lancaster University ISS standards, in particular where they are used for recording identifiable data
- ◉ Yes, but these cannot be encrypted because they do not have encryption functionality. Therefore I confirm that any identifiable data (including audio and video recordings of participants) will be deleted from the recording device(s) as quickly as possible (e.g. when it has been transferred to a secure medium, such as a password protected and encrypted laptop or stored in OneDrive) and that the device will be stored securely in the meantime

Will you be using other portable storage devices in particular for identifiable data (e.g. laptop, USB drive, etc)? (Please read the help text)

- ○ No
- ◉ Yes, and they will be encrypted as per the Lancaster University ISS standards in particular where they are used for recording identifiable data

Will anybody external to the research team be transcribing the research data?

- ○ Yes
- ◉ No

Online Sources

Does your research comply with the site(s) terms and conditions? Before completing the section below please read the 'Social Media Guidance for Researchers'

- ◉ Yes
- ○ No
- ○ It's unclear in the terms and conditions

Is there a reasonable expectation of privacy?

- ◉ Yes
- ○ No

Because there is a reasonable expectation of privacy, you must obtain consent from site users. Therefore you will need to upload a copy of the Participant Information Sheet & Consent form that you intend to use to obtain their informed consent.

Will you be using audio recordings in outputs (e.g. giving a presentation in a conference, using it for teaching)?

○ Yes ◉ No

Will you be using portable devices to record participants (e.g. audio, video recorders, mobile phone, etc)?

○ No

○ Yes, and all portable devices will be encrypted as per the Lancaster University ISS standards, in particular where they are used for recording identifiable data

◉ Yes, but these cannot be encrypted because they do not have encryption functionality. Therefore I confirm that any identifiable data (including audio and video recordings of participants) will be deleted from the recording device(s) as quickly as possible (e.g. when it has been transferred to a secure medium, such as a password protected and encrypted laptop or stored in OneDrive) and that the device will be stored securely in the meantime

Will you be using other portable storage devices in particular for identifiable data (e.g. laptop, USB drive, etc)? (Please read the help text)

○ No

◉ Yes, and they will be encrypted as per the Lancaster University ISS standards in particular where they are used for recording identifiable data

Will anybody external to the research team be transcribing the research data?

○ Yes ◉ No

Online Sources

Does your research comply with the site(s) terms and conditions? Before completing the section below please read the 'Social Media Guidance for Researchers'

◉ Yes ○ No ○ It's unclear in the terms and conditions

Is there a reasonable expectation of privacy?

◉ Yes ○ No

Because there is a reasonable expectation of privacy, you must obtain consent from site users. Therefore you will need to upload a copy of the Participant Information Sheet & Consent form that you intend to use to obtain their informed consent.

General Queries

Does the funder or any organisations involved in the research have a vested interest in specific research outcomes that would affect the independence of the research?

○ Yes ◉ No ○ I don't know

Does any member of the research team, or their families and friends, have any links to the funder or organisations involved in the research?

○ Yes ◉ No ○ I don't know

Can the research results be freely disseminated?

◉ Yes ○ No ○ I don't know

Will you use data from potentially illicit, illegal, or unethical sources (e.g. pornography, related to terrorism, dark web, leaked information)?

○ Yes ◉ No ○ I don't know

Will you be gathering/working with any special category personal data?

◉ Yes ○ No ○ I don't know

Are there any other ethical considerations which haven't been covered?

○ Yes ◉ No ○ I don't know

REC Review Details

Based on the answers you have given so far you will need to answer some additional questions to allow reviewers to assess your application.

It is recommended that you do not proceed until you have completed **all of the previous questions**.

Please confirm that you have finished answering the previous questions and are happy to proceed.

☑ I confirm that I have answered all of the previous questions, and am happy to proceed with the application.

Questions for REC Review

Summarise your research protocol in lay terms (indicative maximum length 150 words).

Note: The summary of the protocol should concisely but clearly tell the Ethics Committee (in simple terms and in a way which would be understandable to a general audience) what you are broadly planning to do in your study. Your study will be reviewed by colleagues from different disciplines who will not be familiar with your specific field of research and it may also be reviewed by the lay members of the Research Ethics Committee; therefore avoid jargon and use simple terms. A helpful format may include a sentence or two about the background/ "problem" the research is addressing, why it is important, followed by a description of the basic design and target population. Think of it as a snapshot of your study.

For people with Parkinson's, the coronavirus has limited normal healthcare and health management practices, impacting health and well-being. Discussions with members of the Northern Ireland branch of Parkinson's UK highlighted the impact of the socio-cultural environment on decisions and experiences of healthcare, as well as key differences compared to mainland UK. In addition, it is evident that the region experiences difficulties in getting people with Parkinson's (pwP) to engage with research. This study will use one-to-one interviews with pwP to investigate how they experience and understand the healthcare system and the impact of the pandemic. The interviews will be analysed using Interpretative Phenomenological Analysis (IPA), a qualitative research approach focusing on lived experiences. The findings will contribute to developing a theoretical understanding of healthcare experiences in an understudied population, as well as enable the Parkinson's UK charity to better tailor their engagement and policy stances to the region.

State the Aims and Objectives of the project in Lay persons' language.

The purpose of this study is to understand in-depth experiences of healthcare for people with Parkinson's in Northern Ireland and how this has changed during the pandemic. We would like to develop a full and meaningful understanding of the healthcare system by seeing it from the viewpoint of those who use it and make suggestions for improvements.

Participant Information

Please explain the number of participants you intend to include in your study and explain your rationale in detail (eg who will be recruited, how, where from; and expected availability of participants). If your study contains multiple parts eg interviews, focus groups, online questionnaires) please clearly explain the numbers and recruitment details for each of these cohorts (see help text).

The study uses a qualitative approach, namely Interpretative Phenomenological Analysis (IPA). This method has an idiographic focus, typically recruiting small homogenous samples. The labour-intensive analysis involved, along with a requirement to provide a detailed exploration of commonalities and divergences in experiences and meaning making across participants, mean samples sizes for IPA are typically in the region of 8-12. The present study will therefore aim to recruit a sample within this range. To be included in the study, participants are required to have experienced Parkinson's related healthcare in Northern Ireland since at least 2018. This timeframe was chosen to ensure participants have experience with accessing healthcare before the pandemic and can therefore reflect on its impact.

Due to anticipated difficulties in recruiting people with Parkinson's living in Northern Ireland (identified by members of Parkinson's UK), the recruitment process is a crucial part of the study and significant planning is required. The first step will be to use our collaboration with the Parkinson's UK Northern Ireland branch to spread knowledge of the study amongst those who are members of the charity. In particular, we are in contact with area managers who have direct involvement with people with Parkinson's through their connection with community activities. We will encourage them to spread knowledge of the study through word of mouth and direct interested individuals to sign up information (listed on the advertising poster), to put up posters at community events, and to advertise the poster on social media platforms associated with the charity. To gain further information about and sign up to the study, potential participants are required to email the address listed on the advertising poster and provide their name, email address, and a postal address (if they prefer physical copies of documents). However, we are aware that Northern Ireland has the lowest sign-up rates to the Parkinson's UK charity. This means we must not depend solely on the association between people with Parkinson's and the charity to gain participants. One method we will use to combat this is snowball sampling, whereby we will encourage those who are aware of the study to inform people with Parkinson's outside of charity membership in, for example, exercise groups. Finally, we will collaborate with Parkinson's UK staff members who work on the ground to identify key areas such as community centres where we could advertise the study.

You have selected that you are not getting written consent using a Participant Information Sheet with a written description of your research. Please indicate why you are not using a Participant Information Sheet, and how you are obtaining consent.

Written consent from the participants cannot be obtained as the interviews will take place via telephone or an online platform. Instead, a Participant Information Sheet and Consent Form will be emailed or posted to participants (depending on their preference). Before the interview commences, the interviewer will go through the documents with the participants, and verbal consent will be recorded. Thus, participants will be fully informed about the nature of the study and the role of participants.

You have selected that the research may involve personal sensitive topics that participants may not be willing to otherwise talk about. Please indicate what discomfort, inconvenience or harm could be caused to the participant and what steps you will take to mitigate or manage these situations.

Participants will be asked to discuss events and experiences related to health and healthcare, which they may not like to discuss in everyday situations. To mitigate any potential negative experiences caused by participation in the study, participants will be informed of the nature of the study and given an indication of topics they will be asked to discuss in the participant information sheet. This will allow them to make an informed decision concerning their willingness to take part. The participant information sheet will be sent to participants after they indicate they are interested in taking part, and before they decide to take part and set up a date for the interview. Moreover, if participants unexpectedly find themselves distressed during the interview, they will be reminded of their right to withdraw at any time and directed to the local support groups listed on page 5 of the Participant Information Sheet. Finally, participants will be informed of their right to withdraw from the study up to 4 weeks after it has been carried out if they are no longer comfortable with taking part. Again, in this circumstance, participants will be directed to the local support groups included on the final page of the Participant Information Sheet.

You have indicated that you will collect identifying information from the participants. Please describe all the personal information that you gather for your study which might be used to identify your participants.

To sign up to the study, participants need to provide their name and email address, as well as a postal address if they want physical copies of documents. Before beginning the interview, participants will be asked background questions. Specifically, they will be asked how old they are, what gender they identify as, what ethnicity they identify as, what religion or religious community they belong to, how long they have been diagnosed with Parkinson's, and how long they have been receiving treatment for Parkinson's. These questions were selected because, while discussing the healthcare context in Northern Ireland with members of the Parkinson's UK Northern Ireland branch, we were made aware of the perceived impact of such contextual factors on healthcare. Understanding the religious background of participants in particular is predicted to provide a greater depth to the understanding of data.

Please describe how the data will be collected and stored.

Data will be collected using various pathways. Firstly, the connection with Parkinson's UK will be used to spread knowledge of the study amongst those who are members of the charity. This may be through word of mouth (directing interested individuals to the sign up poster or directly providing the contact details), putting up posters at community events, or advertising the poster on social media platforms associated with the charity. To sign-up to the study, participants will need to provide their name and an email address to the email address listed on the advertising poster. If participants would prefer hard copies of the consent form and participant information sheet, they will additionally need to provide a postal address. Otherwise, these documents will be sent via email. We are aware that Northern Ireland has the lowest sign-up rates to the Parkinson's UK charity, so we must not depend solely on the association between people with Parkinson's and the charity to gain participants. As such, we will employ snowball sampling by encouraging those who are aware of the study to inform people with Parkinson's outside of charity membership. Finally, we will collaborate with Parkinson's UK staff members who work on the ground to identify key areas such as community centres where we could advertise.

The study itself will consist of a single semi-structured interview, and an audio recording will be taken to enable transcription. These interviews will take place via telephone or an online platform such as Zoom or Teams, depending on the preference of the participants. An audio recording of the interviews will be taken using a Dictaphone, regardless of the platform the interview is carried out on, to enable transcription. Although we believe most participants will have access to the required technology and be capable of using it, we appreciate that this may not always be the case. In most cases, we believe participants will prefer to source and gain support with technology through their own support network of family and friends. However, in the eventuality that a participant wants to take part but does not have access to the relevant technology or support in using it, reasonable attempts will be made to overcome this. Specifically, we will collaborate with staff members of the Parkinson's UK charity to find a private location that is convenient to both actors where the relevant technology (mobile phone or laptop) can be borrowed.

The consent process and interview will initially be recorded on a Dictaphone. The consent and interview will be recorded separately to enable them to be stored separately. As this Dictaphone does not have encryption capabilities, the data will be immediately transferred to a university provided laptop and stored on OneDrive, which is university-approved secure cloud storage. The personal data (consent and details provided at sign up) and interview recording/transcription will be stored in two separately encrypted folders. The voice recording on the unencrypted Dictaphone will be immediately deleted once the upload is complete, and it anticipated that the interview and consent will be stored on the Dictaphone for no longer than an hour after the interview is completed. To ensure the anonymity of participants, all identifiers (e.g., reference to names) will be removed from the interview transcript. A unique identification number will enable identification between the consent and interview.

Please describe how long the data will be stored and who is responsible for the deletion of the data.

Following the completion of the study, the interview transcripts of participants that consented to data sharing will be uploaded to the data repository ReShare, an online database that researchers upload their anonymised data for use by other researchers who may find the data collected valuable to their research. Participants will be informed of the procedure for data storage in the Participant Information Sheet. The upload of the interview transcript to ReShare will only be carried out with the approval of the participants, consent for which will be gained as part of the consent form. In addition to this, the interview transcripts and audio consent files will be uploaded to the university storage system Pure, where they will be stored for 10 years with Professor Jane Simpson as data custodian. All other personal data (name and contact information) will be deleted by the researcher once the study is completed or after the participants have received a summary of the results (depending on which is latest).

You stated that the study could induce psychological stress or anxiety, or produce humiliation or cause harm or negative consequences beyond the risks encountered in a participant's usual, everyday life. Please describe the question(s) and situation(s) that could lead to these outcomes and explain how you will mitigate this.

In the interview, participants will be asked to recall their experience of Parkinson's-related healthcare, and some participants may find these events distressing. The questions that may cause distress are i) their experience around the time of receiving a Parkinson's diagnosis, ii) potentially negative interactions with healthcare professionals, iii) a lack of support, and iv) the impact of the pandemic. This will be mitigated by informing participants that these topics will be discussed in the interview. Specifically, these topics have been listed in the 'what are the disadvantages of taking part?' section of the participant information sheet, where participants are also encouraged to consider if they are comfortable talking about these topics in the interview before agreeing to take part in the study. Moreover, participants have been informed in the participant information sheet and consent form, and will be reminded before the interview begins (during the consent process), that they have the right to withdraw at any time, for any reason, and without an explanation.

Participant Relationships

Your answers about gatekeepers has indicated that there is a power imbalance due to gatekeepers knowing the identity of participants. Please explain the situation and how you plan to mitigate and manage the effects of this.

It is anticipated that some participants will be recruited through their involvement with the Parkinson's UK charity. Although we will use a gatekeeper to aid with participant recruitment, we do not believe there will be a power imbalance. The involvement of the charity will be limited to the distribution of advertising materials and/or verbally informing people with Parkinson's about the study. Thus, they will not be able to identify those who choose to take part in the study unless the participant chooses to share this information. Employees of the charity will not carry out data collection, nor will they have access to the data that is collected. Employees will be informed about the necessity to enable those they inform about the study privacy in their choice about whether or not to take part, and to not treat members of the charity differently if they become aware of their choice. We will also ensure employees are aware that it is important not to probe about an individuals experience if they are made aware of their participation.

Information about the Research

What are your dissemination plans? E.g publishing in PhD thesis, publishing in academic journal, presenting in a conference (talk or poster).

The research will be published in a PhD thesis, and it is also planned to publish the research in an academic journal and to disseminate the findings at conferences, although the time frame for this is unknown. Due to the collaboration with and involvement of the Parkinson's UK charity, it is also important to disseminate the findings to members and employees of the charity, particularly those who were involved in facilitating the research.

Online Sources

You have indicated site users have a reasonable expectation of privacy and therefore you will need to obtain consent to use their data for this project. Please explain how you propose to obtain consent.

Online social media platforms will not be used to collect data but may be used for advertising purposes.

General Queries

You have indicated that you will be gathering/working with special category data. Please confirm here how you will comply with data protection law (GDPR) for use of special category personal data.

Some of the data collected is classed as sensitive personal data, thus must be either encrypted (if stored on a mobile/external storage device) or stored on university Microsoft Office 365 services such as OneDrive. Initially, the data will be collected on a Dictaphone that does not have encryption capabilities. However, immediately after the interview concludes, the data will be uploaded to OneDrive and deleted from the Dictaphone. It is anticipated that this process will take no longer than an hour. In addition, the personal data (consent, name and contact details) will be stored in a separate encrypted folder from the anonymised research data. When it is necessary to dispose of the data, the researcher will make a disposal request via the disposal request form to ensure all traces of the data are removed.

Data Storage

How long will you retain the research data?

Following the completion of the study, the interview transcripts of participants that consented to data sharing will be uploaded to the data repository ReShare (an online database that researchers upload their anonymised data for use by other researchers who may find the data collected valuable to their research) for an indefinite amount of time. Participants will be informed of the procedure for data storage in the Participant Information Sheet. The upload of the interview transcript to ReShare will only be carried out with the approval of the participants, consent for which will be gained as part of the consent form.

In addition to this, the interview transcripts and audio consent files will be uploaded to the university storage system Pure, where it will be stored for 10 years with Professor Jane Simpson as data custodian.

How long and where will you store any personal and/or sensitive data?

The audio recording of the consent process (detailing the participants names) will be stored along with the interview transcripts on the university storage system Pure for 10 years, with Professor Jane Simpson as data custodian. The audio recording of each interview will be deleted after it has been transcribed, which will begin 2 weeks after the interview took place. All other personal data (name and contact details) will be deleted once the study is completed or after the participants have received a summary of the results, depending on which occurs latest.

Please explain when and how you will anonymise data and delete any identifiable record?

When the recording of the consent process and interview have been uploaded to the university OneDrive, a unique code will be given to each participant and the recordings will be stored in separate password-protected folders. Thus, the consent form containing the identifiable data will be stored separately from the interview itself. Once the interview has been transcribed, all identifiers (e.g., references to names) will be removed. The transcription process will start 2 weeks after the interview was carried out to give participants time to opt-out of the study if they decide they no longer want to take part. Following transcription of the interview, the audio file will be deleted by the researcher.

Project Documentation*

Important Notice about uploaded documents:

When your application has been reviewed if you are asked to make any changes to your uploaded documents please highlight the changes on the updated document(s) using the highlighter so that they are easy to see.

Please confirm that you have read and applied, where appropriate, the guidance on completing the Participant Information Sheet, Consent Form, and other related documents and that you followed the guidance in the help button for a quality check of these documents. For information and guidance, please use the relevant link below:

FST Ethics Webpage

FHM Ethics Webpage

FASS-LUMS Ethics Webpage

REAMS Webpage

- [x] I confirm that I have followed the guidance.

In addition to completing this form you must submit all supporting materials.

Please indicate which of the following documents are appropriate for your project:

- [ ] Research Proposal (DClinPsy)
- [x] Advertising materials (posters, emails)
- [ ] Letters/emails of invitation to participate
- [x] Consent forms
- [x] Participant information sheet(s)
- [x] Interview question guides
- [ ] Focus group scripts
- [ ] Questionnaires, surveys, demographic sheets
- [ ] Workshop guide(s)
- [ ] Debrief sheet(s)
- [ ] Transcription (confidentiality) agreement
- [ ] Other
- [ ] None of the above.

Please upload the documents in the correct sections below:

Please ensure these are the latest version of the documents to prevent the application being returned for corrections you have already made.

Please upload all consent forms to be used in this project.

Documents

Type	Document Name	File Name	Version Date	Version	Size
Consent Form	22_09_29__ConsentForm2_HGotheridge	22_09_29__ConsentForm2_HGotheridge.pdf	29/09/2022	V4	145.3 KB

Please upload all Participant Information Sheets:

Documents

Type	Document Name	File Name	Version Date	Version	Size
Participant Information Sheet	22_09_29__ParticipantInformationSheet2_HGotheridge	22_09_29__ParticipantInformationSheet2_HGotheridge.pdf	29/09/2022	V5	184.2 KB

Please upload all advertising materials (posters, emails)

Documents

Type	Document Name	File Name	Version Date	Version	Size
Advertising materials	22_09_28__DraftRecruitmentPoster2	22_09_28__DraftRecruitmentPoster2.pdf	29/09/2022	V3	231.3 KB

Please upload all different Interview Question Guides.

Documents

Type	Document Name	File Name	Version Date	Version	Size
Interview question guide	22_09_29__Interview schedule2_HGotheridge	22_09_29__Interview schedule2_HGotheridge.pdf	29/09/2022	V6	97.9 KB

Declaration

Please Note

Research Services monitors projects entered into the online system, and may select projects for quality control.

All research at Lancaster university must comply with the LU data storage and governance guidance as well as the General Data Protection Regulation (GDPR) and the UK Data Protection Act 2018. (Data Protection Guidance webpage)

☑ I confirm that I have read and will comply with the LU Data Storage and Governance guidance and that my data use and storage plans comply with the General data Protection Regulation (GDPR) and the UK Data Protection Act 2018.

Have you that you have undertaken a health and safety risk assessment for your project through your departmental process? (Health and Safety Guidance)

☑ I have undertaken a health and safety assesment for your project through my departmental process, and where required will follow the appropriate guidance for the control and management of any foreseeable risks.

When you are satisfied that this application has been completed please click "Request" below to send this application to your supervisor for approval.

Signed: This form was signed by Dr Craig Murray (c.murray@lancaster.ac.uk) on 25/11/2022 14:48

Please read the terms and conditions below:

- You have read and will abide by Lancaster University's Code of Practice and will ensure that all staff and students involved in the project will also abide by it.
- If appropriate a confidentiality agreement will be used.
- You will complete a data management plan with the Library if appropriate. Guidance from Library.
- You will provide your contact details, as well as those of either your supervisor (for students) or an appropriate person for complaints (such as HoD) to any participants with whom you interact, so they know whom to contact in case of questions or complaints?
- That University policy will be followed for secure storage of identifiable data on all portable devices and if necessary you will seek guidance from ISS.
- That you have completed the ISS Information Security training and passed the assessment.
- That you will abide by Lancaster University's lone working policy for field work if appropriate.
- On behalf of the institution you accept responsibility for the project in relation to promoting good research practice and the prevention of misconduct (including plagiarism and fabrication or misrepresentation of results).
- To the best of your knowledge the information you have provided is correct at the time of submission.
- If anything changes in your research project you will submit an amendment.

Applicant Only: To complete and submit this application please click "Sign" below:

Signed: This form was signed by Hannah Gotheridge (h.gotheridge@lancaster.ac.uk) on 28/11/2022 11:47

Appendix J. Consolidated criteria for reporting qualitative research

Topic and item no.	Questions	NI study response	Telemedicine study response
Domain 1: Research team and reflexivity			
Personal Characteristics			
	Interviewer/facilitator: Which author/s conducted the interviews?	HG	HG
	Credentials: What were the researcher's credentials? E.g. PhD, MD	MRes	MRes
	Occupation: What was their occupation at the time of the study?	PhD Student	PhD Student
	Gender: Was the researcher male or female?	Female	Female
	Experience and training: What experience or training did the researcher have?	Quantitative background, novel interviewer	Quantitative background, some experience with interviewing
Relationship with participants			
	Relationship established: Was a relationship established prior to study commencement?	No relationships prior to recruitment	No relationships prior to recruitment
	Participant knowledge of the interviewer: What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Rationale was outlined in the participant information sheet. Participants knew research wanted to promote the interests of people with Parkinson's in Northern Ireland.	Rationale was outlined in the participant information sheet.
	Interviewer characteristics: What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Participants knew research wanted to promote the interests of people with Parkinson's in Northern Ireland. Participants knew the researcher was from England.	Participants know the researcher wanted to understand convergences and divergences in experiences with and opinions about telemedicine between and within healthcare professionals and people with Parkinson's

Topic and item no.	Questions	NI study response	TA response
Domain 2: Study design			
Theoretical framework			
	Methodological orientation and Theory: What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Interpretative phenomenological analysis	Reflexive thematic analysis
Participant selection			
	Sampling: How were participants selected? e.g. purposive, convenience, consecutive, snowball	Through gatekeepers (Parkinson's UK), random sampling, snowball sampling	Purposive for healthcare professionals. Random sampling through gatekeepers (Parkinson's UK), random sampling, snowball sampling
	Method of approach: How were participants approached? e.g. face-to-face, telephone, mail, email	The study was advertised online (Parkinson's UK, social media) and participants emailed to register their interest in taking part	The study was advertised online (Parkinson's UK, social media) and participants emailed to register their interest in taking part
	Sample size: How many participants were in the study?	8	16
	Non-participation: How many people refused to participate or dropped out? Reasons?	None. Participants that registered interest but did not take part were ruled out due to ineligibility	None. Participants that registered interest but did not take part were ruled out due to ineligibility
Setting			
	Where was the data collected? e.g. home, clinic, workplace	Telephone or video call	Telephone or video call
	Presence of non-participants?	Once a participant's partner was in attendance.	No
	Description of sample: What are the important characteristics of the sample? e.g. demographic data	Age, gender, years living with Parkinson's, years accessing Parkinson's-related healthcare	People with Parkinson's - Age, gender, years living with Parkinson's, years accessing Parkinson's-related healthcare. Healthcare professionals – Age, gender, year

			providing Parkinson's-related healthcare
Topic and item no.	Questions	NI study response	TA response
Data collection			
	Interview guide: Were questions, prompts, guides provided by the authors? Was it pilot tested?	Prompts were incorporated in the interview guide and used when necessary. An expert by experience provided feedback.	Prompts were incorporated in the interview guide and used when necessary. The guide was informed by relevant discussion with people with Parkinson's a different study.
	Repeat interviews: Were repeat interviews carried out? If yes, how many?	Not by design. However, participants were given the opportunity to continue the interview at a later date if they needed to rest. This option was accepted on one occasion.	Not by design. However, participants were given the opportunity to continue the interview at a later date if they needed to rest. This eventuality did not occur
	Audio/visual recording; Did the research use audio or visual recording to collect the data?	Audio recording were taken	Audio recording were taken
	Field notes: Were field notes made during and/or after the interview or focus group?	Yes	Yes
	Duration: What was the duration of the interviews or focus group?	An average of 49 minutes with a range of 37 to 75 minutes	People with Parkinson's – an average of 44 minutes, with a range of 21 and 80 minutes. Healthcare professionals – an average of 55 minutes, with a range of 22 and 78 minutes
	Data saturation: Was data saturation discussed?	No. Data collection was informed by the concept of information power	No. Data collection was informed by the concept of information power
	Transcripts returned: Were transcripts returned to participants for comment and/or correction?	No	No
Domain 3: analysis and findings Data analysis			

Topic and item no.	Questions	NI study response	TA response
	Number of data coders: How many data coders coded the data?	One	One
	Description of the coding tree: Did authors provide a description of the coding tree?	No	No
	Derivation of themes: Were themes identified in advance or derived from the data?	Themes were generated from the data	Themes were generated from the data
	Software: What software, if applicable, was used to manage the data?	Microsoft Word, Microsoft Excel	Microsoft Word, Microsoft Excel
	Participant checking: Did participants provide feedback on the findings?	No	No
Reporting			
	Quotations presented: Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	Yes	yes
	Data and findings consistent: Was there consistency between the data presented and the findings?	Yes	Yes
	Clarity of major themes: Were major themes clearly presented in the findings?	Yes	Yes
	Clarity of minor themes: Is there a description of diverse cases or discussion of minor themes?	N/a	N/a

Appendix K. Poster advertisement (chapter five)

PARKINSON'S UK
NORTHERN IRELAND
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

Health & Medicine | Lancaster University

Are you a member of the Parkinson's Community in Northern Ireland?

Have you been accessing healthcare services for Parkinson's since at least 2018?

We would like you to take part in a study that will help us to understand how healthcare services are experienced by those who use them

Take part in a 1-hour interview to share your experience

If you are interested in taking part and want to know more about the study, please contact Hannah Gotheridge at: h.gotheridge@lancaster.ac.uk

Appendix L. Interview guide (chapter five)

Northern Ireland Study Topic Sheet

Introduction

Before we begin, can I confirm that you have read the information sheet? Are you okay with the interview being recorded? Do you have any questions about the study before we begin?

Start recording

Initial Questions

The purpose of this study is to understand in-depth your experiences with healthcare relating to Parkinson's and how this has changed during the pandemic. Before we start the interview, could I gather a few background questions from you?

1. How old are you?
2. What gender do you identify as?
3. How would you describe your ethnicity?
4. We're also interested in how people's experiences are related to their religious identity. Can you tell me what religion or religious community you belong to?
5. How long have you been diagnosed with Parkinson's?
6. How long have you been receiving treatment for Parkinson's?

Main interview

Thank you. Are you ready to start the main part of the interview?

Subject 1: *Experience of healthcare before COVID*

The first set of questions are about your experience of healthcare before the pandemic. Healthcare for people with Parkinson's can be complex and involves things that, while not directly related to it, may be affected by Parkinson's, such as dental services. Feel free to talk about all the services that you think are relevant.

1. When you were diagnosed with Parkinson's, what was your experience like with learning about the treatments you would need and could access?

2. Can you talk to me about your relationship with healthcare professionals? You can discuss these individually if that helps.
   Prompt: neurology appointments, appointments with your Parkinson's disease nurse specialist, therapy services or other general health care appointments that are not related to

Parkinson's (e.g., dental services) but might be affected by Parkinson's.

a. How important are they in your healthcare experience?
b. How do you feel about their levels of understanding of your experience and needs as a person with Parkinson's?

3. Thinking back to before the pandemic, was using technology a significant factor in your healthcare experience? For example, offering healthcare appointments online or via telephone.
    a. How do you feel about the role of technology in healthcare?
    b. Is there anything you would change about the use of technology?
        i. Why would you change this in particular? How would this alter you experience?

4. Are there any ways you feel your needs in relation to living with Parkinson's could have been better supported by the healthcare system? Can you talk to me about how this experience affected you? How do you explain why the system does not support you in this way?

5. Overall, how well does the healthcare system support the needs of people with Parkinson's? Can you talk to me about the positives and negatives of the healthcare system?

6. Is there anything you would change about the healthcare system to better support your Parkinsons related care needs?
    a. Why would you change these things in particular? What impact are they having on you that you would like to change?

7. While developing this study we learned that many factors appear to affect healthcare and decisions related to healthcare. In Northern Ireland, religion in particular is thought to play an important role. How do you feel about this in relation to living with Parkinson's?
    a. Do you think there are other factors that are specific to Northern Ireland?

Subject 2 *Healthcare experience during COVID*

The following set of questions concern how your healthcare experience has altered since the beginning of the pandemic.

1. When COVID first appeared and restrictions were introduced, how did this affect your experience of Parkinson's-related healthcare?
    Prompt: neurology appointments, appointments with your Parkinson's disease nurse specialist, therapy services or other general health care appointments that are not related to Parkinson's (e.g., dental services) but might be affected by Parkinson's.
    a. Did it affect areas that you already felt needed improving? Did the pandemic present any new challenges?

2. Overall, do you feel as though the healthcare system has supported you during the pandemic? Can you recall any specific experiences that make you think this?

3. If you had to sum up how covid affected people with Parkinson's' in Northern Ireland, what would you say?

4. Now things are starting to get back to normal, have you noticed any lingering effects on your Parkinson's-related healthcare experience compared to pre-pandemic times? How does this affect you?

5. Do you think the pandemic has stimulated any changes in care practices?
   Prompt: Who will these impact (patients vs professionals)?

6. Do you think the pandemic highlighted key priorities in Parkinson's healthcare?
   Prompt: mental health, attitude towards professionals.
   a. How do you think these will be received in Northern Ireland? Do you think the population is sympathetic to issues with mental health?

7. Generally speaking, how do you think Parkinsons's is received in the population and government? Have you felt any stigma? Do you think enough attention is paid to the importance of such chronic conditions in the wider government?

8. Finally, I previously asked you about the role of technology in Parkinson's -related healthcare. Since the start of the pandemic, have you noticed any changes in the role of technology?
   a. How do you feel about these changes?

Closing question

1. Is there anything else you think would be helpful for me to know?

Is it okay if we contact you for any follow-up questions that may be needed for clarity?

Appendix M. Participant information sheet (chapter five)

A qualitative study of the experience of people with Parkinson's in Northern Ireland before and during the COVID-19 pandemic

My name is Hannah Gotheridge, and I am a PhD student conducting research on Parkinson's and the impact of the pandemic. I would like to invite you to take part in a research project. Before you decide whether to take part, I would like you to understand why the research is being done and what it would involve for you. This document will provide you with this information and should take around 10 minutes to read. Feel free to ask any questions you may have by using the contact information on page 5.

What is the study about?

The purpose of this study is to understand in-depth your experiences with healthcare relating to Parkinson's and how this has changed during the pandemic, and we would like to develop a fuller and meaningful understanding of the healthcare system by seeing it from the viewpoint of those who use it. We know from other surveys that people in Northern Ireland are not always well represented in research findings and therefore want to explore the views of people from the region. We expect the findings to facilitate theoretical insights, inform the improvement of Parkinson's-related healthcare, and direct the policy stances of the Parkinson's UK charity to better reflect the region.

Why have I been approached?

You have been approached because the study requires data from people that have experience with Parkinson's-related healthcare in Northern Ireland.

What does taking part involve?

You will be asked to take part in a single interview between December 2022 and July 2023.

While developing this project, we came to understand that a number of factors may influence healthcare decisions and experiences. Because of this, we have incorporated a few background questions at the beginning of the interview. These are age, what gender you identify as, ethnicity, what religion or religious community you belong to, how long you have been diagnosed with Parkinson's, and how long you have been receiving treatment for Parkinson's.

The interview will consist of questions surrounding your experience of healthcare and how this changed during the pandemic. You will be asked questions about, for example, your experience with understanding and accessing treatment at the beginning of your diagnosis, and your relationship with healthcare professionals and the importance or impact this has on you. These questions will act as prompts for you to consider different aspects of your experience, however the specific areas of discussion within these topics will be dependent on what you feel is important. After the interview has finished and data analysis has begun, it may be possible that the researcher follow-up questions about something that was unclear during the interview or an important topic that has emerged in subsequent interviews. Thus, the researcher may try to contact you at a later date to organise a follow-up interview. Importantly, in the eventuality that the researcher feels this would be beneficial, agreeing to take part is not a necessary requirement for involvement in the present interview.

The interview(s) will be conducted on a date and at a time that is convenient for you and will be completed either via telephone call or online video call using an online platform such as Zoom or Teams. If you do not have access to this technology, we will attempt to make other arrangements to enable the interview to be carried out. The interviews will be recorded to allow us to transcribe (change the call from verbal to written format) and analyse the interviews at a later point.

Do I have to take part?

Your participation is completely voluntary. If you agree to take part, we will go through a consent form together on the day of the interview. When the interview

begins, you do not have to answer any questions you do not wish to and you have the right to stop the interview and withdraw from the study at any time, without giving a reason. You also have the right to withdraw your data from the study once the interview is completed. We ask that you request to withdraw from the study within 2 weeks of participation. If you request to withdraw from the study after more than 2 weeks has passed since your interview was completed, we will make all reasonable attempts to fulfil your request, although it may not be possible.

Will my data be identifiable?

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will be deleted once the interview has been transcribed, and the transcription will be carried out by a member of the research team.
- The files on the computer containing your contact details, consent and interview transcript will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself will be password protected.
- The transcript of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.
- All your personal data will be confidential and will be kept separately from your interview responses.
- At the end of the study, we would like to upload your interview transcript and verbal consent to the university storage system Pure, where it will be kept for 10 years with Professor Jane Simpson as data custodian and subsequently deleted.

There are limits to confidentiality: if the researcher thinks that you or someone else is at a significant risk of harm, they may have to break confidentiality and speak to

a member of staff about this. If possible, the researcher will tell you if they have to do this.

Will my data be made publicly available?

Following the completion of the study, we would like to upload your interview transcript to the data repository ReShare, an online database that researchers upload their anonymised data for use by other researchers who may find the data collected valuable to their research. It is only accessible by affiliates of universities and therefore anyone who is not affiliated with a university cannot access the data. Furthermore, your data will only be used for non-commercial purposes such as use in other research projects and/or teaching purposes. You will be given the opportunity to opt out of sharing your data on ReShare as part of the consent form. Doing so will not impact your ability to take part in the study.

What are the disadvantages to taking part?

We acknowledge that you may feel some discomfort when recalling events such as receiving your Parkinson's diagnosis, negative interactions with healthcare professionals, the stress of the pandemic, and times you lacked support. We would therefore like you to consider if you are comfortable talking about these topics during the interview before agreeing to take part. If you feel any discomfort during the study, you have the right to withdraw at any time, and we encouraged you to inform the researcher and contact the resources provided on pages 5 and 6. If you take part, we predict the interview will take 1 hour of your time, although this may vary depending on responses in your interview.

Are there any benefits to taking part?

The study was developed in collaboration with Parkinson's UK's Northern Ireland branch meaning the aims of the study are in line with issues the organisation has highlighted surrounding the improvement of care in the region. The research will provide an insight into the experience of Parkinson's care from the viewpoint of those who depend on the system, as well as the impact of the pandemic. The

research may be used by the organisation to inform and support policy stances, as well as to provide theoretical insights in academic literature.

Who is organising the study?

The study is being carried out by Lancaster University in partnership with Parkinson's UK.

Who is funding the research?

The research is funded by the UK Research and Innovation (UKRI) Economic and Social Research Council (ESRC) as part of the North West Social Science Doctoral Training Partnership (NWSSDTP).

Who has reviewed the project?

The study has been approved by Lancaster University's Faculty of Health and Medicine Research Ethics Committee which is responsible for ensuring that ethical considerations and issues are addressed in the conduct of research.

Where can I obtain further information about the study if I need it?

If you have any questions about the study and would like further information, please contact:

Hannah Gotheridge **Email:** h.gotheridge@lancaster.ac.uk

Professor Jane Simpson **Email:** j.simpson2@lancaster

Complaints

If you have a concern about any aspect of this study, or if you wish to gain further information, please contact:

Hannah Gotheridge **Email:** h.gotheridge@lancaster.ac.uk

Professor Jane Simpson **Email:** j.simpson2@lancaster.ac.uk

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Mark Limmer
Head of the Division of Health Research
Faculty of Health and Medicine
Lancaster University
Lancaster, LA1 4YG
Email m.limmer@lancaster.ac.uk

If you would prefer to speak to someone outside of the Department of Health Research, please contact:

Dr Laura Machin
Chair of the Faculty of Health and Medicine Research Ethics Committee
Faculty of Health and Medicine (Lancaster Medical School)
Lancaster University
Lancaster, LA1 4YG
Telephone: 01524 594 973 **Email:** l.machin@lancaster.ac.uk

Resources in the event of distress

Should you feel distressed, either as a result of taking part in the study or in the future, the following resources may be of assistance:

The Parkinson's UK helpline: 0808 800 0303
MindWise lifeline: 0808 808 8000
Samaritans helpline: 116 123
Aware Belfast: 028 9035 7820; or **Email:** info@aware-ni.org
Aware Derry/Londonderry: 028 7162 0602; or **Email:** info@aware-ni.org

Appendix N. Consent form (chapter five)

A qualitative study of the experience of people with Parkinson's in Northern Ireland before and during the COVID-19 pandemic

We are asking you to take part in a research project concerning your experience of Parkinson's healthcare both before and during the pandemic. Before you consent to participating in the study, we ask that you read the participant information sheet and mark each box below with your initials if you agree.

Note to interviewer

- With the person's consent, please audio record this conversation (where the participant is taking part in an interview, this must be a separate audio file to the interview itself).
- Read each statement to the participant and ask them to indicate their consent to each statement.
- Complete the consent of behalf of the participant and offer to email/post a copy of the consent to them.

Please read each statement carefully and confirm whether you consent or not.	
I confirm that I have read the information sheet and fully understand what is expected of me within this study	
I confirm that I have had the opportunity to ask any questions and to have them answered.	
I understand that my interview will be audio recorded and then made into an anonymised written transcript.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
I understand that I have two weeks to withdraw my data from this study after completing the interview, and that after two weeks, if I request for my data to be withdrawn it might not be possible, though reasonable attempts will be made to extract my data up to the point of publication.	
I understand that I may be asked to take part in a follow-up interview, and that I have the right to refuse to take part in this without it affecting my ability to take part in the present interview.	
I consent to information and quotations from my interview being used in reports, conferences, and training events on the basis that all information used is anonymised.	
I understand that the researcher will discuss data with their supervisor as needed.	
I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or	

others, in which case the principal investigator will need to share this information with their research supervisor.	
I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.	
I consent to taking part in this study.	

Ask the participant to state their name and the date.

Explain to the participant that the following statements are specifically in relation to data sharing, and that if participants do not consent to this component, it will have no impact on their ability to take part in the study.

Please read each statement to the participant and confirm if they consent or not.	
I have read the component of the participant information sheet regarding data sharing, and I have had the opportunity to ask any questions and to have them answered.	
I understand that my agreeing to share data collected from my participation in this study is completely optional, and has no bearing on my eligibility to take part in this study.	
I understand that while my data will be made publicly available, every effort will be made so that no identifiable information will be released to maximise the likelihood my anonymity is maintained.	
I understand that my data may be used for research and/or teaching purposes by other researchers in different fields of study.	
I understand that my data cannot be used for anything other than research and/or teaching purposes.	
I consent to my data being made publicly available on the online repository ReShare.	

Ask the participant to state their name and the date.

Appendix O. Sample experiential coding (chapter five)

Parkinson's nurse 'doesn't ever seem to want to get hold of people' – 'I feel quite disappointed sometimes'. Justifying resource use - 'it's not like I'm ringing here every week'. Who would I turn to if something went wrong? Accessing care by any means necessary Hearing back quickly 'makes me feel that at least somebody there is interested in me'. Pursuing healthcare was worthwhile'.	P: Well, the only negative experience I've had was, a few times, this is after covid, um there is a dedicated, um Parkinson's nurse, who really doesn't ever seem to want to get a hold of people, because I've had to ring here several times, but I really feel, I feel quite disappointed sometimes that she hasn't responded. And it's not like I'm ringing here every week, this would be something like maybe once a year. But they are very slow to get back and that, that annoys me, and also worries me because if I was really really bad, you know, who would I turn to, what would happen, and, I have also had occasion to ring the doctors secretary, I don't know how I managed it but I found her phone number, and I rang her twice and left messages and she got back to me immediately. And that reassured me because it made me feel that at least somebody there is interested in me, or doing their job or wanting to help. And both times his secretary was able to get messages to the doctor, and then they resulted in me having a consultation at the hospital which I really felt I needed and were worthwhile.

Appendix P. Example narrative summary (chapter five)

P 10 - I'm very independent. but sometimes I feel like there should be somebody there

The diagnosis came as a shock because the healthcare workers were unclear about what was going on

Communication about potential diagnosis was unclear

Enquired about DBS and 'went along with it' when the GP said yes

Did not have time to think the DBS treatment through because it progressed quickly

Hasn't had a checkup in two years – 'I feel as though nobody really knows how I'm progressing'

Not seeing the consultant because of the pandemic – 'I know I'm very independent and stubborn, but sometimes I feel, like there should be somebody there'.

The participant talks about various times she didn't feel in control during her diagnosis and treatment and appears to use information about treatment options to protect against this. This may itself stem from her formative diagnostic experience which was unclear and uncertain. Minimal information was given and there was ambiguity about whether she had Parkinson's. This was particularly difficult for her to cope with and meant that she was in a state of limbo where she could not confront the diagnosis. Likely because of this experience (but also her self-described independent nature) she began to take charge of her treatment and the choices that were made. However, she does express some desire for this not to be a necessity ('I know I'm very independent and stubborn, but sometimes I feel like there should be somebody there').

Information seems to be a guard to ensure that she is not swept up in what healthcare professionals want her to do. Information is how she feels in control and on top of things. She expresses discomfort when she is not

Care is affected by delays

The consultant can't understand how she is doing with no visuals

The pressures of COVID mean 'there is no longer a joined-up approach with Parkinson's'

Hasn't seen her consultant since before COVID

At this stage now (post pandemic) it's me guiding my treatment, my medication.

aware of what e.g., medication is for and how it will help her. This may be related to the lack of contact with healthcare professionals at times. She talks about needing to be in control of her treatment currently because she hasn't seen the consultant in so long. She talks about how because of this, she feels that no one knows how she is doing ('nobody really knows how I'm progressing'). In this sense, being informed and active in decision making is a defense mechanism against the possibility of being let down by the system and healthcare professionals, who can't always be relied upon. This was particularly apparent during the pandemic where contact with healthcare professionals was severely disrupted.

Appendix Q. Example group experiential theme narrative summary (chapter five)

Theme 1 - The impact of and reaction to limited resources in the healthcare system[12]

Grace - We're at the behest of healthcare

Grace - Being a conscious user of limited resources

Cillian - Managing expectations

Cillian - Feeling pressure to supplement healthcare.

Silas - The staff just seem to be slaughtered

Ronan - If ever I need help, I get it

Aiden - The quality of healthcare is fine - the issue is actually receiving it

Siobhan - Parkinson's is the poor relation of neurological conditions.

Cian - Being grateful for the 'help'

Most participants referenced limits to the ability of the healthcare service to provide sufficient support as a result of it being underfunded and under resourced. Experiences of this vary but for some can be extreme and lead to feeling totally out of control (P10). Poor experiences around the time of diagnosis appear to be particularly important and a lack of information or direction to relevant information can be particularly impactful. The time of diagnosis appears to be a formative time where experiences with specific individuals and the care that is provided set the scene for future feelings about healthcare. Overall, this can lead people to feel as though the system and healthcare professionals don't actually know how they are progressing (P10). Explanations about why the system cannot fulfil needs vary. Some talk about the system being underfunded, the staff and system have been slaughtered. Some take this a step further and say the system is underfunded because the government is not in session and they can't make financial decisions. Others point to general trends regarding societies view of Parkinson's. That is, Parkinson's isn't deadly and so it is given less attention and financial priority than other conditions (P10).

Consistently, people take care to note and mention that they know the fault does not lie in the hands of the healthcare workers. Many express sympathy and others talk about the shared experience of limited fundings (P*). However, in some cases, this can lead to difficulty because it means that no one is responsible or can be held accountable. For example, when an individual received a blunt letter about

[12] Theme 1 as it was before later refinement of the topic and structure

their diagnosis, it wasn't their fault, it was the fault of the system causing the neurologist time constraints (PY, P2, P3). This forms part of the reason why some people are reluctant to complain about the care they receive. Additionally, many people express a lack of awareness of other peoples' experiences, especially with regard to how they feel about the quality of their treatment. This also stops people from wanting to complain.

The overall knock on effect of this for many people is that they adapt their expectation of what the healthcare system can provide them. Often the difficulty of not being able to control the situation leads people to managing what they can control (expectations; P2, PY). People accept they cannot have everything, look for other avenues (e.g., private healthcare, peer support) to supplement their needs, become grateful for what they do have, and sometimes criticize others for wanting too much (P2, PY).

Appendix R. Group experiential themes (chapter five)

Participant	Personal Experiential theme title
Theme 1 - We're at the behest of healthcare': Shaping care expectations around perceived resource limitation	
Grace	We're at the behest of healthcare.
Grace	Being a conscious user of limited resources.
Cillian	Managing expectations
Cillian	Feeling pressure to supplement healthcare.
Silas	The staff just seem to be slaughtered
Ronan	If ever I need help, I get it
Aiden	The quality of healthcare is fine, the issues is actually receiving it.
Siobhan	Parkinson's is the poor relation of neurological conditions.
Cian	Being grateful for the 'help'
Theme 2 - If you don't ask you don't get': Protecting healthcare needs	
Grace	Letting HCPs lead the way
Silas	I have the right to say no I don't like that
Ronan	You just talk to them about your experience, and they advise you
Aiden	It's my role to feed back into the system
Torin	I seem to get everything I need
Cian	Receiving the care you feel you need
Theme 3 - Chuck a few pills at you, do some exercise, you'll be fine': The limited nature of Parkinson's-related healthcare	
Grace	Being put at ease is half of the battle.
Cillian	Needing a holistic approach to living with Parkinson's.
Cillian	Using peer support to fill in the gaps in healthcare.
Silas	The 'extra-curricular' support is not well enough signposted.
Aiden	The diagnosis felt sudden.
Siobhan	He was interested in me as a patient, I felt.
Siobhan	I tried to ignore it for as long as I could.
Torin	Doctors and nurses are representative of society - there are good ones and bad ones.
Cian	Getting your head on right – finding support in healthcare workers and peers.

Note. PETs not grouped into themes are not shown

Appendix S. Ethics application (chapter six)

Research Ethics Application Form v1.9.7

Research Ethics Application Form v1.9.7 RECR

A dual-perspective qualitative investigation of the adoption of technology in Parkinson's care in a post-COVID world - Approved

Information Regarding this Research Project

Are you conducting a research project?

(for more information on research projects please see our ethics pages)

(•) Yes ( ) No

Does your research only involve animals?

( ) Yes (•) No

Are you undertaking this research as/are you filling this form out as:

( ) Academic/Research Staff
( ) Non Academic Staff
( ) Staff Undertaking a Programme of Study
(•) PhD or DClinPsy student or MPhil
( ) Undergraduate, Masters, Master by Research or other taught postgraduate programme

Which Faculty are you in?

Faculty of Health and Medicine

Which department are you in?

Health Research

Will your project require NHS REC approval? (If you are not sure please read the guidance in the information button)

○ Yes ◉ No

Do you need Health Research Authority (HRA) approval? (Please read the guidance in the information button)

○ Yes ◉ No

Have you already obtained, or will you be applying for ethical approval, from another institution outside of Lancaster University? (For example, an external institution such as: another University's Research Ethics Committee, the NHS or an institution abroad (eg an IRB in the USA)? Please select one of the following:

◉ No, I do not need ethical approval from an external institution.
○ Yes, I have already received ethical approval from an external institution.
○ Yes, I will be applying for ethical approval from an external institution after I have received confirmation of ethical approval from my Faculty Research Ethics Committee (FREC) at Lancaster University, if the FREC grants approval.

Is this an amendment to a project previously approved by Lancaster University?

○ Yes ◉ No

Will your research involve any of the following? (Multiple selections are possible, please see i icon for details)

☑ Human Participants
☐ Data relating to humans (Secondary/Pre-existing data only)
☐ Data collection from online sources such as social media platforms, discussion forums, online chat-rooms
☐ Human Tissue
☐ None of the above

Project Information

Please confirm/amend the title of this project.

A dual-perspective qualitative investigation of the adoption of technology in Parkinson's care in a post-COVID world

E

E

Is this a funded Project?

○ Yes ◉ No

Research Site(s) Information

Will you be recruiting participants from research sites outside of Lancaster University? *(E.g. Schools, workplaces, etc; please read the guidance in the information button for more information)*

○ Yes ◉ No

Applicant Details

Are you the named Principal Investigator at Lancaster University?

◉ Yes ○ No

Please check your contact details are correct. You can update these fields via the personal details section located in the top right of the screen. Click on your name and email address in the top right to access "Personal details". For more details on how to do this, please read the guidance in the information button.

First Name

Hannah

Surname

Gotheridge

Department

Health Research

Faculty

Faculty of Health and Medicine

Email

h.gotheridge@lancaster.ac.uk

Principal Investigator

You have stated that you are the Principal Investigator for this project.

First Name

Hannah

Surname

Gotheridge

Department

Health Research

Email

h.gotheridge@lancaster.ac.uk

Supervisor Details

Search for your supervisor's name. *If you cannot find your supervisor in the system please contact rso-systems@lancaster.ac.uk to have them added.*

First Name

Craig

Surname

Murray

Department

Health Research

Faculty

Faculty of Health and Medicine

Email

c.murray@lancaster.ac.uk

Do you need to add a second supervisor to sign off on this project?

○ Yes ◉ No

Additional Team Members

Other then those already added, please select which type of team members will be working on this project:

- ☐ I am not working with any other team members.
- ☑ Staff
- ☐ Student
- ☐ External

Search for the names of all other internal staff here:

First Name

Fiona

Surname

Eccles

Department

Health Research

Faculty

Faculty of Health and Medicine

Email

f.eccles@lancaster.ac.uk

Search for the names of all other internal staff here:

First Name

Jane

Surname

Simpson

Department

Health Research

Faculty

Faculty of Health and Medicine

Email

j.simpson2@lancaster.ac.uk

Details about the participants

As you are conducting research with Human Participants/Tissue you will need to answer the following questions before your application can be reviewed.

If you have any queries about this please contact your Ethics Officer before proceeding.

What's the minimum number of participants needed for this project?

15

What's the maximum number of expected participants?

20

Do you intend to recruit participants from online sources such as social media platforms, discussion forums, or online chat rooms?

(•) Yes ( ) No

Will you get written consent and give a participant information sheet with a written description of your research to all potential participants?

( ) Yes (•) No ( ) I don't know

Will any participants be asked to take part in the study without their consent or knowledge at the time or will deception of any sort be involved?

( ) Yes (•) No ( ) I don't know

Is your research with any vulnerable groups?

(Vulnerable group as defined by Lancaster University Guidelines)

( ) Yes (•) No ( ) I don't know

Is your research with any adults (aged 18 or older)?

(•) Yes ( ) No

Is your research data collected with completely anonymous adult (aged 18 or older) participants, with no contact details or other uniquely identifying information (e.g. date of birth) being recorded?

( ) Yes (•) No

Is your research with adult participants (aged 18 years, or older) in private interactions (for example, one to one interviews, online questionnaires)?

(•) Yes ( ) No

Is your research with any young people (under 18 years old)?

( ) Yes (•) No ( ) I don't know

Does your research involve discussion of personally sensitive subjects which the participant might not be willing to otherwise talk about in public (e.g. medical conditions)?

(•) Yes ( ) No ( ) I don't know

Could the study induce psychological stress or anxiety, or produce humiliation or cause harm or negative consequences beyond the risks encountered in a participant's usual, everyday life?

(•) Yes ( ) No ( ) I don't know

Is there a risk that the nature of the research topic might lead to disclosures from the participant concerning either:

- Their own or others involvement in illegal activities
- Other activities that represent a threat to themselves or others (e.g. sexual activity, drug use, or professional misconduct)?

( ) Yes (•) No ( ) I don't know

Does the study involve any of the following:

- Physically intrusive procedures including touching or attaching equipment to participants
- Administration of substances
- Ultrasound or sources of non-ionising radiation (e.g. lasers)
- Sources of ionising radiation, (e.g. X-rays)
- Collection or use of samples of Human Tissue (e.g. Saliva, skin cells, blood etc.)

( ) Yes (•) No ( ) I don't know

Details about Participant relationships

Do you have a current or prior relationship with potential participants? For example, teaching or assessing students or managing or influencing staff (this list is not exhaustive).

( ) Yes (•) No ( ) I don't know

If you need written permission from a senior manager in an organisation where research will take place (e.g. school, business) will you gain this in advance of undertaking your research?

( ) Yes ( ) No ( ) I don't know (•) N/A

Will you be using a gatekeeper to access participants?

(•) Yes ( ) No ( ) I don't know if I will be using a gatekeeper

The gatekeeper will be in a position of authority or have influence over potential participants (e.g., a teacher or manager). However, I will take the gatekeeper's assurance that they will stay completely impartial and that I will ensure that there is no perceived pressure to participate, and I will explain to participants that their decision on whether to participate or not will have no effect on their treatment or rights (e.g., learning or assessment).

(•) Yes ( ) No ( ) I don't know

The gatekeeper will be able to tell who has participated (e.g., participants' responses will be made directly to the gatekeeper or if the researcher will inform the gatekeeper of who has participated), but I have assurance that they will not use this knowledge to treat participants differently.

( ) Yes (•) No ( ) I don't know

Will participants be subjected to any undue incentives to participate?

( ) Yes (•) No ( ) I don't know

Will you ensure that there is no perceived pressure to participate?

(•) Yes ( ) No ( ) I don't know

Participant data

Will you be using video recording or photography as part of your research or publication of results?

( ) Yes (•) No

Will you be using audio recording as part of your research?

(•) Yes ( ) No

Will you be using audio recordings in outputs (e.g. giving a presentation in a conference, using it for teaching)?

( ) Yes (•) No

Will you be using portable devices to record participants (e.g. audio, video recorders, mobile phone, etc)?

- ○ No
- ○ Yes, and all portable devices will be encrypted as per the Lancaster University ISS standards, in particular where they are used for recording identifiable data
- ◉ Yes, but these cannot be encrypted because they do not have encryption functionality. Therefore I confirm that any identifiable data (including audio and video recordings of participants) will be deleted from the recording device(s) as quickly as possible (e.g. when it has been transferred to a secure medium, such as a password protected and encrypted laptop or stored in OneDrive) and that the device will be stored securely in the meantime

Will you be using other portable storage devices in particular for identifiable data (e.g. laptop, USB drive, etc)? (Please read the help text)

- ○ No
- ◉ Yes, and they will be encrypted as per the Lancaster University ISS standards in particular where they are used for recording identifiable data

Will anybody external to the research team be transcribing the research data?

○ Yes ◉ No

Online Sources

Does your research comply with the site(s) terms and conditions? Before completing the section below please read the 'Social Media Guidance for Researchers'

◉ Yes ○ No ○ It's unclear in the terms and conditions

Is there a reasonable expectation of privacy?

◉ Yes ○ No

Because there is a reasonable expectation of privacy, you must obtain consent from site users. Therefore you will need to upload a copy of the Participant Information Sheet & Consent form that you intend to use to obtain their informed consent.

General Queries

Does the funder or any organisations involved in the research have a vested interest in specific research outcomes that would affect the independence of the research?

○ Yes ◉ No ○ I don't know

Does any member of the research team, or their families and friends, have any links to the funder or organisations involved in the research?

○ Yes ◉ No ○ I don't know

Can the research results be freely disseminated?

◉ Yes ○ No ○ I don't know

Will you use data from potentially illicit, illegal, or unethical sources (e.g. pornography, related to terrorism, dark web, leaked information)?

○ Yes ◉ No ○ I don't know

Will you be gathering/working with any special category personal data?

◉ Yes ○ No ○ I don't know

Are there any other ethical considerations which haven't been covered?

○ Yes ◉ No ○ I don't know

REC Review Details

Based on the answers you have given so far you will need to answer some additional questions to allow reviewers to assess your application.

It is recommended that you do not proceed until you have completed **all of the previous questions**.

Please confirm that you have finished answering the previous questions and are happy to proceed.

☑ I confirm that I have answered all of the previous questions, and am happy to proceed with the application.

Questions for REC Review

Summarise your research protocol in lay terms (indicative maximum length 150 words).

Note: The summary of the protocol should concisely but clearly tell the Ethics Committee (in simple terms and in a way which would be understandable to a general audience) what you are broadly planning to do in your study. Your study will be reviewed by colleagues from different disciplines who will not be familiar with your specific field of research and it may also be reviewed by the lay members of the Research Ethics Committee; therefore avoid jargon and use simple terms. A helpful format may include a sentence or two about the background/ "problem" the research is addressing, why it is important, followed by a description of the basic design and target population. Think of it as a snapshot of your study.

The use of technology in the diagnosis and treatment of healthcare, often referred to as telemedicine (e.g., video consultations, online therapeutic interventions), rose in prominence during the COVID-19 pandemic where it enabled the continuation of services without the need for face-to-face contact. The delivery of services is particularly important for people with chronic health conditions such as Parkinson's whose care involves significant interaction with various services and professionals. While the use of such technology has become a feature of post-COVID healthcare, views about its usefulness and validity vary.

The study will use one-to-one, semi-structured interviews to investigate experiences and views about the use of telemedicine in Parkinson's-related healthcare. Thematic analysis, a qualitative research method focusing on the generation of themes will be used to analyse the data. If possible, the interviews will take place with both pwP and healthcare providers (15 – 20 participants in total) to enable a broad and balanced insight to develop.

State the Aims and Objectives of the project in Lay persons' language.

The purpose of the study is to gain a broad perspective on the changing use of telemedicine in Parkinson's-related healthcare in a post-COVID world. We would like to develop an understanding about the nature of this change, experiences with such telemedicine, and feelings and opinions about its usage for those who provide and receive care in this manner.

Participant Information

Please explain the number of participants you intend to include in your study and explain your rationale in detail (eg who will be recruited, how, where from; and expected availability of participants). If your study contains multiple parts eg interviews, focus groups, online questionnaires) please clearly explain the numbers and recruitment details for each of these cohorts (see help text).

A group of people with Parkinson's (pwP) will be sought and, if possible, a group of healthcare providers will also be recruited. It is anticipated that healthcare providers will be more difficult to recruit and, if this is the case (see below), the study will focus on the viewpoints of pwP only. The study will use a qualitative approach, namely Thematic Analysis (TA). Sample size in thematic analysis can range from 2 to 400 and no universal guidelines are provided. In line with Mayor et al. (2022), the concept of information power rather than data saturation was adopted when deciding the number of participants to include. A provisional sample size of 15 to 20 across the two groups of participants was judged to be a suitable number and has precedence in literature (e.g., Anestis et al., 2022; Mayor et al., 2022), although this will be reviewed during the data collection period. Importantly, the concept of information power will be used to judge when the minimum number of participants required for each group has been achieved as the data is collected. If a sufficient number of healthcare workers cannot be recruited, all 15-20 participants will be recruited for the Parkinson's group.

PwP will be recruited to enable a patient-centred viewpoint to be explored. If possible, healthcare workers involved in the provision of Parkinson's-related healthcare (e.g., Parkinson's nurses, consultants) will also be recruited to contrast the view of those using the services. Participants from both groups must have been involved with Parkinson's-related healthcare for five or more years to enable some reflection on the pre-COVID state of technology use. Additionally, all participants must access/administer Parkinson's-related healthcare in the UK. Finally, all participants must have some experience of the use of telemedicine and/or technology in Parkinson's-related healthcare.

Data will be collected using various pathways. As the research is a collaboration with the Parkinson's UK charity, the primary method of recruitment will be to use this connection to advertise the study amongst those who are members of, or associated with, the charity. Because of this, the charity is regarded as a gatekeeper that will enable access to the target population(s). In particular, the Excellence Network, a collection of Parkinson's UK staff members and various healthcare professionals, will be key to advertising the study to healthcare professionals. The professional relationships developed with the head of this network as well as with that of the charities Head of Strategic Intelligence will be important in advertising the study and these individuals will be key gatekeepers. The Parkinson's UK Take Part Hub will also be used to advertise the study to members of the charity, and it is anticipated that this will primarily aid with the recruitment of pwP. More generally, the charity has various capabilities that will be utilised such as social media accounts, mailing lists, newsletters, research groups, and support groups. However, recruitment will not rely solely on this connection. Various social media accounts such as those run by researchers or support groups for people with Parkinson's are well placed to advertise the study. In such an instance, the researcher will not post using their private account and consent will be gained by the owner/administrator of the account or group before the study is advertised.

Due to the research experiences and collaborative research relationships that the research supervisors have in relation to Parkinson's, difficulty in recruiting pwP is not anticipated. However, recruitment of healthcare workers may be more difficult. Consequently, if recruitment of enough healthcare workers for the study is not possible, it will revert to a single group and data will only be collect from people with Parkinson's. This feasibility of recruiting enough healthcare workers will be judged by the initial interest in the study when it is first advertised and will be gauged by the number of expressions of interest received.

You have selected that you are not getting written consent using a Participant Information Sheet with a written description of your research. Please indicate why you are not using a Participant Information Sheet, and how you are obtaining consent.

Written consent from the participants cannot be obtained as the interviews will (in most cases) take place via telephone or an online platform. Instead, a Participant Information Sheet and Consent Form will be emailed or posted to participants (depending on their preference). Before the interview commences, the interviewer will go through the documents with the participants, and verbal consent will be recorded. Thus, participants will be fully informed about the nature of the study and the role of participants.

You have selected that the research may involve personal sensitive topics that participants may not be willing to otherwise talk about. Please indicate what discomfort, inconvenience or harm could be caused to the participant and what steps you will take to mitigate or manage these situations.

The participants with Parkinson's will be asked to discuss events and experiences related to health and healthcare, which they may not like to discuss in everyday situations. The healthcare workers will be asked to recall potentially distressful events relating to their profession. To mitigate any potential negative experiences caused by participation in the study, participants will be informed of the nature of the study and given an indication of topics they will be asked to discuss in the participant information sheet. This will allow them to make an informed decision concerning their willingness to take part. Moreover, if participants become distressed during the interview, they will be reminded of their right to withdraw and directed to the local support groups listed on page 5 of the participant information sheet. Finally, participants will be informed of their right to withdraw from the study up to 2 weeks after it has been carried out.

You have indicated that you will collect identifying information from the participants. Please describe all the personal information that you gather for your study which might be used to identify your participants.

To sign up to the study, participants need to provide their name and email address/mobile phone number, as well as a postal address if they want physical copies of documents. Before beginning the interview, participants will be asked background questions to collect important contextual information and help to better understand their experiences. Specifically, they will be asked how old they are, what gender they identify as, and what ethnicity they identify as. Additionally, people in the Parkinson's group will be asked how long they have been diagnosed with Parkinson's and how long they have been receiving treatment for Parkinson's. Healthcare workers will additionally be asked for their job title and how long they have provided Parkinson's-related healthcare.

Please describe how the data will be collected and stored.

To sign-up to the study, participants will need to provide their name and an email address and/or phone number to the email address or phone number listed on the advertising poster. If participants would prefer hard copies of the consent form and participant information sheet, they will additionally need to provide a postal address. Otherwise, these documents will be sent via email. The study itself will consist of a single semi-structured interview, and an audio recording will be taken to enable transcription. These interviews will take place via telephone or an online platform such as Teams depending on the preference of the participants. Interviews may also be conducted in person if feasible. An audio recording of the interviews will be taken using a Dictaphone, regardless of the platform the interview is carried out on, to enable transcription.

The consent process and interview will be recorded on a Dictaphone. The consent and interview will be recorded separately to enable them to be stored separately. As the Dictaphone does not have encryption capabilities, the data will be immediately transferred to a university provided laptop and stored on OneDrive, which is university-approved secure cloud storage. The personal data (consent and details provided at sign up) and interview recording/transcription will be stored in separately folders. The voice recording on the unencrypted Dictaphone will be immediately deleted once the upload is complete, and it is anticipated that the interview and consent will be stored on the Dictaphone for no longer than an hour after the interview is completed. To ensure the anonymity of participants, all identifiers (e.g., reference to names) will be removed from the interview transcript. A unique identification number will enable identification between the consent and interview.

Please describe how long the data will be stored and who is responsible for the deletion of the data.

Following the completion of the study, the interview transcripts of participants that consented to data sharing will be uploaded to the data repository ReShare, an online database that researchers upload their anonymised data for use by other researchers who may find the data collected valuable to their research. Participants will be informed of the procedure for data storage in the Participant Information Sheet. The upload of the interview transcript to ReShare will only be carried out with the approval of the participants, consent for which is incorporated into the consent form. In addition to this, the interview transcripts and audio consent files will be uploaded to the university storage system Pure, where they will be stored for 10 years with Professor Jane Simpson as data custodian. All other personal data (name and contact information) will be deleted by the researcher once the study is completed or after the participants have received a summary of the results (depending on which is latest).

You stated that the study could induce psychological stress or anxiety, or produce humiliation or cause harm or negative consequences beyond the risks encountered in a participant's usual, everyday life. Please describe the question(s) and situation(s) that could lead to these outcomes and explain how you will mitigate this.

In the interview, participants in the Parkinson's group will be asked to recall their experience of Parkinson's-related healthcare, and some participants may find these events distressing. Specifically, the interview will involve questions surrounding the use of technology in healthcare and preliminary research indicates mixed feelings and experiences. Thus, the interview may involve the discussion of unpleasant healthcare experiences. Participants in the healthcare workers group may be required to recall potentially negative experiences when providing services or negative aspects of the work environment. This will be mitigated by informing participants of the nature of the topic that will be discussed in the interview. Specifically, the topics have been listed in the 'what are the disadvantages of taking part?' section of the participant information sheet, where participants are also encouraged to consider if they are comfortable talking about this in the interview before agreeing to take part in the study. Moreover, participants have been informed of their right to withdraw from the study at any point, for any reason, and without an explanation in the participant information sheet and consent form and will be reminded before the interview begins (during the consent process).

Information about the Research

What are your dissemination plans? E.g publishing in PhD thesis, publishing in academic journal, presenting in a conference (talk or poster).

The research will be published in a PhD thesis, and it is also planned to publish the research in an academic journal and to disseminate the findings at conferences, although the time frame for this is unknown. Due to the collaboration with and involvement of the Parkinson's UK charity, it is also important to disseminate the findings to members and employees of the charity, particularly those who were involved in facilitating the research.

Online Sources

You have indicated site users have a reasonable expectation of privacy and therefore you will need to obtain consent to use their data for this project. Please explain how you propose to obtain consent.

Social media will only be used to advertise the study meaning the personal details of the participants will not be publicly available. Instead, the social media posts will direct interested participants to contact the (university) email address or phone number (created for the purpose of the study - not the researchers personal number) listed on the advertisement.

General Queries

You have indicated that you will be gathering/working with special category data. Please confirm here how you will comply with data protection law (GDPR) for use of special category personal data.

Some of the data collected is classed as sensitive personal data, thus must be either encrypted (if stored on a mobile/external storage device) or stored on university Microsoft Office 365 services such as OneDrive. Initially, the data will be collected on a Dictaphone that does not have encryption capabilities. However, immediately after the interview concludes, the data will be uploaded to OneDrive and deleted from the Dictaphone. It is anticipated that this process will take no longer than an hour. In addition, the personal data (consent, name and contact details) will be stored in a separate folder from the anonymised research data. When it is necessary to dispose of the data, the researcher will make a disposal request via the disposal request form to ensure all traces of the data are removed.

To maintain the anonymity of participants names will not be included in the participant profiles (age, gender, ethnicity, length of diagnosis, length of time accessing services, length of time providing Parkinson's-related healthcare, job title), although pseudonyms may be included to facilitate understanding of the analysis. Additionally, identifiable information such as the names of family, friends, and healthcare professionals will be removed and therefore not be included in any quotations used in the publication. This procedure is in line with similar published studies in the field (e.g., Simpson et al., 2021). We expect participants to retain their anonymity, however, participants will be fully informed of the data that will be collected and how this will be used in the publication to ensure they make a fully informed decision.

Data Storage

How long will you retain the research data?

Following the completion of the study, the anonymised interview transcripts of participants that consented to data sharing will be uploaded to the data repository ReShare (an online database that researchers upload their anonymised data for use by other researchers who may find the data collected valuable to their research) for an indefinite amount of time. Participants will be informed of the procedure for data storage in the Participant Information Sheet. The upload of the interview transcript to ReShare will only be carried out with the approval of the participants, consent for which will be gained as part of the consent form. In addition to this, the interview transcripts and audio consent files will be uploaded to the university storage system Pure, where it will be stored for 10 years with Professor Jane Simpson as data custodian.

How long and where will you store any personal and/or sensitive data?

The audio recording of the consent process (detailing the participants names) will be stored along with the interview transcripts on the university storage system Pure for 10 years, with Professor Jane Simpson as data custodian. The audio recording of each interview will be deleted after it has been transcribed, which will begin 2 weeks after the interview took place to enable participants time to withdraw from the study. All other personal data (name and contact details) will be deleted once the study is completed or after the participants have received a summary of the results, depending on which occurs latest.

Please explain when and how you will anonymise data and delete any identifiable record?

When the recording of the consent process and interview have been uploaded to the university OneDrive, a unique code will be given to each participant and the recordings will be stored in separate password-protected folders. Thus, the consent form containing the identifiable data will be stored separately from the interview itself. Once the interview has been transcribed, all identifiers (e.g., references to names) will be removed. The transcription process will start 2 weeks after the interview was carried out to give participants time to opt-out of the study if they decide they no longer want to take part. Following transcription of the interview, the audio file will be deleted by the researcher.

Project Documentation*

Important Notice about uploaded documents:

When your application has been reviewed if you are asked to make any changes to your uploaded documents please highlight the changes on the updated document(s) using the highlighter so that they are easy to see.

Please confirm that you have read and applied, where appropriate, the guidance on completing the Participant Information Sheet, Consent Form, and other related documents and that you followed the guidance in the help button for a quality check of these documents. For information and guidance, please use the relevant link below:

FST Ethics Webpage

FHM Ethics Webpage

FASS-LUMS Ethics Webpage

REAMS Webpage

☑ I confirm that I have followed the guidance.

In addition to completing this form you must submit all supporting materials.

Please indicate which of the following documents are appropriate for your project:

- ☐ I have no updated documents and confirm that all relevant documents were included in previous submissions.
- ☑ Advertising materials (posters, emails)
- ☐ Research Proposal (DClinPsy)
- ☐ Letters/emails of invitation to participate
- ☑ Consent forms
- ☑ Participant information sheet(s)
- ☑ Interview question guides
- ☐ Focus group scripts
- ☐ Questionnaires, surveys, demographic sheets
- ☐ Workshop guide(s)
- ☐ Debrief sheet(s)
- ☐ Transcription (confidentiality) agreement
- ☐ Other
- ☐ None of the above.

Please upload the documents in the correct sections below:

Please ensure these are the latest version of the documents to prevent the application being returned for corrections you have already made.

Documents

Type	Document Name	File Name	Version Date	Version	Size
Consent Form	23_07_03_ConsentForm_HealthcareWorkers	23_07_03_ConsentForm_HealthcareWorkers.pdf	03/07/2023	1	142.7 KB
Consent Form	23_07_03_ConsentForm_PwParkinson's	23_07_03_ConsentForm_PwParkinson's.pdf	03/07/2023	1	142.7 KB

Please upload all Participant Information Sheets:

Documents

Type	Document Name	File Name	Version Date	Version	Size
Participant Information Sheet	PIS healthcare workers_2	PIS healthcare workers_2.pdf	13/08/2023	2	186.2 KB
Participant Information Sheet	PIS parkinsons_2	PIS parkinsons_2.pdf	13/08/2023	2	187.2 KB

Please upload all advertising materials (posters, emails)

Documents

Type	Document Name	File Name	Version Date	Version	Size
Advertising materials	Poster_HealthcareWorkers_2	Poster_HealthcareWorkers_2.pdf	13/08/2023	2	176.6 KB
Advertising materials	Poster parkinsons_2	Poster parkinsons_2.pdf	13/08/2023	2	177.0 KB

Please upload all different Interview Question Guides.

Documents

Type	Document Name	File Name	Version Date	Version	Size
Interview question guide	Interview schedule healthcare workers_2	Interview schedule healthcare workers_2.pdf	13/08/2023	2	103.2 KB
Interview question guide	Interview schedule parkinson's_2	Interview schedule parkinson's_2.pdf	13/08/2023	2	104.0 KB

Declaration

Please Note

Research Services monitors projects entered into the online system, and may select projects for quality control.

All research at Lancaster university must comply with the LU data storage and governance guidance as well as the General Data Protection Regulation (GDPR) and the UK Data Protection Act 2018. (Data Protection Guidance webpage)

☑ I confirm that I have read and will comply with the LU Data Storage and Governance guidance and that my data use and storage plans comply with the General data Protection Regulation (GDPR) and the UK Data Protection Act 2018.

Have you that you have undertaken a health and safety risk assessment for your project through your departmental process? (Health and Safety Guidance)

☑ I have undertaken a health and safety assesment for your project through my departmental process, and where required will follow the appropriate guidance for the control and management of any foreseeable risks.

When you are satisfied that this application has been completed please click "Request" below to send this application to your supervisor for approval.

Signed: This form was signed by Dr Craig Murray (c.murray@lancaster.ac.uk) on 13/08/2023 15:10

Please read the terms and conditions below:

- You have read and will abide by Lancaster University's Code of Practice and will ensure that all staff and students involved in the project will also abide by it.
- If appropriate a confidentiality agreement will be used.
- You will complete a data management plan with the Library if appropriate. Guidance from Library.
- You will provide your contact details, as well as those of either your supervisor (for students) or an appropriate person for complaints (such as HoD) to any participants with whom you interact, so they know whom to contact in case of questions or complaints?
- That University policy will be followed for secure storage of identifiable data on all portable devices and if necessary you will seek guidance from ISS.
- That you have completed the ISS Information Security training and passed the assessment.
- That you will abide by Lancaster University's lone working policy for field work if appropriate.
- On behalf of the institution you accept responsibility for the project in relation to promoting good research practice and the prevention of misconduct (including plagiarism and fabrication or misrepresentation of results).
- To the best of your knowledge the information you have provided is correct at the time of submission.
- If anything changes in your research project you will submit an amendment.

Applicant Only: To complete and submit this application please click "Sign" below:

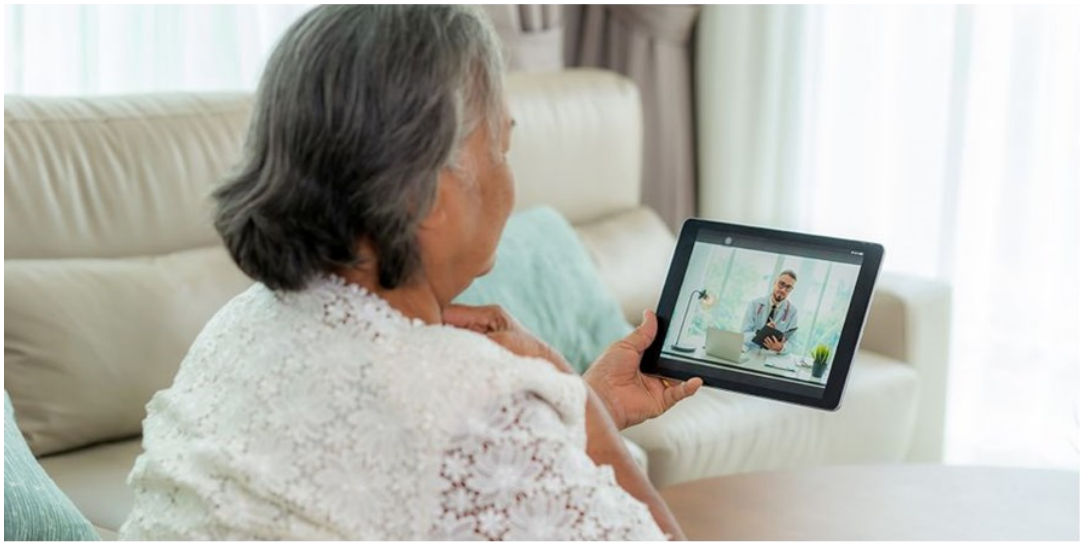
Signed: This form was signed by Hannah Gotheridge (h.gotheridge@lancaster.ac.uk) on 14/08/2023 14:33

Appendix T. Poster advertisement (chapter six)

Appendix T1. People with Parkinson's

PARKINSON'S UK
HANGE ATTITUDES. FIND A CURE. JOIN US.

Health & Medicine | Lancaster University



Have you provided healthcare services for people with Parkinson's in the UK since 2018?

We want to hear about your experience with telemedicine or the use of technology when providing Parkinson's-related healthcare services.

Take part in a dual-perspective study alongside people with Parkinson's to provide a nuanced understanding of the use of technology

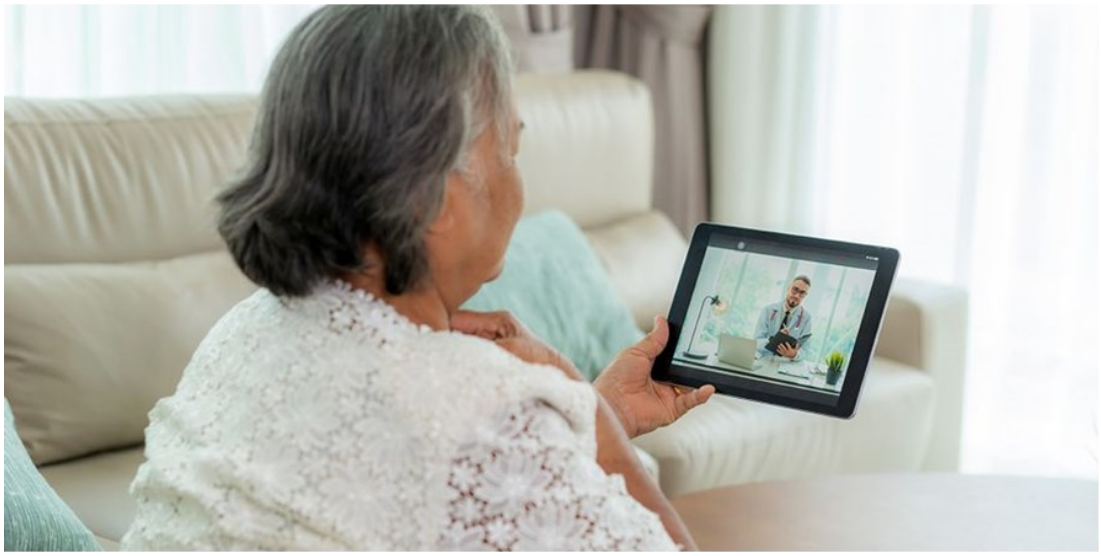
Take part in a one-to-one 60 - 90-minute interview

If you are interested in taking part and want to know more about the study, please contact Hannah Gotheridge at: h.gotheridge@lancaster.ac.uk or text 07818914296

Appendix T2. Healthcare professionals

PARKINSON'S UK
CHANGE ATTITUDES. FIND A CURE. JOIN US.

Health & Medicine | Lancaster University



Have you provided healthcare services for people with Parkinson's in the UK since 2018?

We want to hear about your experience with telemedicine or the use of technology when providing Parkinson's-related healthcare services.

Take part in a dual-perspective study alongside people with Parkinson's to provide a nuanced understanding of the use of technology

Take part in a one-to-one 60 - 90-minute interview

If you are interested in taking part and want to know more about the study, please contact Hannah Gotheridge at: h.gotheridge@lancaster.ac.uk or text 07818914296

Appendix U. Participant information sheet (chapter six)

Appendix U1. People with Parkinson's

People's experiences of the use of technology in healthcare for Parkinson's

My name is Hannah Gotheridge, and I am a PhD student conducting research on Parkinson's and the impact of the pandemic. I would like to invite you to take part in a research project. Before you decide whether to take part, I would like you to understand why the research is being done and what it would involve for you. This document will provide you with this information and should take around 10 minutes to read. Feel free to ask any questions you may have by using the contact information on page 4.

What is the study about?

The purpose of this study is to understand your experience and views on the use of technology and telemedicine in Parkinson's-related healthcare which has been impacted by the COVID-19 pandemic. Examples of this include video consultations and online therapeutic interventions We know from research that the use telemedicine is rising in healthcare, but opinions and experiences vary. Thus, we would like to gain a broad perspective from both the people who deliver these services as well as those who access them. We expect the findings to inform the improvement of Parkinson's-related healthcare and direct the policy stances of the Parkinson's UK charity.

Why have I been approached?

You have been approached because the study is interested in the views and experiences of people that have provided healthcare services for people with Parkinson's in the UK using telemedicine or technology. To take part in the study, we ask that you have been providing Parkinson's-related healthcare for at least five years.

What does taking part involve?

You will be asked to take part in a single interview between September 2023 and December 2024. The interview is expected to take around 1 hour but may be between 45-90 minutes depending on your answers.

At the beginning of the interview, we will ask you your age, what gender you identify as, your ethnicity, how long you have provided Parkinson's-related healthcare, and your job title. The interview itself will include questions about your experience of and opinions about the use of technology and telemedicine in Parkinson's healthcare. You will be asked questions about, for example, positive and negative experiences with the use of technology in healthcare, the development of rapport with service users, and your opinions on the quality of care. However, the specific areas of discussion within these topics will be dependent on what you feel is important. After the interview it may be possible that the researcher has follow-up questions for you about something that was said during the interview. Thus, the researcher may try to contact you at a later date.

If you agree to take part, the interview will be conducted on a date and at a time that is convenient for you. This will be completed either via telephone call or online video call using a platform such as Teams. In-person interviews may take place under certain circumstances. If you do not have access to the required technology, we will attempt to make other arrangements to enable the interview to be carried out. The interviews will be recorded to allow us to type what is said and extracts from this would be used in written reports.

Do I have to take part?

Your participation is completely voluntary. If you agree to take part, we will go through a consent form together on the day of the interview. When the interview begins, you do not have to answer any questions you do not wish to and you have the right to stop the interview and withdraw from the study at any time, without giving a reason. You also have the right to withdraw your data from the study once the interview is completed. We ask that you request to withdraw from the study within 2 weeks of participation. If you request to withdraw from the study after

more than 2 weeks has passed since your interview was completed, we will make all reasonable attempts to fulfil your request, although it may not be possible. This is due to the data being anonymised after this 2-week period before then being grouped into themes alongside the data of other participants.

Will my data be identifiable?

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will be deleted once the interview has been typed into a document, which will be done by a member of the research team.
- The files on the computer containing your contact details, consent and interview transcript will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself will be password protected.
- The typed document of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.
- All your personal data will be confidential and will be kept separately from your interview responses.
- At the end of the study, we would like to upload your interview transcript and verbal consent to the university storage system Pure, where it will be kept for 10 years with Professor Jane Simpson as data custodian and subsequently deleted.

There are limits to confidentiality: if the researcher thinks that you or someone else is at a significant risk of harm, they may have to break confidentiality and speak to a member of staff about this. If possible, the researcher will tell you if they have to do this.

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

What will happen to the data I provide?

As previously mentioned, we will collect background data such as your age and gender. These data will be included in the publication to provide context to the data that was collected and analysed. Real names will not be included alongside this information although pseudonyms may be included to facilitate understanding of the analysis. Additionally, the interviews will be analysed and grouped into key themes which will be supported by quotations from the interviews. These quotations will be anonymised by removing uniquely identifying information such as names and places. Because of this, we do not believe that the data you provide will be identifiable when the study is published.

Will my data be made publicly available?

Following the completion of the study, we would like to upload your typed interview to the data repository ReShare, an online database that researchers upload their anonymised data for use by other researchers who may find the data collected valuable to their research. It is only accessible by affiliates of universities and therefore anyone who is not affiliated with a university cannot access the data. Furthermore, your data will only be used for non-commercial purposes such as use in other research projects and/or teaching purposes. You will be given the opportunity to opt out of sharing your data on ReShare as part of the consent form. Doing so will not impact your ability to take part in the study.

What are the disadvantages to taking part?

We acknowledge that you may feel some discomfort when talking about, for example, potentially negative experiences in the work environment. We would therefore like you to consider if you are comfortable talking about these topics during the interview before agreeing to take part. If you feel any discomfort during

the study, you have the right to withdraw at any time, and we encourage you to inform the researcher and contact the resources provided on page 5. If you take part, we predict the interview will take between 60 and 90 minutes of your time, although this may vary depending on responses in your interview.

Are there any benefits to taking part?

The study was developed in collaboration with Parkinson's UK's and will enable them to better understand experiences of and beliefs about the use of technology in healthcare and subsequently contribute to how they advocate for people with Parkinson's. The research may be used by the organisation to inform and support policy stances, as well as to provide theoretical insights in academic literature.

Who is organising the study?

The study is being carried out by Lancaster University in partnership with Parkinson's UK.

Who is funding the research?

The research is funded by the UK Research and Innovation (UKRI) Economic and Social Research Council (ESRC) as part of the North West Social Science Doctoral Training Partnership (NWSSDTP).

Who has reviewed the project?

The study has been approved by Lancaster University's Faculty of Health and Medicine Research Ethics Committee which is responsible for ensuring that ethical considerations and issues are addressed in the conduct of research.

Where can I obtain further information about the study if I need it?

If you have any questions about the study and would like further information, please contact:

Hannah Gotheridge **Email:** h.gotheridge@lancaster.ac.uk

Professor Jane Simpson **Email:** j.simpson2@lancaster

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Mark Limmer
Head of the Division of Health Research
Faculty of Health and Medicine
Lancaster University
Lancaster, LA1 4YG
Email: m.limmer@lancaster.ac.uk

If you would prefer to speak to someone outside of the Department of Health Research, please contact:

Dr Laura Machin
Chair of the Faculty of Health and Medicine Research Ethics Committee
Faculty of Health and Medicine (Lancaster Medical School)
Lancaster University
Lancaster, LA1 4YG
Telephone: 01524 594 973 **Email:** l.machin@lancaster.ac.uk

Resources in the event of distress

Should you feel distressed, either as a result of taking part in the study or in the future, the following resources may be of assistance:

Frontline: Text 'FRONTLINE' to 85258
Samaritans helpline: 116 123
SANEline: 0300 304 7000
AWARE (Belfast) helpline: 028 9035 7820
AWARE (Derry/Londonderry) helpline: 028 9035 7830
AWARE email: info@aware-ni.org

We also encourage you to discuss your experiences with family or friends, or a trusted colleague.

Thank you for reading this participant information sheet!

Appendix U2. Healthcare professionals

People's experiences of the use of technology in healthcare for Parkinson's

My name is Hannah Gotheridge, and I am a PhD student conducting research on Parkinson's and the impact of the pandemic. I would like to invite you to take part in a research project. Before you decide whether to take part, I would like you to understand why the research is being done and what it would involve for you. This document will provide you with this information and should take around 10 minutes to read. Feel free to ask any questions you may have by using the contact information on page 4.

What is the study about?

The purpose of this study is to understand your experience and views on the use of technology and telemedicine in Parkinson's-related healthcare which has been impacted by the COIVD-19 pandemic. Examples of this include video consultations and online therapeutic interventions We know from research that the use telemedicine is rising in healthcare, but opinions and experiences vary. Thus, we would like to gain a broad perspective from both the people who use such services as well as those who deliver them. We expect the findings to inform the improvement of Parkinson's-related healthcare and direct the policy stances of the Parkinson's UK charity.

Why have I been approached?

You have been approached because the study is interested in the views and experiences of people that have accessed healthcare services with the use of technology or telemedicine in Parkinson's-related healthcare in the UK. To take part in the study, we ask that you have been receiving Parkinson's-related healthcare for at least five years.

What does taking part involve?

You will be asked to take part in a single interview between September 2023 and August 2024. The interview is expected to take around 1 hour but may be between 45-90 minutes depending on your answers.

At the beginning of the interview, we will ask you your age, what gender you identify as, your ethnicity, how long you have been diagnosed with Parkinson's, and how long you have been receiving treatment for Parkinson's. The interview itself will include questions about your experience of and opinions about the use of technology and telemedicine in Parkinson's healthcare. You will be asked questions about, for example, positive and negative experiences with the use of technology in healthcare, the development of rapport with healthcare professionals, and your opinions on the quality of care. However, the specific areas of discussion within these topics will be dependent on what you feel is important. After the interview it may be possible that the researcher has follow-up questions for you about something that was said during the interview. Thus, the researcher may try to contact you at a later date.

If you agree to take part, the interview will be conducted on a date and at a time that is convenient for you. This will be completed either via telephone call or online video call using a platform such as Teams. In-person interviews may take place under certain circumstances. If you do not have access to the required technology, we will attempt to make other arrangements to enable the interview to be carried out. The interviews will be recorded to allow us to type what is said and extracts from this would be used in written reports.

Do I have to take part?

Your participation is completely voluntary. If you agree to take part, we will go through a consent form together on the day of the interview. When the interview begins, you do not have to answer any questions you do not wish to and you have the right to stop the interview and withdraw from the study at any time, without giving a reason. You also have the right to withdraw your data from the study once the interview is completed. We ask that you request to withdraw from the study

within 2 weeks of participation. If you request to withdraw from the study after more than 2 weeks has passed since your interview was completed, we will make all reasonable attempts to fulfil your request, although it may not be possible. This is due to the data being anonymised after this 2-week period before then being grouped into themes alongside the data of other participants.

Will my data be identifiable?

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will be deleted once the interview has been typed into a document, which will be done by a member of the research team.
- The files on the computer containing your contact details, consent and interview transcript will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself will be password protected.
- The typed document of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.
- All your personal data will be confidential and will be kept separately from your interview responses.
- At the end of the study, we would like to upload your interview transcript and verbal consent to the university storage system Pure, where it will be kept for 10 years with Professor Jane Simpson as data custodian and subsequently deleted.

There are limits to confidentiality: if the researcher thinks that you or someone else is at a significant risk of harm, they may have to break confidentiality and speak to a member of staff about this. If possible, the researcher will tell you if they have to do this.

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

What will happen to the data I provide?

As previously mentioned, we will collect background data such as your age and gender. These data will be included in the publication to provide context to the data that was collected and analysed. Real names will not be included alongside this information although pseudonyms may be included to facilitate understanding of the analysis. Additionally, the interviews will be analysed and grouped into key themes which will be supported by quotations from the interviews. These quotations will be anonymised by removing uniquely identifying information such as names and places. Because of this, we do not believe that the data you provide will be identifiable when the study is published.

Will my data be made publicly available?

Following the completion of the study, we would like to upload your typed interview to the data repository ReShare, an online database that researchers upload their anonymised data for use by other researchers who may find the data collected valuable to their research. It is only accessible by affiliates of universities and therefore anyone who is not affiliated with a university cannot access the data. Furthermore, your data will only be used for non-commercial purposes such as use in other research projects and/or teaching purposes. You will be given the opportunity to opt out of sharing your data on ReShare as part of the consent form. Doing so will not impact your ability to take part in the study.

What are the disadvantages to taking part?

We acknowledge that you may feel some discomfort when talking about, for example, your health or potentially negative healthcare experiences. We would therefore like you to consider if you are comfortable talking about these topics during the interview before agreeing to take part. If you feel any discomfort during the study, you have the right to withdraw at any time, and we encourage you to

inform the researcher and contact the resources provided on page 5. If you take part, we predict the interview will take between 60 and 90 minutes of your time, although this may vary depending on responses in your interview.

Are there any benefits to taking part?

The study was developed in collaboration with Parkinson's UK's and will enable them to better understand experiences of and beliefs about the use of technology in healthcare and subsequently contribute to how the advocate for people with Parkinson's. The research may be used by the organisation to inform and support policy stances, as well as to provide theoretical insights in academic literature.

Who is organising the study?

The study is being carried out by Lancaster University in partnership with Parkinson's UK.

Who is funding the research?

The research is funded by the UK Research and Innovation (UKRI) Economic and Social Research Council (ESRC) as part of the North West Social Science Doctoral Training Partnership (NWSSDTP).

Who has reviewed the project?

The study has been approved by Lancaster University's Faculty of Health and Medicine Research Ethics Committee which is responsible for ensuring that ethical considerations and issues are addressed in the conduct of research.

Where can I obtain further information about the study if I need it?

If you have any questions about the study and would like further information, please contact:

Hannah Gotheridge **Email:** h.gotheridge@lancaster.ac.uk

Professor Jane Simpson **Email:** j.simpson2@lancaster

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Mark Limmer

Head of the Division of Health Research

Faculty of Health and Medicine

Lancaster University

Lancaster, LA1 4YG

Email: m.limmer@lancaster.ac.uk

If you would prefer to speak to someone outside of the Department of Health Research, please contact:

Dr Laura Machin

Chair of the Faculty of Health and Medicine Research Ethics Committee

Faculty of Health and Medicine (Lancaster Medical School)

Lancaster University

Lancaster, LA1 4YG

Telephone: 01524 594 973 **Email:** l.machin@lancaster.ac.uk

Resources in the event of distress

Should you feel distressed, either as a result of taking part in the study or in the future, the following resources may be of assistance:

The Parkinson's UK helpline: 0808 800 0303

The Parkinson's UK email: hello@parkinsons.org.uk

The Parkinson's NI helpline: 028 0992 3370

The Parkinson's NI email: northernireland@parkinsons.org.uk

Samaritans helpline: 116 123

SANEline: 0300 304 7000

AWARE (Belfast) helpline: 028 9035 7820

AWARE (Derry/Londonderry) helpline: 028 9035 7830

AWARE email: info@aware-ni.org

We also encourage you to discuss your experiences with family or friends, or a trusted healthcare provider.

Thank you for reading this participant information sheet!

Appendix V. Consent form (chapter six)

People's experiences of the use of technology in healthcare for Parkinson's

We are asking you to take part in a research project concerning your experience of the changing use of technology in Parkinson's healthcare. Before you consent to participating in the study, we ask that you read the participant information sheet.

Note to interviewer

- With the person's consent, please audio record this conversation (where the participant is taking part in an interview, this must be a separate audio file to the interview itself).
- Read each statement to the participant and ask them to indicate their consent to each statement.
- Complete the consent of behalf of the participant and offer to email/post a copy of the consent to them.

Please read each statement carefully and confirm whether you consent or not.	
I confirm that I have read the information sheet and fully understand what is expected of me within this study	
I confirm that I have had the opportunity to ask any questions and to have them answered.	
I understand that my interview will be audio recorded and then made into an anonymised written transcript.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
I understand that I have two weeks to withdraw my data from this study after completing the interview, and that after two weeks, if I request for my data to be withdrawn it might not be possible, though reasonable attempts will be made to extract my data up to the point of publication.	
I consent to information and quotations from my interview being used in reports, conferences, and training events on the basis that all information used is anonymised.	
I understand that the researcher will discuss data with their supervisors as needed.	
I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with their research supervisors.	
I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.	
I consent to taking part in this study.	

Ask the participant to state their name and the date.

Explain to the participant that the following statements are specifically in relation to data sharing, and that if participants do not consent to this component, it will have no impact on their ability to take part in the study.

Please read each statement to the participant and confirm if they consent or not.	
I have read the component of the participant information sheet regarding data sharing, and I have had the opportunity to ask any questions and to have them answered.	
I understand that my agreeing to share data collected from my participation in this study is completely optional, and has no bearing on my eligibility to take part in this study.	
I understand that while my data will be made publicly available, every effort will be made so that no identifiable information will be released to maximise the likelihood my anonymity is maintained.	
I understand that my data may be used for research and/or teaching purposes by other researchers in different fields of study.	
I understand that my data cannot be used for anything other than research and/or teaching purposes.	
I consent to my data being made publicly available on the online repository ReShare.	

Ask the participant to state their name and the date.

Appendix W. Interview guides (chapter six)

Appendix W1. People with Parkinson's

Telemedicine study Topic Sheet

People with Parkinson's

Start recording

Initial questions

1. How old are you?

   Read options:

   1) ≤19, 2) 20-29, 3) 30-39, 4) 40-49, 5) 50 - 59, 6) 60 – 69, 7) 70 – 79, 8) 80 – 89, 9) 90<

2. What gender do you identify as?

   Read options:

   1) Male, 2) Female, 3) Other

3. How would you describe your ethnicity?

   Read options:

   1) White, 2) Irish Traveller, 3) Mixed/ Multiple ethnic groups, 4) Asian/ Asian British, 5) Black/ African/ Caribbean/ Black British, 6) Chinese, 7) Arab, 8) Other ethnic group.

4. How long have you been diagnosed with Parkinson's?

5. How long have you been receiving Parkinson's-related healthcare?

Main interview

1. To contextualise the rest of our discussion, can you give me an overview of your Parkinson's-related healthcare over the years (2018 – present)?
    a. How your treatment progressed, who was involved at the various points

2. One of the things were interested in is how the use of telemedicine/technology has (or hasn't) changed over the years, especially in relation to the pandemic. So, talking specifically with regards to Parkinson's-related healthcare, can you talk to me about how technology/telemedicine is used? It may be useful to structure this as before, during, and after the pandemic.

    Prompt: When the pandemic hit, did the use of technology change? If applicable, reference the technology use the participant previously described.

    Prompt: Are there any ways in which the pandemic has fundamentally changed the way technology is used to provide healthcare - that is, are there ways in which technology is used now, as things are returning to normal, that were not used before the pandemic?

3. Have there been any changes in the use of technology that began in the pandemic that have continued now the pandemic is over?
    a. If yes, why do you think this happened?

4. Have you ever experienced barriers to using or accessing telemedicine?
    a. Do you think this is the same for other people?

5 Speaking more generally (so not in a specific time frame), how do you feel about the use of technology in healthcare, do you think it is useful?
    a. Can you describe why you think this? Can you talk about specific benefits and disadvantages? What do your family or carers think?

6. Do you think it effects the quality of healthcare you receive?
    a. How do you think other people feel about the use of technology in healthcare?

    Prompt: Other people with Parkinson's? Healthcare professionals?

7. If you have any problems or are unhappy with the use of technology in your healthcare, how would you deal with this, is there anyone you could speak to?

8. How is the use of technology in your healthcare decided? Can you talk to me about the process of its implementation?

9. Can we talk more about the specific impact of using technology and how it may affect how you interact with your healthcare? Does it affect your relationship with the people that you receive healthcare from?
    a. Do you think other people with Parkinson's share this opinion?
    b. Do you think healthcare workers share this opinion?

10. How do you think the future of technology in healthcare will look?
    Prompt. How do you think it will be used? How would you like it to be used? Are you happy with the prospect of technology use in the future? Specific strengths and weaknesses? How do you think it will affect Parkinson's care for the population more generally?

11. What do you think about using technology in healthcare as symptoms progress or as you age?

12. In relation to Parkinson's healthcare, how would you like the use of technology to change in the future?
    a. Can you think of any ways it could be used to improve the provision of care?

13. What do you think healthcare workers is the impact of technology on health and social care?

14. Picking up on the changes we discussed earlier, if you could give a message to healthcare providers or those organising care, what would you say?

15. Is there anything I haven't asked you that you think I should know?

End recording

Appendix W2. Healthcare professionals

Telemedicine study Topic Sheet

Healthcare workers

Start recording

Initial questions

1. How old are you?

   Read options:

   2) ≤19, 2) 20-29, 3) 30-39, 4) 40-49, 5) 50 - 59, 6) 60 – 69, 7) 70 – 79, 8) 80 – 89, 9) 90<

2. What gender do you identify as?

   Read options:

   2) Male, 2) Female, 3) Other

3. How would you describe your ethnicity?

   Read options:

   1) White, 2) Irish Traveller, 3) Mixed/ Multiple ethnic groups, 4) Asian/ Asian British, 5) Black/ African/ Caribbean/ Black British, 6) Chinese, 7) Arab, 8) Other ethnic group.

4. How long have you been working in Parkinson's-related healthcare?

5. What is your job title?

Main interview

1. I'm speaking to a number of healthcare workers who, as I'm sure you can imagine, have very different roles in supporting pwP. So, to contextualise the rest of our discussion, can you give me an overview of your role in providing care for people with Parkinson's over the years (2018 – present)?

2. One of the things were interested in is how the use of telemedicine/technology has (or hasn't) changed over the years, especially in relation to the pandemic. So, talking specifically with regards to your role in providing healthcare for pwP, can you talk to me about how technology/telemedicine is used? It may be useful to structure this as before, during, and after the pandemic.

   Prompt: When the pandemic hit, did the use of technology change? If applicable, reference the technology use the participant previously described.

   Prompt: Are there any ways in which the pandemic has fundamentally changed the way technology is used to provide healthcare - that is, are there ways in which technology is used now, as things are returning to normal, that were not used before the pandemic?

3. Were there any barriers to incorporating technology?
   a. Procedure, guidelines, resource limitations, the specific context at the time these changes were happening (e.g., COVID)

4. In your experience, what are the main drivers behind how technology is used in healthcare, what influences how you use it?
   a. Are you given guidelines/practices to follow, do you have freedom to use it in the way you see fit?

5. Are you aware of how the people to whom you provide services feel about the use of telemedicine?

6. If you or people you provide healthcare to are unhappy, can you alter things?

7. Speaking more generally, do you think telemedicine/technology is a useful tool in supporting healthcare provision?
   a. Can you talk about specific benefits and disadvantages?
   b. Are there any aspects of telemedicine that you think need to be improved or developed further? Accessibility, quality of assessment, procedure, guidelines, systems

   c. In your role, I imagine you have contact with a number of other healthcare professionals that work with pwP - do you think other people in the multidisciplinary care team (e.g., nurses, consultants) share this opinion?

8. Does using technology affect your relationship with the people to whom you provide healthcare?
   a. Do you think it effects the quality of the care you can provide?

9. Would you like the use of technology to change in the future, and if so, how?
   a. Are there any things you think worked better prior to the pandemic?

10. Are you aware of any potential future trends in the telemedicine and the use of technology?

11. Is there anything I haven't asked you that you think I should know?

End recording

Appendix X. Sample of iterative coding (chapter six)

Participant	Excerpt	Iteration 1	Iteration 2	Iteration 3	Final code
P2	I didn't mind having my consultation last week online or by video, but I would have been happier to have gone and met with Dr [name redacted].	Prefers in-person ones	Prefers in-person ones	In-person > video > telephone	In person>video> telephone
P2	Professor [name redacted] is quite good because he said quite clearly. categorically that he wants to see me in six months. So, I've got confidence in that he wants to make that work	Feels confident new consultant wants to build relationship through in-person consultations	Build relationship through in-person consultations	Being seen in-person is a necessary part of healthcare	In-person contact is fundamental
P2	It's not a working relationship but, it is a working relationship between doctor and patient. He knows I'm not a stupid guy, so when for instance, the likes of, I did the three peaks a few years ago… because he knows that I'm sensible I just rang up and said look I'm going to be doing this over 24-hour period, I think I'll need to take maybe an extra tablet…he said 'yes, that's fine. I know you're not stupid, crack on with it'.	Developing a working relationship builds mutual understanding that facilitates personalised care	Working relationships facilitate mutual understanding and improves care	In-person relationships facilitate detailed knowledge of patient and shared understanding	Understanding of healthcare needs is facilitated by relationships with HCP's

Participant	Excerpt	Iteration 1	Iteration 2	Iteration 3	Final code

P2	I have my medical driving licence which lasts three years. With [name redacted] it’s just, he knows me, signs me off. Because he knows that I’m, how I am ten years in, and I'm quite capable of driving, there is no problem. Somebody who is ten years in, writing to the GP or to their doctor whose got no real working relationship with that person, they're gonna think ‘oh 10 years, might not be too cable of driving’. And it immediately sets you off on the wrong footing.	Quality of relationships (built in-person) effects quality of care	Quality of relationships (built in-person) effects quality of care	In-person relationships facilitate detailed knowledge of patient and shared understanding	Understanding of healthcare needs is facilitated by relationships with HCP's
P2	But I would have been happier to have gone and met with Dr [name redacted], and let him see my movement, let him see my posture, see everything else.	Feels that in-person visits allow the doctor to get a fuller assessment of his state	Limitations to what telemedicine can do successfully	Telemedicine reduces the amount of information that can be shared	Telemedicine hinders full assessment

Appendix Y. Example narrative summary (chapter six)

Theme 1 - Telemedicine limits expert assessment by healthcare professionals and relies on reporting by people with Parkinson's[13]

This theme explores how the balance between the reporting of problems by pwP (e.g., symptoms, difficulties, response to medication) and the assessment of these problems by HCP's is affected by the use of telemedicine. From the HCP perspective, this is pertinent to situations where HCPs are using their expertise to understand the difficulties pwP are having in order to provide appropriate treatment/refer them to relevant services. Put simply, the use of telemed reduces the amount of information that is available to HCP's (e.g., non-verbal cues, understanding of their home environment, assessing movement). This means HCPs rely on the ability of pwP to identify, flag and coherently explain the problem they are facing to the HCP. This experience is mirrored for pwP who think the use of telemedicine reduces the amount of 'information' that can be conveyed, and a 'complete assessment' is only possible in-person. Because of this, pwP see in-person as the most desirable and comprehensive type of healthcare which enabled HCPs to understand their experience. Congruently, HCPs view in-person contact as a vital component of healthcare for situations when telemedicine is not sufficient to understand a problem, or when a patient is particularly complex. Both groups highlighted that relationships between HCP's and pwP play an important role because they increase the 'comprehension' of the issue that pwP are facing with limited information/cues. For pwP, the use of telemedicine reduces or 'pauses' the relationship, and some degree of in-person contact is necessary for telemedicine to be suitable. Relatedly, HCPs should be wary of the healthcare they provide to pwP they are unfamiliar with. Additionally, HCPs should be careful to understand which pwP are 'suitable' for telemed (e.g., can account for themselves, not facing complex issues), and which circumstances are suitable for telemed (e.g., follow-ups, X percentage of check-ups).

[13] Theme title as it was before later refinement.

Appendix Z. Thematic grouping of merged codes

Participant group	Code
Theme 1 - Telemedicine is in the early stages of integration into healthcare	
Parkinson's	The quality of healthcare is constrained by poor systems
Parkinson's	The potential of telemedicine has not yet been met
Parkinson's	Support people with the use of telemedicine
HCP's	HCP's and pwP are more tech savvy post-pandemic
HCP's	The pre-pandemic healthcare system was not set up for telemedicine
HCP's	Using telemedicine in the pandemic was a steep learning curve for HCP's and pwP
HCP's	In the pandemic, needs must
HCP's	Telemedicine will become more viable
HCP's	The current NHS climate is not geared towards widespread use of telemed
Theme 2 - The promise (and concern) of telemedicine in a resource strained healthcare environment	
Parkinson's	Technology could improve self-management
Parkinson's	The promise of telemedicine to feel more comprehensively assessed
Parkinson's	Concern about and experience with the improper application of telemedicine
Parkinson's	Physical distance means you can be ignored
HCP's	Telemedicine will increase the quality of healthcare
HCP's	Telemedicine increases the efficiency of the system
HCP's	Telemed will reduce the financial strain on the system

Participant group	Code
Theme 3 - Phone and video assessments increase the reliance on the reporting of issues by pwP	
Parkinson's	Telemedicine hinders full assessment by HCP's
Parkinson's	Telemedicine reduces the amount of 'information' that can be conveyed
Parkinson's	Being understood is facilitated by relationships with HCP's
Parkinson's	Telemedicine negatively impacts relationships
Parkinson's	In-person contact is a fundamental component of healthcare
Parkinson's	Receiving comprehensive advice and assessment requires being seen in-person
Parkinson's	In person>video>telephone
HCP's	Telemedicine increases the reliance on reporting by pwP
HCP's	Telemedicine impacts the amount and type of information available for HCPs to assess
HCP's	Telemedicine can/should not replace all face-to-face contact
Theme 4 - Making the most of telemedicine with the hybrid model	
Parkinson's	Telemedicine is a useful tool for specific aspects of healthcare
Parkinson's	Telemedicine appointments are better than not being seen
Parkinson's	Telemedicine enables flexibility for pwP and HCP's
HCP's	Utility depends on the profession
HCP's	The hybrid model is a useful tool
HCP's	Telemed is more convenient and less stressful for many pwP
HCP's	Telemedicine overcomes geographical restrictions for HCP's and pwP
HCP's	The suitability of telemedicine depends on what ends need to be met

Participant group	Code
Theme 5 – (lack of) Freedom of choice in the use of telemedicine	
Parkinson's	Patient choice' is limited by resource strain
Parkinson's	Feeling a lack of autonomy in the use of telemedicine
Parkinson's	The need to accommodate preference and needs over time
Parkinson's	Telemedicine is used because it is time/cost effective
HCP's	The importance of communicating changes to the use of telemedicine
HCP's	Facilitating choice
HCP's	Some pwP are in a better position to use telemed than others

Note. HCP's = Healthcare professionals