Investigating sensemaking in Parkinson's self-tracking : a lived approach to chronic disease self-management

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Investigating Sensemaking in Parkinson’s Self-tracking

A Lived Approach to Chronic Disease Self-management

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I, Evgenia-Xenia (Jenny) Vafeiadou, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

E X Vafeiadou, September 2023

Abstract

This thesis presents a series of studies aiming to investigate and support sensemaking of Parkinson's Disease (PD) self-tracking in the context of self-management. PD is a complex neurodegenerative disease with more than 10 million people with Parkinson's (PwP) worldwide. PD is multidimensional in its presentation, including physical, cognitive, and emotional symptoms, and it usually exists with other comorbidities. Health technologies designed for this group have primarily focused on improving the clinical assessments of the disease. Whilst PwP engage in self-tracking as part of their health self-management, less attention has been given to how PwP use technology to track and manage their disease in their everyday experience and how technologies could support disease sensemaking. The overarching goal of this thesis has been to stimulate how one might approach design for sensemaking in PD self-tracking while accounting for the *lived* efforts of self-management.

I conducted three studies combining qualitative and design methods to achieve this goal. The findings of these studies, comprising this thesis, make three new contributions to the field of CSCW and HCI. Firstly, by taking a lived perspective on PD self-tracking, the thesis offers theoretical insights into how PD self-tracking happens in everyday life, informing how HCI and Digital Health research can approach PD self-tracking. Secondly, this thesis takes a holistic approach to PD self-management, offering theoretical insights to the HCI and CSCW on how PwP make sense of their data individually and through peer-to-peer social interactions and the interplay between these two processes. Thirdly, this thesis offers a sensemaking-driven design exploration leveraging empirically informed design principles, and a proposed design concept illustrating these principles. These can motivate and inspire researchers and designers working in HCI and CSCW to design alternative self-tracking tools that transcend the traditional design approaches in PD self-tracking.

Overall, this thesis provides a qualitative account and design perspective that demonstrates the value of designing for the lived efforts of self-management. These findings are particularly relevant to researchers and designers aiming to design PD self-tracking technologies supporting PwP in making sense their PD in the context of everyday life.

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List of Abbreviations

Computer-Supported Cooperative Work	CSCW
Human-Computer Interaction	HCI
HealthUnlocked	HU
Human Immunodeficiency Virus	HIV
Irritable Bowel Syndrome	IBS
National Health Service	NHS
Online Health Communities	OHC
Parkinson’s Disease	PD
Personal Informatics	PI
PwP	Person/People with Parkinson’s

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Chapter 1: Introduction

This chapter provides the framing of this PhD thesis, including my motivation to engage with the chosen research area. Specifically, this chapter explains why Parkinson's disease (PD) is the focus of this thesis. Then, it presents the research questions the thesis answers and outlines its structure, including a summary of every chapter that follows.

1.1 Motivation

One-third of people worldwide live with a chronic disease (Hajat & Stein, 2018). To address the challenges resulting from the increasing numbers of people with chronic diseases, public health systems are revisiting the traditional doctor-driven healthcare model and embracing a patient-centric approach (World Health Organisation, 2015). A central tenet of this approach is for patients to be informed and thus empowered to practice self-management, which refers to "the systematic process of learning and practising skills, which enable individuals to manage their health condition on a day-to-day basis" (Self-management UK, 2020).

In response to this changing healthcare landscape, technology is seen as a core enabler that can help address the challenges and decisions involved in self-management, such as following a demanding treatment plan, changing long-standing routines and habits, or managing physical symptoms (Swendeman et al., 2015). Personal Informatics (PI), a "class of systems that help people collect personal information to improve self-knowledge" (Li et al., 2010), have been identified as key technologies to deliver this change. In line with this goal, research has been oriented towards studying and supporting the use of self-tracking technologies in a chronic disease context either by investigating how people use widely available consumer health technologies in relation to their disease self-management (e.g., Matthews et al., 2017; Swendeman et al., 2015), or by designing and evaluating new self-tracking tools (e.g., Brown et al., 2017; Karkar et al., 2017). In this context, researchers have investigated a wide range of PI applications and sensing domains, including symptom tracking (MacKrill et al., 2020), tracking physiological measurements such as sleep (Weatherall et al., 2018), and lifestyle activities (Miller et al., 2016).

Despite the advancements in healthcare mentioned above, there are quite a few studies that have shown that people only engage with health technologies briefly (Rapp & Cena, 2016) in the context of chronic disease (Ancker et al., 2015). This leads to high abandonment rates of tracking technologies (Clawson et al., 2015). Choosing a Human-Computer Interaction (HCI) lens which does not promote technological solutionism and the introduction of technology at all costs (Cunningham et al., 2023) can help us understand and address the complex nuances of this issue. More specifically, the strength of such an HCI lens is in understanding everyday self-care practices and in trying to improve people's quality of life *potentially* through the use of technology (Nunes et al., 2015). Storni (2014), a scholar working on the space of self-tracking in chronic disease, highlighted the need to understand chronic disease not only as a biomedical condition but also as a complex lifestyle issue with many parameters.

To this end, in this thesis, I adopt a broader definition for the concept of self-tracking that focuses on the *practice* rather than the use of PI technology. Additionally, my self-tracking definition encapsulates quantitatively (e.g., vital signs[1]) and qualitatively (e.g., sleep quality) measured data. Specifically, I define self-tracking as any practice embedded in everyday experience that supports an individual "to collect personally relevant information for the purpose of self-reflection and gaining self-knowledge" (Li et al., 2010). This information could be self-reported lifestyle and quality of life data (e.g., diet, exercise) in a structured or unstructured form (e.g., "machine-readable or not, numeric, text, image, waveform, etc.") (Shapiro et al., 2012).

Furthermore, while self-tracking and self-management have predominantly been framed as activities employed by the individual, Murnane et al. (2018: 1) have argued that "health management even when self-driven, is inherently social and depends on a person's direct relationships and broader socio-cultural contexts". Notably, the social dimensions of self-management are evident within Online Health Communities (OHCs) (e.g., Liang et al., 2021). OHCs are digital spaces[2] where people diagnosed with a specific disease or people experiencing similar medical concerns gather to discuss a particular health issue and/or connect with peers for support and advice (Neal et al., 2007). Given the importance of OHC in self-management, my thesis explores self-tracking within the context of OHC. Previous HCI research has investigated how this social support through online interactions helps people with chronic conditions cope with their day-to-day self-management and get practical tips. For example, Young and Miller (2019) found that women with vulvodynia, a chronic gynaecological condition in women, learn how to navigate the lived experience of their condition by getting advice on how to handle certain practical issues that come with the disease self-management (e.g., what type of clothes alleviate the pain).

Given this background, my research explores the nuances of self-tracking that People with Parkinson's (PwP) employ in everyday life. It is possible that some elements which people with

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[1] Vital signs include body temperature, pulse rate, respiration rate, blood pressure.

[2] OHCs can include standalone sites such as PatientsLikeMe or sub-forums within a larger online community, such as Facebook.

chronic diseases are interested in tracking may not seem relevant to their clinical profile – which has been the main focus of the PD technology research – but may be important to their self-management in the context of everyday life. Also, given the importance of OHCs and the role of peer-to-peer communication in disease self-management, my thesis aims to understand how self-tracking fits within this social context of OHCs.

1.2 Parkinson's Disease and Self-tracking

In this thesis, I focus on PD, the second most commonly occurring neurodegenerative disease (Parkinson's UK, 2017) and one of the most common illnesses in later life. More than 10 million people worldwide live with PD and 18,000 are newly diagnosed each year in the United Kingdom alone(Parkinson's UK, 2017). PD is multidimensional in its presentation, including physical, cognitive, and emotional symptoms (Parkinson's UK, 2017). Hence, it requires numerous daily self-management decisions and significant alterations to one's lifestyle as the disease progresses (Parkinson's UK, 2017). Moreover, PwP often experience other comorbidities, further affecting their everyday life (Santiago et al., 2017).

Previous studies in PD self-tracking have mainly investigated the design and use of information-technology tools that support the clinical agenda, including self-tracking of motor symptoms and medication adherence (Arroyo-Gallego et al., 2017; Heldman et al., 2012; Kabelac et al., 2019). To this end, we need to rethink, in the first place, whether the way we approach PD self-tracking should be reconsidered; and then, assess the values underpinning technology in the context of chronic disease self-management. Nunes & Fitzpatrick (2018) argue that the design of the current PD technologies focus primarily on the clinical aspect of the disease and that they do not account for the mundane ways in which self-care is achieved.

Moreover, there is little knowledge about how and why PwP decide to engage in self-tracking in the context of everyday life, what their self-tracking needs are, and how technologies could support perceived benefits and overcome limitations of existing self-tracking approaches. More specifically, little attention has been given to the lived efforts of self-management with a view to examine the complexities that result from living with a chronic disease such as PD. The practices employed by PwP, and the specific challenges that may arise from these practices during self-tracking, can extend our current understanding of how self-tracking informs the process of self-management. Such an examination can also shed light on how PwP make sense of the information tracked, to support their self-management in everyday experience.

Finally, this thesis aims to allow for a meaningful and reflective discussion between projects that focus on PD self-tracking with different framings (clinical vs. lived) and ultimately lead to the design of self-tracking technologies, which meet PwP's self-management needs in everyday life.

1.3 Thesis Approach and Research Questions

The topic of this research, self-tracking in PD, is of interdisciplinary interest because Digital health and HCI, as well as Health and Social Sciences, all study this area. I therefore took an interdisciplinary approach that considers, explores and draws from these different disciplines (Blandford et al., 2018). I have also focused on combining my knowledge, skills, and expertise to improve the rigour and strengthen the contributions this thesis makes, primarily to HCI and Digital Health. Considering the lack of previous research on a similar area, I adopted an exploratory research approach (Stebbins, 2001) to understand how PwPs' real-world self-tracking practices are shaped, the individual sensemaking practices of self-tracked data, and how online social interactions mediate sensemaking of self-tracked data.

In contrast to many studies on PD self-tracking (e.g., Powers et al., 2021; Elm et al.; 2019, Kassavetis et al., 2016), I do not analyse the experience of living with medical devices used for PD self-management or how clinicians can use the data captured in everyday life for clinical purposes. In this thesis, I take a *lived* perspective on self-tracking, "a view that emphasises the practical, prospective and felt aspects of personal tracking for health and wellbeing" (Rooksby et al., 2014). Specifically, I conceptualise self-tracking as a practice that highlights e*veryday life* as "a domain of interpretation, reflection and ambiguity", and further, "offers an analytical entry point to a more profound understanding of how people engage with their personal data" (Pantzar & Ruckenstein, 2017: 3). To this end, I focus on how PwP make sense of their data individually but also as part of a social sensemaking process.

I also move away from the physician-centric approach with a focus on the "passiveness" (Neuberger, 1999) of people's role as patients (Attard & Coulson, 2012; Visser et al., 2016). In line with this approach and throughout this thesis, I follow Vizer et al., (2019), using the term "people with Parkinson's" rather than "patients" to acknowledge the whole person who has a chronic disease and not just their patient role. The role of patient may not resonate outside of the clinical setting, and it is important to highlight through this *lived* approach that self-management activities take place overwhelmingly in the context of everyday life rather than in the doctor's room.

The overarching goal of this thesis is to stimulate how one might approach design for PD self-tracking in the context of everyday life. This thesis presents a series of studies (referred as Study I, Study II and Study III) considering different ways of investigating and describing PD self-tracking in the context of self-management. My research questions evolved iteratively, building on the findings and the gaps of the previous study. My initial research began with the overarching goal mentioned above, however, there was a progressive development of the focus of the three conducted studies. I started with investigating what PwP track, why, and what tools they are using (Study I) to understand PD self-tracking in the context of everyday life. I also asked how PwP make sense of the tracked information (Study I). As the data used for the Study came from an OHC, I realised that I should also investigate how the social context within the self-tracked data is shared and the role of peer-to-peer social sensemaking. As a result, the focus of Study II shifted to explore the social sensemaking of self-tracking among PwP. In my last study, I focused on exploring how we design for PD self-tracking, and I identified data visualisations as a key element to leverage in this process. To achieve this goal, this work answered the following research questions:

- What information do PwP self-track and why in everyday life? (RQ1)
- What tools do PwP use for self-tracking, and how do they make their choice? (RQ2)
- How do PwP engage in individual sensemaking of self-tracked information and what practices underpin individual sensemaking? (RQ3)
- What is the role of self-tracking in PwP's peer-to peer social interactions within the OHC, and how does it contribute to social sensemaking of PD self tracking? (RQ4)
- How can a sensemaking-driven approach motivate new ways of designing for PD self-tracking? (RQ5)

To answer the research questions, each of them approaches a different perspective of self-tracking in PD, using qualitative and design methods that complement each other. More specifically, I conducted three studies that make the core of this thesis. Table 1.1. provides an overview of these studies, including their key concepts and the research questions that each one aimed to answer.

Concept	**Study I**			**Study II**	**Study III**
	What information do PwP self-track and why? (RQ1)	What tools do PwP use for self-tracking and how do they make their tool choice? (RQ2)	How do PwP engage in individual sensemaking of self-tracked information and what self-tracking practices underpin individual sensemaking? (RQ3)	What the role of self-tracking is in PwPs' peer-to-peersocial interactions within the OHC and how it contributes to social sensemaking? (RQ4)	How can a sensemaking-driven approach motivate new ways of designing for PD self-tracking? (RQ5)
PD Self-tracking	✓	✓	✓	✓	✓
Individual Practice	✓	✓	✓		✓
Social Practice				✓	✓
Everyday experience	✓	✓	✓	✓	✓
Lived efforts of self-management	✓	✓	✓	✓	✓
Individual Sensemaking			✓		✓
Social sensemaking				✓	✓
Online Health Communities				✓	✓
Data visualisation					✓

Table 1.1: Overview of Thesis Studies, Research Questions and Key Concepts

1.4 Contributions

The PhD thesis offers three main contributions based on the characterisation of different types of contributions in HCI research (Wobbrock & Kientz, 2016):

1) **A *lived* approach to self-tracking**: The thesis offers empirical insights on how PD self-tracking happens in everyday life, informing how HCI and Digital Health can approach PD self-tracking. Also, these empirical insights may have implications for Person-centred Outcomes Research and Health Education. This contribution is underpinned by the findings from RQ1, RQ2 and RQ3.
2) **A holistic approach to PD self-management**: The thesis offers empirical insights to the HCI and Computer-Supported Cooperative Work (CSCW) on how PwP make sense of their sef-tracking data individually and socially and the interplay between these two processes as part of their PD self-management. This contribution is underpinned by the findings from RQ3 & RQ4.
3) **Sensemaking driven design exploration:** This thesis offers a new methodological approach by building upon existing research and design practices to explore sensemaking while leveraging data visualisations to motivate alternative designs for PD self-tracking. This can inspire researchers and designers working in HCI, CSCW, and Digital Health on how to approach self-tracking in the context of everyday life. This contribution is underpinned by the findings from RQ5.

As outlined above, my findings inform different fields including HCI, Digital Health, Health Education and Person's centred Outcomes Research. I would like to note that I primarily approach the discussion of my findings from a design perspective within the individual study chapters (Chapter 4, 5, and 6). I reserve General Discussion (Chapter 7) for addressing in more detail the implications across the other fields.

1.5 Thesis Structure

To present my investigation in PD self-tracking, this PhD thesis is structured as follows:

Chapter 2: Background and Related Work

This chapter presents the theoretical and conceptual context upon which this thesis is built. It offers an overview of how existing work has studied self-tracking in chronic disease self-management more broadly and then situates my research in the context of PD. It describes PD's basic disease characteristics and unpacks the symptom manifestation's complexity and diversity. Next, it presents an overview of health technologies designed for PwP, showing that previous research has focused on improving the clinical assessments of the disease. This synthesis of previous work on PD technology highlights a gap in HCI work regarding PD self-tracking in everyday experience, as existing research has given less attention to identifying how PwP use technology to track and manage their disease as part of their lived efforts of self-management. Then, it introduces the concept of sensemaking as an alternative perspective for investigating this research area.

Then, it presents the concept of self-tracking as a social practice and the importance of examining the social context of self-management and situating self-tracking within OHCs. Finally, it introduces social sensemaking as a conceptual framework to examine PD self-tracking and its role in peer-to-peer online interactions.

Chapter 3: Methodology

This chapter presents the epistemological underpinnings of this thesis and the human-centred methodology employed. It outlines the combination of qualitative and design methods used in the thesis and unpacks the ethical considerations deriving from my methodological choices.

Chapter 4: Study I

This chapter presents an exploratory qualitative study of Parkinson's movement, an OHC embedded in the social network 'HealthUnlocked'. Its aim is to understand how self-tracking currently fits within people's self-management and further identify the ways in which PwP engage in sensemaking. It does this by adopting a broader definition for the concept of self-tracking that focuses on *practice* rather than on the use of PI technology and using an existing framework of sensemaking for chronic disease self-management (Mamykina et al., 2015). The contributions of this empirical study are threefold. First, the study provides a descriptive account of how PwP carry out self-tracking and sensemaking for their self-management. Second, it demonstrates that the characteristics of PD pose particular challenges during the process of sensemaking by contextualising a previously developed framework of sensemaking for chronic disease self-management (Mamykina et al., 2015). Lastly, building on the empirical understanding of self-tracking practices and sensemaking, this study presents several design considerations for self-tracking technologies aimed at supporting individuals with PD.

Chapter 5: Study II

This chapter presents the second study of this PhD thesis. This empirical and qualitative study examines posts from the same OHC of Study I in order to understand a) how OHC serves as a catalyst to social disease sensemaking and b) how sensemaking becomes a social practice in terms of self-tracking data and PD self-management. Study II makes three contributions. First, it offers a descriptive account of social sensemaking among PwP within an OHC by describing how communication practices enabled its different dimensions. Second, it introduces a new perspective for PD self-tracking: a social sensemaking approach. Third, it reveals several design implications for self-tracking with a social lens.

Chapter 6: Study III

This chapter presents this thesis's third and final study, which is design-oriented. This study extends the findings of the first two empirical studies reported in Chapter 4 (Study I) and Chapter 5 (Study II). This study builds on the concepts of *self-tracking as an individual practice* and *individual sensemaking* (Study I) and *self-tracking as a social practice* and *social sensemaking* (Study II) while introducing another dimension of self-tracking, namely data visualisation. The contributions of this study are three-fold. First, by acknowledging the social and situated nature of self-tracking, this study's approach provides a methodological contribution to adapting existing design approaches for motivating the design of alternative PD self-tracking technologies. The second contribution is offering a set of new design principles, which researchers and designers can use in the future when designing self-tracking for PD in the context of PwPs' everyday experience. A third contribution of this study is a design concept that illustrates the sensemaking-driven approach by utilizing data visualisations to support both individual and social sensemaking.

Chapter 7: General Discussion

This chapter concludes the thesis by consolidating the three overarching contributions of this PhD thesis (outlined in Section 1.3). It also discusses the transferability of the thesis findings in different contexts, its potential limitations, and the opportunities that arise for future work.

Chapter 2: Background and Related Work

2.1 Introduction

This chapter introduces the theoretical and conceptual research on which this thesis is built. Specifically, I present the theoretical perspectives and approaches which have informed what is understood about chronic disease self-management and self-tracking in PD. When I started studying self-tracking in PD, it became evident this is a multidisciplinary research area spanning across HCI and CSCW, Health Informatics, Social Sciences including the Sociology of Health and Studies of Science and Technology, and the Medical Sciences including Neurology and Public Health. Reviewing the literature of these different disciplines informed my research approach and allowed me to identify the research gap I aimed to address with this thesis which has been to offer an alternative approach for designing PD self-tracking technologies.

This thesis is based on two main conceptual pillars: s*elf-tracking as an individual practice* and *self-tracking as a social practice*. In this chapter, I present work building on these two pillars which motivate the directions for the studies, which will be presented in subsequent chapters.

More specifically, this chapter is structured as follows. Firstly, I identify the boundaries of how existing work has studied *self-tracking as an individual practice* in chronic disease self-management more broadly. I, then, situate my research in the context of a specific chronic disease, namely PD. I describe PD's disease characteristics and unpack the symptom manifestation's complexity and diversity. The disease's character largely shapes how people manage their disease, bringing specific nuances to self-tracking. Therefore, I unpack the disease's characteristics to inform my analytical focus on the studies presented in the following chapters.

Next, I present some characteristic examples of health technologies designed for PwP, which show that previous research has focused on improving the clinical assessments of the disease (e.g., Stamate et al., 2018). By presenting this work, I highlight a gap in HCI work regarding PD self-tracking, the lived efforts of self-management, and the nuances of everyday experience. As defined in Chapter 1, self-management is "the systematic process of learning and practising skills which enable individuals to manage their health condition on a day-to-day basis" (Self-management UK, 2020). Hence, I argue that existing research has given less attention to identifying how PwP use technology to track and manage their disease as part of everyday life and the nuances that derive from a lived self-management perspective (Kaziunas, 2018). Building on this gap, I suggest an alternative perspective for investigating this research area and, to this end, introduce the concept of *sensemaking*, a cognitive process that informs health-related actions reflecting people's efforts to make sense of information (Lahtiranta et al., 2015) and suggests an active inquiry that recognises the individual's agency (Blatt et al., 2006).

The second pillar hinges on conceptualising *self-tracking as a social practice* that encompasses the social dimensions when tracking with others or sharing self-tracked data (Lupton, 2014). To design for and support PD self-tracking, we must understand its different dimensions. To this end, I present relevant literature examining self-tracking as a social practice and highlight how this applies to the context of self-management. I argue that the social practice of PD self-tracking is primarily explored in medical settings, where data is shared with healthcare. Previous literature has also examined PD self-tracking involving carers whilst sharing with peers is an underexplored aspect of this research area.

Furthermore, I situate self-tracking within the context of OHCs as they comprise an essential part of PwPs' self-management as previous research has shown that people with chronic diseases share their data with peers within this context (Neff & Nafus, 2016). Finally, I introduce social sensemaking as a conceptual framework to understand how self-tracking informs PwPs' online peer interactions.

2.2 Self-tracking in Chronic Disease Self-management

Research has shown that a one-size-fits-all approach to chronic disease self-management is inefficient for maintaining patient well-being. People's needs differ substantially even when they have the same disease or condition in part because their symptoms or their response to treatment might manifest differently (Trappenburg et al., 2013). The National Health Service (NHS) has identified the need for personalised care, meaning that healthcare should be tailored to the needs and preferences of individual people, taking into consideration their personal circumstances, for them to make decisions about managing their health (NHS, 2019b).

Trying to address this need for personalisation, a growing number of studies explore how self-tracking through PI can support people to collect personally meaningful data that inform decisions about their health. Previous research has taken different perspectives to understand self-tracking and its benefits in managing a chronic disease. For example, self-tracking has been viewed from a clinical lens with a focus on how PI tools can support clinical consultation goals, including helping people take medications as prescribed to reduce treatment non-adherence (Lakshminarayana et al.,

2017) or examining how data from existing fitness technologies such as Fitbit can reshape the clinical practice (Mentis et al., 2017).

Other research has explored the use of PI tools in people's self-management from the point of view of the person living with the disease rather than the clinician's perspective (Macleod et al., 2013). This work has demonstrated that people with chronic disease can benefit from self-tracking because it enables them to better understand the elements of their disease through increased awareness (McKillop et al., 2018), to work on a specific goal that improves their health (Schroeder et al., 2018), to facilitate self-monitoring as a self-directed intervention strategy for self-management (Swendeman et al., 2015) or to use it as a self-diagnostic strategy for finding associations and cause-effect patterns (Mamykina et al., 2017; Rooksby et al., 2014). Furthermore, the study also shows that people employ a variety of tools for self-tracking and that their motivation for self-tracking, as well as the questions they want to answer through the collection of personal data, vary significantly (Macleod et al., 2013). This diversity stems from the broader complexities that derive from the everyday self-management experience. Whilst self-management can include predictable tasks linked to the clinical aspect of the disease, such as treatment, it should also be recognised that, for many people, "their needs arise from circumstances beyond the purely medical" and are also informed by their informational, emotional and even technological needs (Mathieu-Fritz & Guillot, 2017). In line with this holistic lens to self-management, this thesis acknowledges a need to appreciate multiple dimensions of living with a chronic disease, an experience that includes more than the manifestation of the symptoms and the medical activities that come with it. Therefore, it argues for a need to see the person as a whole, not just in their role as a patient.

Previous work has also recognised that clinical needs may not resonate with people living with the disease in everyday life (Macleod et al., 2013) and thus, researchers have begun to investigate the alignment between the clinical requirements of self-tracking for self-management and the everyday experience of living with a chronic disease (Nunes et al., 2015; Storni, 2011). For example, Karkar et al. (2017) built a self-tracking tool to identify food triggers for people with irritable bowel syndrome (IBS). In evaluating this tool, the researchers found that users sometimes could not sustain the clinical requirements of a scientifically rigorous self-tracking process as this did not always fit with the messy nature of the everyday experience. Moreover, getting a binary result (yes/no) to the question of whether a food category was a trigger for their IBS was not helpful for everyone as some people were more interested in the question of how much of a particular food they could have without a significant effect on their quality of life.

Similarly, Storni (2010) examined how people with diabetes employ self-monitoring technologies (e.g., glucose meters) and found that people often appropriated them in unique and sometimes idiosyncratic ways. Furthermore, by choosing an ethnographic approach, Storni (2014) showed how the realities of living and dealing with diabetes can be open-ended and uncertain. These did not align with the medical model, which informed the design of self-monitoring technology and its rigid clinical use criteria.

This previous research shows that the use of self-tracking technology based on principles of clinical practice is often reshaped by the lived efforts of self-management in the context of everyday experience. In line with this work, this thesis acknowledges that everyday experience includes many factors at play that differ from person to person and there is not a single way of practising self-management. As described in Chapter 1, I frame self-tracking in the context of the lived efforts of self-management to examine the complexities that result from living with a chronic disease such as PD.

2.3 Parkinson’s Disease

The previous section presented how the literature has approached self-tracking in the context of self-management and how everyday life affects how self-management is practised. As my research on self-tracking focuses on PD (outlined in Chapter 1), I will introduce its main disease characteristics, including symptoms and treatment. As the nature of the disease shapes self-management, I will unpack how these PD characteristics can affect self-management and, thus, inform my analytical focus.

PD is a **complex** chronic disease and one of the most common neurodegenerative illnesses in ageing, affecting more than 10 million people worldwide (Parkinson’s Foundation, 2020). It is estimated that 137.000 PwP live in the UK (Parkinson’s UK, 2017). PwP experience **many physical, cognitive and emotional symptoms** (NHS, 2019a). The most visible symptoms include four motor impairments: tremor, bradykinesia (slowness of movement), rigidity, and postural instability disorder (Jankovic, 2008). PwP also experience non-motor symptoms, including cognitive impairment (Watson & Leverenz, 2010), dementia (Aarsland et al., 1996), constipation (Stocchi & Torti, 2017), fatigue (Friedman et al., 2007), sleep disturbances (Menza et al., 2010), drooling (Kalf et al., 2007)and depression (Aarsland et al., 2012). This wide range of symptoms causes multifaceted difficulties by affecting the individual’s functional ability to perform everyday tasks but also have psychological implications which are central to well-being, such as curtailing their self-confidence and impairing their stress management skills (McNaney et al., 2012) in different aspects of everyday life (e.g., family, work, travel). PD symptoms vary between people, affecting them differently at motor, cognitive and emotional levels (Parkinson's UK, 2017). Most PwP need to deal with a variety of symptoms which demand daily self-management decisions. As described in the previous section, there is no single way of practising self-management. However, in the context of PD, the heterogeneity of the disease also adds another layer of complexity in identifying the optimal way to self-manage.

The idiosyncratic character of PD presents similarities with the idiosyncrasies of other chronic diseases, such as migraines and diabetes (O'Kane et al., 2016). PD symptoms are also heterogeneous in their temporal pattern and can vary from day to day, causing **intra-personal variability**. This makes PD self-management more complicated as PwP experience relatively short-term and reversible changes in an individual's performance across repeated instances of the same task (Frias et al., 2007). Moreover, as symptoms fluctuate, PwP also experience "off periods" during which PD medication, namely levodopa, is not working optimally and as a result, symptoms return. These can include both motor symptoms, such as tremor and rigidity, and non-motor symptoms, such as anxiety. This can happen for different reasons: the transient effect of the medication dose that runs out after some hours (Politis et al., 2010) or contextual and lifestyle factors, such as the weather or emotions (Nunes, 2018). "Off periods" can also appear suddenly or unexpectedly without any obvious explanation. In addition, there is a long-term cause for "off-periods". Specifically, after several years of taking levodopa medication, its effect starts to wear off before the next dose is due. This means that the period that effective symptom controls for PD gets shorter, causing symptoms to reappear sooner than expected (Mantri et al., 2021).

Another PD characteristic is **disease progression,** and one clinical challenge is difficulty predicting the disease trajectory (Li & Le, 2020) as there are different progression patterns. For some people, the condition may take many years to develop; for others, it may take less time. Clinicians use validated rating scales[3] to assess the condition's symptoms and progression (Sampaio et al., 2012). Motor scales are well-established and widely used. Non-motor symptom scales are equally important but are not always given equal attention (Todorova et al., 2014). Non-motor symptoms can define a person's quality of life to a great extent, so combining motor and non-motor scales gives a more balanced picture of how a person is affected by the disease (Sampaio et al., 2012). Ideally, more than one scale is used to give a broader picture. The MDS Unified Parkinson's Disease Rating Scale (UPDRS) is a comprehensive 50 question assessment of both motor and non-motor

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[3] A rating scale is a means of providing information on a particular feature by assigning a value to it. In Parkinson's, rating scales require the 'rater' (the person deciding on the points scored) to put a value to the feature or symptom in question, according to a set scale. The rater may be the person with Parkinson's or a healthcare professional.

symptoms associated with PD. It is often used alongside with two other Parkinson's rating scales: the Hoehn and Yahr, and Schwab and England Activities of Daily Living (ADL) Scale (Parkinson's Europe, 2017).

As the disease progresses, PwP face an increasing set of physiological, emotional, and medical issues that introduce new needs for information and healthcare support and significant alterations to one's lifestyle, with major effects on people's routines. Given the disease's progressive and often non-predictable nature, adhering to a consistent self-management plan is generally not feasible throughout a PwP's life. This contrasts with self-management of other chronic conditions considered relatively stable, such as diabetes, hypertension, or asthma (Lam & Lauder, 2000) where the status of the symptom manifestation in these diseases does not change dramatically over a person's life if an appropriate treatment plan is in place (Østbye et al., 2005). Consequently, these diseases do not require persistent changes to how they are managed. However, in the case of PD, PwP must engage in high-quality, frequent self-reflection and have an adaptive attitude for their self-management plans to work effectively.

In addition, a broad spectrum of **comorbidities** has been associated with PD (Santiago et al., 2017), which require management alongside PD symptoms. The most frequent comorbidities are hypertension and diabetes (Santos García et al., 2017). As the PD progresses, it is even more likely for PwP to experience more psychiatric and non-psychiatric comorbidities (Minar et al., 2019). Co-morbidities may be particularly challenging for PwP as healthcare services are typically organised around single conditions. Hence, this often leads to people receiving fragmented care (McLean et al., 2017). Polypharmacy[4] is also a significant issue deriving from the complex nature of the treatment of PD itself and the comorbidities (McLean et al., 2017). It is not uncommon for PwP to receive combinations of three or more medications for PD and additional medications for comorbidities. Overall, this means that PwP face increasing challenges to self-manage efficiently.

Finally, certain conditions share heterogeneous symptoms across several diseases, unexplained differences in treatment responses (McKillop et al., 2018) and different temporal symptom manifestations (Pichon et al., 2021). PD shares these characteristics, and its complex clinical profile introduces challenges to the PwP, who seek to find a way to approach their PD self-management. My thesis accounts for the specific challenges that come with these disease characteristics as the complex disease character informed my analytical approach.

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[4] The use of multiple medicines.

2.4 Parkinson’s Disease and Health Technologies

In the previous section, I presented the disease characteristics of PD and the implications for PwP and self-management. I will now examine indicative examples of technologies developed for PD. Notably, in the past few years, there has been an increased interest in PD from researchers working in Health Informatics and HCI; therefore, many technologies have been developed for PwP. According to a recent systematic review of wearable and mobile applications for PD in the last decade, there are four main areas that Parkinson’s health technologies have focused on, namely diagnosis, prognosis and monitoring, predicting response to treatment, and rehabilitation (Deb et al., 2022). The authors also reported that most of the included studies have focused on motor symptoms, indicating that non-motor symptoms are less explored in relation to Parkinson’s technologies (Deb et al., 2022).

Two primary goals have often underpinned this type of research;

a. To improve in clinical assessments (e.g., Stamate et al., 2018), researchers try to address the current limitations of performing a one-off assessment of PD symptoms, which provides a limited view of the progression of the disease and PwPs’ overall condition. Technologies, therefore, focus on supplying doctors with long-term patient data, particularly motor symptoms.
b. To support self-management activities with a focus on adherence and compliance with treatment and care plans as devised by clinicians (e.g., Tsiouris et al., 2017).

This type of research reflects a considerable body of literature, so I will now present a few indicative examples of PD technologies coming from this work, which illustrate how previous research has prioritised improvements in clinical assessments and supporting adherence and compliance. A recent example of PD technology is a mobile application called STOP, which offers tracking hand-motor symptoms and a medication journal for recording medication intake (Kuosmanen et al., 2019). Health Informatics researchers and a medical expert designed this technology specialised in Deep Brain Stimulation[5]. Another example is the Roche PD Mobile Application v2, developed by the pharmaceutical company and academic and clinical researchers to measure the motor symptom

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[5] Deep brain stimulation is an established treatment for people with Parkinson’s and it involves implanting electrodes within certain areas of the brain. These electrodes produce electrical impulses that regulate abnormal impulses. The electrical impulses can affect certain cells and chemicals within the brain. The amount of stimulation in the deep brain stimulation process is controlled by a pacemaker-like device placed under the skin in the upper chest of the PwP. A wire that travels under the skin connects this device to the electrodes in the brain. (Mayo Clinic Staff, 2022)

severity and progression in PD (Lipsmeier et al., 2022). Moreover, Stamate et al. (2017) developed a medical device that performs a smartphone clinical assessment of motor symptoms and could be used by PwP and their carers, at home. This self-tracking technology provided high-quality data collection while minimising the data-collection time to facilitate user adherence. Another example is the uMotif app, which was designed to support medication adherence and clinical consultation in PD (Lakshminarayana et al., 2017) and offered a variety of self-tracking features (i.e., symptoms and general well-being, reminders of the time to take medication, health diary function) to facilitate these clinically orientated goals.

Even though the research and development of PD technologies has been prolific, and this work has contributed a range of new tools for PD, which can support clinicians in providing better care to PwP, previous research has also identified a misalignment in the current approach of PD health technologies and patient-centred outcomes (Grosjean et al., 2020). Specifically, Nunes and Fitzpatrick (2018) argued that current PD health technologies are medicalised and designed to fit structured medical processes. Meanwhile, everyday life is more complex and entails competing needs, such as disease-related tasks and practical and routine activities, including family and work responsibilities.

Similarly, alongside the complex tensions PwP face in managing their disease in their everyday experience, other work has shown how disease characteristics can introduce particular challenges for a medicalised view of PD technology in everyday life. For example, Mishra et al. (2019) conducted a qualitative study interviewing PwP and care partners to understand the role of PD symptom trackers in how PwP coped with their progressive chronic disease. To achieve this, the researchers interviewed participants about their experiences with self-tracking. They asked about what symptoms participants tracked, why they tracked them, how they prepared for doctor's appointments, and what information they thought was important to include in tracking. After interviewing the third participant, the researchers also used storyboards to explore four potential use cases of self-tracking: long-term tracking, sharing data with doctors, identifying symptom triggers, and care partner involvement in tracking symptoms. It is noteworthy that the storyboards prioritised use cases chosen by the researchers, not necessarily those deemed most significant by the participants. Three out of four storyboards even focused on the finger tap test, which is a limited representation of many physical, cognitive and emotional symptoms that PwP experience and may want to track. While this helped explore specific use cases, it might not capture the full range of symptoms or lifestyle information that PwP find meaningful. In their findings, the authors described the ambiguity of PD symptoms, sometimes making it hard to determine if something suggests a symptom. They also highlighted the importance of environmental and behavioural factors in disease manifestation. The researchers further proposed the need to design flexible self-tracking technologies that would allow PwP to track whatever is meaningful to them by letting them define and track various symptoms and contextual factors. The most common issue is the lack of variety in tracking or logging features

This thesis addresses these points by proposing a different approach to PD self-tracking technology. I argue that to design PD technology which aligns with PwPs' lived efforts of self-management, we need first to understand PwPs' needs in the context of everyday life by examining PwPs' practices, including what they track and how, as well as how they make sense of this information. By taking this approach, the thesis contributes to a fast-growing part of the PD literature that has focused on person-centred outcomes (e.g., Bloem et al., 2020; Lee et al., 2015; Sjödahl Hammarlund et al., 2018) and understanding the impact of living with PD from the PwP's perspective by identifying how clinical, technological or any other interventions can improve PwPs' quality of life on their own terms.

2.5 A Sensemaking Approach to Chronic Disease Self-management

As explained in the previous section, my initial focus is understanding PD self-tracking in everyday life. In the Introduction (Chapter 1), I also defined self-tracking as a practice carried out through PI tools or other self-tracking means to foster individuals' self-knowledge and self-reflection (Li et al., 2010). As I argued in Section 2.1, in this thesis, I examine PD self-tracking through a sensemaking lens. This allows me to not only study what PwP track and why but also to build an understanding of how they make sense of their disease through self-tracking and how this affects the way they can engage in self-management (e.g., Young & Miller, 2019). Sensemaking is a cognitive process that informs health-related actions reflecting people's efforts to make sense of information (Lahtiranta et al., 2015) and suggests an active inquiry that recognises the individual's agency (Blatt et al., 2006). Drawing on this theoretical concept, my thesis contributes a new understanding of PD self-tracking and further recommends ways in which digital technology can support PwPs' agency to chronic disease self-management.

Specifically, sensemaking in chronic disease self-management entails "a process that considers various interconnected components ranging from medical readings to [measures] of the surrounding environment and associated lifestyle" (Faisal et al., 2012: 200). This conceptualisation reflects the complexities of living with a chronic disease, as described in section 2.1. Therefore, this sensemaking view sheds light on how PwP approach the complexity of PD on a cognitive level and unpack the many interconnected factors that PwP try to make sense of. In the case of PD, this aligns with the view that PwP need to understand and manage a range of symptoms and treatment options and the progressive nature of the disease, as outlined in Section 2.2. Moreover, as described in Chapter 1, I aim to capture PwPs' lived self-management efforts. Understanding how PwP make decisions regarding their self-management is central to achieving this aim. Also, making sense of the multiple facets of a disease requires people to draw on a range of information – such as medical records, treatment planning, as well as contextual information related to lifestyle, routine tasks, and personal goals (Faisal et al., 2012), aligning with my definition of self-tracking as a practice.

Past research has theorised how people collect and integrate data, then act on the collected data, typically with a goal of behaviour change. A foundational study in this field, conducted by Li et al. (2010), introduced the empirically grounded stage-based model of personal informatics. This model posits self-tracking as a five-step process: preparation, collection, integration, reflection, and action. The researchers conducted a survey of people who collect and reflect on their personal information and also carried out follow-up interviews with a subset of the survey respondents.

The model describes self-tracking as a 5-stage process. At the preparation stage, people determine what they would like to track and decide what kind of tools they would like to use. During the collection stage, people collect personal information about themselves and, afterwards, at the integrations stage, they prepare and aggregate the collected data. At the reflection stage, they reflect upon visualised data and, finally, at the action stage, people "choose what they are going to do with their newfound understanding of themselves" (Li et al., 2010: 562). While providing a valuable framework, the model's technology-centric perspective is a limitation. Assuming that all self-trackers are tech-savvy and solely rely on digital tools is problematic, as evidenced by the study's participant demographics. Also, this model does not account for the self-tracking needs of people who do not necessarily want to change a behaviour including people with chronic diseases.

In my work, I adopt the definition and framework of sensemaking developed by Mamykina et al. (2015: 407) who define sensemaking as a process through which people "organise the chaos of lived experience, finding patterns, discovering connections and dependencies and making a myriad of daily choices in regards to essential self-management activities". This sensemaking definition accounts for the complexities of managing a chronic disease while emphasising the cognitive process underpinning disease management. By highlighting "the chaos of lived experience", this framework aligns with the findings by Nunes and Fitzpatrick (2018) who showed that PwP might juggle a complex combination of everyday self-management tasks to minimise the disruption of their lifestyle and maintain an acceptable quality of life. Thus, adopting this Sensemaking Framework is in conceptual alignment with my focus on the *lived* character of self-tracking, describing the cognitive process that informs health-related actions reflects people's efforts to make sense of their health (Lahtiranta et al., 2015). It also offers a theoretical understanding of sensemaking as an active inquiry in self-management.

2.6 Sensemaking Framework

Having motivated the choice of the Sensemaking Framework (Mamykina et al., 2015) to examine Parkinson's self-management, I will now present its theoretical basis and main concepts. Mamykina et al. (2015) argued that while the Sensemaking Framework (see Figure 2.1) is built on the case of diabetes, it is also generalisable to other chronic diseases that require self-tracking as part of their self-management.

Firstly, Mamykina et al. (2015) explained that the chaos of diabetes self-management is underpinned by a new, unfamiliar world that comes with the diagnosis. Specifically, individuals diagnosed with diabetes must understand the underlying dynamics of the disease and the impact of daily activities on their health by re-examining mundane everyday activities such as grocery shopping and eating meals, and adjusting their practices to the new demands of diabetes self-management. Next, according to the framework, self-management activities are carried out in a *habitual* or a *sensemaking* mode. Both modes include a cycle of three interdependent activities: perception, inference, and action. Habitual self-management is the default state for people with a chronic disease. The habitual mode captures the idea that disease self-management results from experience and comes naturally to individuals without requiring explicit effort and attention. An individual engages in perception by monitoring and classifying new information about one's health. For example, measuring the blood sugar level every day provides new information with every measurement. In this example, explaining the blood sugar level measurement activates existing and relevant mental models, instantiating the inference phase. Inferences, in turn, allow individuals to select an appropriate course of action to carry out routine activities without considering new alternatives.

In contrast to the habitual mode, the sensemaking mode is triggered when new information related to the disease is encountered, causing a disruption in understanding that requires a new explanation. During the perception phase, the individual characterises and classifies their observations. When new information does not align with the pre-existing mental models, this creates a gap in understanding. In the inference phase, individuals combine their general knowledge, past experiences, and knowledge from others to construct possible explanations and new models consistent with the new information. In the action phase, the individual selects the most plausible explanation, allowing them to integrate it within their disease self-management and return to their routine. The individual may choose to experiment to test their assumption. If successful, their self-management model is updated accordingly, and the new action becomes routine. Therefore, the habitual mode is re-established, and the self-management model is in place until new observations and experiences challenge the individuals' existing mental models, requiring re-examining inferences or redefinition of variables.

While the authors argued that the framework is generalisable to other chronic conditions, I make the point that each time we use the framework to understand sensemaking in a different condition, we need to account for the nature of the disease and lived efforts of self-management for different groups of people. Living with a different chronic disease means self-management varies depending on disease characteristics and nuances. Section 2.1 highlighted how people engage in self-management by using self-tracking, for example, to achieve a goal or as a diagnostic tool. Section 2.2 also showed that PD characteristics can shape self-management and sense-making in particular ways. When applying this framework in the context of PD, for example, the progressive nature of the disease is likely to increase gaps that trigger the sensemaking mode. These points show the importance of redefining the chaos of the lived efforts of self-management based on the specific disease examined and, thus, the importance of contextualising the framework in the nuances of the PD, which my thesis implements.

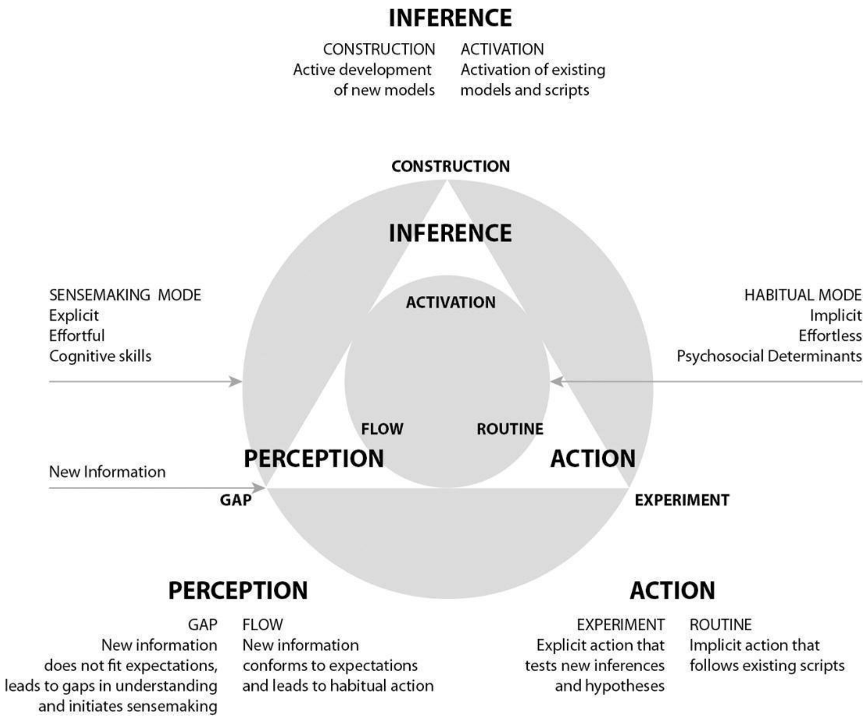

Figure 2.1: Sensemaking Framework for chronic disease self-management (Mamykina et al., 2015)

2.7 Self-tracking as a Social Practice

In the previous sections, I unpacked the role of self-tracking in health self-management, and further, I introduced sensemaking as a lens to examine self-tracking in the context of self-management. The literature I presented reflects the predominant view of self-tracking as an individual practice, aligning with the broader Personal Informatics perspective that emphasizes an ego-centric approach in engaging with personal data (Murnane et al., 2018).

An emerging line of HCI work has identified that self-tracking is also a *social practice* as it happens in various social contexts such as family relationships and online communities (Lupton, 2014; Rooksby et al., 2014) and is underpinned by social interactions and communication (Elsden et al., 2016; Lomborg & Frandsen, 2016). To this end, I present how scholars have approached the social dimensions of self-tracking. In the following section, I will further show how this thesis embraces this concept by examining its role within an Online Health Community (OHC) context, which adds a new dimension to how PD self-management has been conceptualised.

One of the earlier conceptualizations of the social aspect of self-tracking can be found in the Lived Informatics model (Epstein et al., 2015). Building upon Li's model and sharing the same philosophical commitments, Epstein et al. (2015) refined the initial model by dividing the preparation stage into two distinct stages, namely deciding and selecting. They also introduced a tracking and acting cycle, describing an iterative progression through collection, integration, and reflection stages. Finally, the model identifies lapsing temporarily or permanently. This model offers a more nuanced understanding by acknowledging the social context in which tracking takes place in everyday life but still the model doesn't explicitly depict it.

In the domains of activity tracking and food tracking, previous research has shown the value of sharing self-tracked data in a social context (e.g., Ehrlén, 2021; Lu et al., 2021). For example, Puussaar et al. (2017) implemented an online platform called Citizens Makers that provides functionality for group sharing, annotating, and discussing fitness tracker data. The researchers then showed that reciprocal sharing of fine-grained activity data could help people reflect and make sense of their individual data, helping them contextualise their observations and experiences by relating them to the experiences of others (Puussaar et al., 2017b).

To my current interest, in the context of chronic conditions, previous research has started to explore the social dimensions of self-tracking. Vizer et al. (2019) argued that it is impossible to isolate self-tracking for chronic disease self-management from the social context within which it happens. They highlighted communication between people living with chronic conditions and different stakeholders as an essential element in self-tracking. There is a range of stakeholders who are involved in self-tracking for chronic disease self-management, such as healthcare professionals (Chung et al., 2016; Mamykina et al., 2008), carers (Mead, 2022), and peers (Vaala et al., 2018). Nevertheless, Felipe et al., (2015) identified a gap in the sharing of health data with various stakeholders. While sharing data with healthcare providers for improved care is recognized, the authors highlighted the underutilized potential of sharing data with social others. Indeed, previous literature on PD has primarily focused on how PwP can share self-tracking data with their healthcare professionals to inform and improve clinical consultation (Lakshminarayana et al., 2017; Mentis et al., 2017; Stamate et al., 2018). Nevertheless, previous research on other chronic conditions has also shown that people with chronic diseases often want to share their self-tracking data with their others living with the same disease, namely their **peers** (Bussone et al., 2017; Cerón-Guzmán et al., 2022). This thesis aims to contribute to this line of work which studies sharing data with peers and, specifically, examines how PwP share their self-tracking with other people living with PD and further engage in disease sensemaking together.

2.8 Social Self-tracking in OHCs for Chronic Disease

The previous section established that self-tracking for chronic disease is social, and that people want to share their data with peers within OHCs. Moving forward, this section will describe why this happens, unpack the healthcare limitations and, consequently people's unmet needs contributing to the extensive use of OHCs and the social sensemaking process that takes place within these communities. Subsequently, I will elucidate the mechanism of sharing self-tracking data with peers and provide illustrative examples of OHCs tailored for chronic disease management.

People with chronic diseases must regularly engage in disease-related activities and decision-making about the best practices to maintain efficient self-management over time. However, they often do not have the right tools to manage their disease. Historically, people have predominantly been supported in their disease within the primarily dyadic doctor-patient relationship, which occurred through direct in-person communication (Walther & Boyd, 2002). However, nowadays, people rely significantly on the Internet to access and use health and disease information (Neal et al., 2007). This change has mainly occurred due to two reasons. Firstly, the internet has infiltrated our lives, and secondly, considerable constraints derive from clinical consultation (Henwood et al., 2003) which often takes place under time pressure (Radder et al., 2020). Doctors do not get to communicate the person's care plan in detail or discuss how it fits the individual's daily life (Bacon et al., 2017). These constraints result in people not feeling confident enough that the prescribed care plan is optimal for them (Coulter & Collins, 2011) and further create the need for people to fill the informational and emotional gap derived from the consultation. Furthermore, a power dynamic between patient-clinician is still evident in some cases where clinicians act as an authority (Paiva et al., 2019), not encouraging people to ask questions and making shared decision-making in treatment choices unlikely (Belcher et al., 2006). This leaves people unsatisfied with the level of care they receive (Coulter & Collins, 2011). To this end, people with chronic diseases turn more and more to computer-mediated support (Walther & Boyd, 2002), such as social media and OHCs, to meet their informational and emotional needs (Nambisan et al., 2011) and address the shortcomings of the dominant medical model of managing health conditions (Papoutsaki et al., 2021). People with chronic diseases have been shown to share self-tracking information and make sense of their condition by capitalising on the collaborative practices of OHCs (e.g., Young & Miller, 2019).

While self-tracking data is one type of information people with chronic diseases want to share with their peers, self-tracking tools designed for chronic conditions often lack features that enable the social sharing of data (Schroeder et al., 2018). Despite this lack of explicit design support for social self-tracking available within technology designed for chronic disease (Bussone et al., 2017; Schroeder et al., 2018), people still share their data by appropriating the use of other types of technology, such as social media (Ayobi et al., 2018).

In the context of PD, the social aspect of self-tracking has mainly focused on healthcare professionals and carers. While a few studies have examined online PD communities (e.g., Lieberman & Golant, 2005; Visser et al., 2016), there is a gap in the literature regarding how PwP use self-tracking within OHCs. Attard and Coulson (2012) studied social support within a Parkinson’s OHC and reported that PwP shared experiences and knowledge and helped each other cope with the challenges of living with PD. Through their sharing, PwP created a sense of togetherness and common ground in Parkinson’s experience. Nevertheless, the authors also explained that a lack of personal information, misunderstandings, and disagreements created negative experiences for PwP suggesting that challenging ideas and unproductive conflict seem to hinder the benefits of social support.

Furthermore, Sik Chu and Young Jang (2022) examined the unmet informational needs that PwP try to address within an OHC and found a need for treatment-specific information, such as anti-Parkinson drugs, deep brain stimulation, and complementary alternative therapies. Previous research on OHCs focusing on PD has provided valuable insights into the importance and function of an OHC for PwP, describing the topics of discussion and the areas in which PwP receive social support. However, it hasn’t paid the same attention to the **sensemaking process** to understand how PwP make sense of their disease together and why this process happens in specific ways.

Previous research on other chronic conditions has described how members self-track their symptoms, triggers, and self-management strategies and share their data to get help and help others within an OHC (e.g., Mamykina, Nakikj, et al., 2015). For example, Bussone et al. (2017) studied an OHC for Human Immunodeficiency Virus (HIV), which is an incurable condition caused by a virus that damages the immune system and, if left untreated, weakens the body's natural defence system, leaving it vulnerable and prone to various negative conditions. The researchers found that people with HIV experienced a gap in their understanding of interpreting their personal health information, similar to what was described in the Sensemaking Framework in Section 2.6. These gaps included self-tracked information such as their emotions, food, weight, generic health indicators (e.g., blood pressure), and disease-related information. Therefore, they asked questions and sought social support to address their gaps in understanding. The difficulty in interpreting their personal information, including self-tracked data, was mainly associated with a gap in understanding the normalcy of their health information. Given their circumstances, people were mainly unsure whether their viral load was normal. Also, people with HIV shared their data when they could not understand the cause of a change in their disease in their attempt to identify a causal relationship between two information types, for example, the level of their cholesterol and specific treatment. Sharing their self-tracking data along with a question prompted the process of social sensemaking. Others responded to these questions by providing informational support and, more specifically, by sharing their personal information. This information often included their self-tracking data as a reference point in their responses.

The second example comes from an OHC for vulvodynia, a chronic pain condition in women characterised by severe pain or discomfort in the vulvar region that lasts for at least three months (Young & Miller, 2019). This condition does not have a single and objective stabilising factor that can be easily measured and monitored, and thus, tracking does not include standardised metrics and tools. In the case of vulvodynia, people seek social support to identify best practices regarding what to measure and how to make sense of their condition (Young & Miller, 2019). People often work collaboratively to re-construct individualised solutions regarding their health management.

Another study examined a diabetes OHC where researchers found that people used shared personal experiences and data such as blood glucose levels in their interactions (Sharma & Land, 2019). The study showed that the sharing of their data, alongside storytelling, enabled people to (a) communicate lessons learned from one's own experiences that could be translated to another participant's situation, (b) challenge previously shared information through (c) illustrate practices or procedures coming from experts, and (d) connect with others (Sharma & Land, 2019).

As shown by the previous examples, self-tracking plays different roles in OHCs depending on the nature of the condition. In enigmatic diseases such as vulvodynia, where what should be tracked is not well-established, people try to make sense of what their self-tracking practice should be. In diseases such as diabetes, where self-tracking is a well-understood practice, people share their data to get recommendations or even challenge previously shared information. To my current interest, it is noteworthy that while OHCs can share similar characteristics, it has also been found that how members interact within the OHC is primarily shaped by the disease focus of the OHC (Zhang, 2017). As presented in this section, HCI research has extensively studied OHCs, focusing on various diseases. However, there is a gap in the literature on how PwP make sense of their disease together and how the nature of the disease affects the social sensemaking process.

2.9 Social Sensemaking Framework

I have, so far, presented that sensemaking happens when people track as part of their chronic self-management, and I also showed that self-tracking is shared within OHCs. Thus, social interactions and communication underpin the process, making the case for social sensemaking. In this thesis, I use the concept of "social sensemaking" to describe the activities and interactions that comprise the collaborative practices that facilitate sensemaking (Murnane et al., 2018) among PwP. This is briefly recognised in the Sensemaking Framework (Mamykina, Smaldone, et al., 2015), but the social aspects of sensemaking are not described. Therefore, this thesis also unpacks the social dimension of health management and specifically examine how the community of peers contributes to disease sensemaking within an OHC. By developing self-tracking as a social practice, I will show how this happens in the context of PD self-management. To achieve this, I develop a conceptual framework by building upon previous research which examined OHCs as sensemaking spaces where members engage in collaborative practices around their health (e.g., Figueiredo et al., 2017; Patel et al., 2019).

To understand how PwP make sense of self-tracking and their condition together, I devised a conceptual framework elucidating the theoretical constructs and their presumed interconnections (Miles & Huberman, 1994). I adopt the definition of social sensemaking as "the back-and-forth negotiation of meaning" (Mamykina et al., 2015: 3220). This definition underscores that social sensemaking is a process shaped by the *interactions* within the social context. In my effort to theorise and examine social sensemaking and comprehend its underlying mechanisms, I created a conceptual framework explaining the key theoretical constructs and their presumed relationships (Miles & Huberman, 1994).

Before I present this conceptual framework, I will present how my work addresses a gap in the existing framework by Mamykina et al. (2015) presented in Section 2.6. In summary, alongside its focus on the cognitive processes involved in creating inferences, the authors described that during this phase, individuals could activate their social networks and look to others for insights regarding possible explanations. Even though this creates opportunities for social sensemaking, the framework does not describe how this social element plays out in the sensemaking process. The authors actually suggest that "much of sensemaking in diabetes self-management occurs in isolation when individuals are limited to their own experiences and conclusions"(Mamykina et al., 2015: 411). This contrasts with what I have presented so far, showing that self-tracking is a social practice (Section 2.6). It is often shared in OHC (Section 2.7), and thus, social interactions facilitate the sensemaking of self-tracking (Section 2.7). These points also align with previous research showing that "health management, even when self-driven, is inherently social and depends on a person's direct relationships and broader sociocultural contexts" (Murnane et al., 2018: 1). Therefore, while the previous Sensemaking Framework (Mamykina, Smaldone, et al., 2015) provides insights into the individual level of sensemaking and how it can help people better manage their condition independently, it does not account for the social relationships that are part of health management and affect disease sensemaking.

I will now present my conceptual framework for social sensemaking, which is built on three integral dimensions of the social interactions taking place within an OHC and contribute to the back-and-forth negotiation of meaning:

a. common ground
b. challenging ideas
c. knowledge sharing

These dimensions are my guiding concepts, which work as a lens through which I view the research field (Boeije, 2010). I present below each dimension and exemplify relevant work from the literature.

a) Common Ground

Establishing common ground involves practices that build shared knowledge, beliefs, and assumptions (Clark & Brennan, 1991) between people with chronic diseases. For example, Huh and Ackerman (2012) studied the online interactions of people with diabetes regarding seeking and receiving help. They found that people develop a common understanding of their disease self-management through sharing and aligning their personal histories and opinions. Common ground can also be critical when people seek validation regarding having a "normal" experience. As O'Kane et al. (2016) explained, when people with migraines compare their personal experiences, normal does not "mean 'typical', but rather 'acceptable', which suggests that what a person has discovered about their own health experience is close to what is experienced by others". Nakikj and Mamykina (2017) have argued that shared experiences and interests are critical for people to engage in social sensemaking and to develop common ground within an OHC.

b) Challenging Ideas

Challenging and transforming ideas entails actively identifying and negotiating boundaries and misalignments about chronic disease self-management. For example, Mamykina, Nakikj, et al. (2015) examined the patterns of communication within an online diabetes community and found that people built shared meanings through discussions but also through *perspective negotiation* and *conflict resolution*. Specifically, perspective negotiation happened as members of the OHC often interrogated each other's perspectives, weighing evidence, and presenting and critiquing new arguments and evidence supporting either of the contrasting positions. However, ultimately, members would seek to resolve conflicting perspectives. Values and personal experiences could not be reduced to one single truth, and, therefore, the diversity of opinions was recognised as an essential element of the interaction.

On the other hand, when discussions about more objective topics, such as new scientific discoveries, took place, deeper engagement through active back-and-forth negotiation of different perspectives and negating ideas could lead to a resolution. Moreover, Mankoff et al. (2011) studied how *competing* viewpoints online affect the disease understanding of individuals recently diagnosed with Lyme disease. They found that online communities give access to information beyond the dominant explanatory model of the disease, which is often associated with how the medical community understands it. As the authors explain, even when an online community predominantly supports alternative perspectives on causality, management, and cure, this does not mean that members accept the opinions shared without looking at them critically. Ultimately, people's disease understanding can evolve owing to these competing viewpoints and even empower some members to take a more active role by creating online content and advising others affected by the disease.

c) Knowledge Sharing

The third dimension of social sensemaking is knowledge sharing. The literature has established that exchanging knowledge and information is the most critical activity in OHCs (Guo et al., 2020; Yan et al., 2016), which aligns with findings from other types of online communities. Nevertheless, OHCs differ from other online communities because their knowledge is closely related to members' physical and mental health (Zhang & Liu, 2022). According to Yan et al. (2016), there are two types of knowledge sharing within OHCs; the first is described as general/public knowledge sharing, while the second is labelled as specific/private knowledge sharing. The first one encompasses publicly available information, which can include, for example, hospital and medical information. Therefore, this type of information is usually more clinically oriented. The second type of knowledge sharing, specific to the person, includes personal health information such as medical treatment and the lived experiences of disease. This type of knowledge deriving from lived experience would not always be shared with GPs or specialists as it does not often conform to clinical knowledge or norms. For example, Greene et al. (2011) found that people with Type I diabetes described how to count carbohydrates to enable extended alcoholic drinking sessions without risking ketoacidosis. Thus, this type of knowledge is experiential mainly as it is often gained through the trial and error of managing the lived experience of a chronic disease (Hartzler & Pratt, 2011).

Developing this conceptual framework allows me to examine the process of social sensemaking in a Parkinson's OHC and unpack its three key dimensions: common ground, challenging ideas, and knowledge sharing. This thesis contributes to this line of research, which has started to explore social sensemaking about complex (e.g., Chopra et al., 2021) and progressive (e.g., Zou, 2022) conditions. Specifically, it focuses on PD, a complex disease with causal mechanisms which are challenging to interpret regarding the symptoms, treatment, and side effects but is also **progressive** with a range of cognitive, emotional and physical symptoms.

2.10 Summary

The goal of this chapter has been to establish the background of my area of research, which was underpinned by two theoretical conceptualisations: *self-tracking as an individual practice* and *self-tracking as a social practice*. At the start of the chapter, I began reviewing previous work on self-tracking for chronic disease. I have shown that there is no single way of practising self-management because of the complexities of everyday life. As a result, I established that my work embraces a *lived* view of self-tracking in the context of PD self-management. Then, I presented the disease characteristics of PD, which can be summarised in three main points: a) a wide range of physical, cognitive, and emotional symptoms, b) intra-personal variability, and c) disease progression. These characteristics shape how PwP can practise self-management and, thus, inform my analytical approach on PD tracking and sensemaking.

Next, I discussed how previous work had approached health technologies specifically for PwP. I demonstrated that health technologies designed for this group have primarily focused on improving the clinical assessments of the disease. While this work supports the clinical agenda and, thus, is very important, previous work has also shown that there is often a misalignment between clinical requirements and the needs of everyday life. Considering the insights this work has generated, we need to understand how PwP perform self-tracking in everyday life before we move on and design more self-tracking technologies for PwP. Building on previous literature on theoretical perspectives on self-management, this thesis considers a different framing of PD self-tracking that acknowledges the nuances of everyday life.

To do this, and in line with taking a lived perspective of self-management, I introduced sensemaking as an approach to understanding how PwP make sense of their self-tracking data and self-management. I chose the Sensemaking Framework because it focuses on chronic disease self-management. Nevertheless, the literature presented at the beginning of the chapter indicated that these sensemaking framework has focused, so far, on non-progressive diseases such as diabetes. As the nature of the disease is likely to affect how people practise self-management and make sense of their disease, so it remains unclear how this framework can be applied to the PD context. Furthermore, I unpacked the second pillar of the background work, namely self-tracking as a social practice, by re-introducing the concept of self-tracking — which is the focus of the thesis — but this time, with a social lens. More specifically, I showed that people with chronic conditions share their data with others. Therefore, the social aspects of self-tracking are essential in self-management. Whilst a large portion of PD work has focused on how self-tracking data can be shared with clinicians, opportunities remain for exploring ways of sharing self-tracking data with peers. In addition, I showed that OHCs are spaces where people with chronic conditions share their data and where social sensemaking happens. While OHCs have been studied extensively, research on OHC for PwP has not examined the process of social sensemaking, especially in the context of self-tracking. I further identified that this social aspect is not captured in the Sensemaking Framework for self-management (Mamykina, Smaldone, et al., 2015). To address these two gaps, I developed a conceptual framework for social sensemaking of chronic disease self-tracking, drawing from previous work on OHCs, self-management and sensemaking. This framework describes the different dimensions of social sensemaking including sharing common ground, challenging ideas, and knowledge sharing.

Finally, this literature review confirms that before we design more self-tracking technologies for PwP, future work on PD self-tracking should examine how PwP practise self-tracking in everyday life and interpret their data, as well as understand how PwP make sense of their data with their peers in social contexts such as OHCs. The subsequent chapters will work towards this direction. More specifically, Study I (Chapter 4) examines self-tracking in PD through a sensemaking lens. Study II (Chapter 5) delves into the social aspects of chronic disease self-management by focusing on how PwP make sense of their PD together and the role of self-tracking in social sensemaking within OHCs.

Lastly, I bring all the main thesis concepts together in a design-oriented study (Chapter 6) where I investigate how we can design for PD self-tracking in a way that accounts for individual and social sensemaking to support the lived efforts of self-management.

Chapter 3: Methodology

3.1 Introduction

In the previous chapter, I introduced the relevant literature to my research area, presenting the theoretical background of this work. In this chapter, I delve into the epistemological underpinnings of this thesis and provide the overarching methodology used to address the research questions in this thesis. More specifically, I start by introducing social constructivism and the epistemological and ontological principles it adheres to. Then, I present a human-centred methodology, including online data and co-design informed methods. Finally, I discuss the ethical considerations that underpin my methodological choices. As this thesis uses a combination of methods, every study chapter (Chapters 4, 5, and 6) has a separate section describing the methodology in detail, including elements of the data collection and analysis of the respective study (Study I, II, and III).

3.2 Social Constructivism

Before describing social constructivism, I would like to reflect on how I perceive its role in my research. I did not see my methodology as a rigid framework throughout this journey. Instead, I conceptualised it as the combination of my interests, perspective on the world, and thoughts towards creating knowledge (Braun & Clarke, 2013; Clough & Nutbrown, 2012). My epistemological position is grounded in a social constructivist view (Charmaz, 2006), which recognises experience as the starting point of the inquiry and asks how people construct it. Its ontological underpinning is relativism, which takes the perspective that reality cannot be separated from our human intentions or knowledge – our view of reality will always be shaped by our thoughts (Braun & Clarke, 2013). According to social constructivism, understanding the phenomenon observed is reached by viewing its multiple realities and placing it in a network of connections and constraints (Willig, 2016). Also, interpreting the phenomenon of interest is itself a construction (Suter, 2012).

As presented in Chapter 2, the current literature on PD self-tracking privileges clinical measurements of the disease. Thus, I argue that it lacks "epistemological heterogeneity", meaning that it does not currently reflect the "complicated co-existence of different ways of acquiring knowledge about" this chronic disease (Storni, 2015: 271). To address this, I move away from an epistemological position that promotes one objective truth and views chronic disease only in its clinical metrics (Wilson, 2000). I choose a social constructivist view on PD self-tracking, which challenges the objective basis of conventional knowledge (Gergen, 1985), recognises the diversity of self-management and validates different ways of experiencing and knowing a chronic disease.

3.3 Human-centred Methodology

This thesis applies a human-centred methodology combining qualitative research and design methods. This orientation is inspired by previous human-centred research methodologies that aim to understand people’s practices and experiences before iteratively engaging in design work (e.g., Ayobi, 2020; Ibrahim, 2020; Patel, 2023).

At the beginning of my PhD work, the research area I sought to understand and learn about could not be answered through experimentation or quantification. Instead, I needed to understand the world of those living with PD – what they needed in self-tracking technologies and what they sought to achieve – by indirectly observing their experiences and listening to their thoughts. As such, I adopted a qualitative orientation in my research, facilitating, understanding and describing rather than measuring and explaining (Storni, 2014). Empirical research aims to understand the world by directly or indirectly observing it (Goodwin & Goodwin, 2016), and qualitative methods seek to understand the thoughts and lives of individuals without emphasising measuring or quantifying them (Silverman, 2005). This approach was essential before I engaged in design work, as it would entail learning from those living with PD rather than making assumptions about what they felt and wanted.

Next, I used co-design informed methods for the last study of this thesis. As participatory and co-design-led methods can illustrate how we can build bridges between different stakeholders to provide human-centred care, I borrow from these to enrich my research practice. More specifically, I describe an approach toward conducting a co-design-informed study with PwP, carrying out research with (rather than about) PwP and iteratively engaging with design.

3.4 Online Data

For Study I (Chapter 4) and Study II (Chapter 5), I explored an OHC to investigate self-tracking and sensemaking in chronic disease self-management. For three main reasons, I used online data (texts produced by the OHC members and documented in their forum posts) to understand life with PD better. First, considering the retrospective nature of interview methods and our cognitive limitations to recall situated actions (Blandford et al., 2016), there is a potential discrepancy between participants' descriptions and everyday activities. Second, insights from online data are based on naturally occurring phenomena consisting of a less intrusive method of gathering insights into people’s lives, as in the absence of the researcher, there is no potential influence on the responses provided by participants (Ayobi, 2020). Third, I collected a large data set, which was expected to yield rich data within a short period.

Ethical Considerations for Using Online Data

I was granted ethical approval by the Birkbeck Ethics Committee to carry out both studies. Using online data for research is a topic of debate within the HCI research community (Proferes et al., 2021) as it raises ethical considerations regarding informed consent, anonymisation, and harm minimisation (Webb et al., 2017). Therefore, I considered carefully the ethical implications of undertaking a study using data online. My main priority was to not cause distress or harm to any community or individual through my work. Content within the OHCs can be defined as sensitive; in many cases, the users discuss their personal health experiences, including their relationship with their doctors and their family, as well as personal details from their lived efforts of self-management. Some users shared moments of emotional vulnerability, and as a researcher, I was responsible for being respectful towards this sensitive topic. Therefore, ensuring users' confidentiality and anonymity was very important to me.

To address the ethical challenges, I started by exploring what processes and practices had been followed by similar studies. I found that previous studies either reported using publicly available data (e.g., Bussone, 2018), formal ethical approval (Ayobi et al., 2018), or did not discuss the concept of ethics or ethical approvals to carry out a study using publicly available data (e.g., Mamykina et al., 2015). However, data available online does not mean there is an open and unrestricted right to use it. When people publicly share their data online, it cannot be assumed that they are aware of the fact that different organisations and actors could reproduce it. Best practices for online research include obtaining permission to reuse comments for research purposes (Townsend & Wallace, 2016). While it seemed common practice to use data from the open web, I preferred to collaborate with the social network of HealthUnlocked to get data from the Parkinson’s Movement community within this platform. Part of the signup process on HealthUnlocked included the consent request to use HealthUnlocked data for research purposes. Therefore, data provided by HealthUnlocked came only from users who had consented for their data to be used in research studies. Lastly, I familiarised myself with the ACM Code of Ethics to ensure that I adhered to the core principles of avoiding harm, being honest and trustworthy, and respecting privacy during data collection, analysis and report (Association for Computing Machinery, 2018).

3.5 Co-design informed Methods

As mentioned in Section 3.4, I used co-design informed methods in Study III (Chapter 6). The way we design has epistemological underpinnings; thus, I acknowledge that my epistemological position informed my choices of design methods. More specifically, design can potentially privilege certain forms of knowledge and reaffirm the assumptions attached to them (for instance, what counts as relevant information). Participatory and co-design methods have been especially helpful in medical settings to address different stakeholder perspectives and needs in technology design. These methods engage participants throughout the design process to sensitively understand the complex settings and participant groups being explored (Lupton, 2017). In this thesis, co-design-informed research is therefore concerned with “re-establishing the asymmetry between designers and the end users and between their knowledge, values and expertise” (Storni, 2013) and ensuring the design process is human-centred.

Ethical Consideration for Co-design informed Methods

Before conducting this study (and before the pandemic breakout), I spoke with several PwP in person and shadowed a neurologist treating PwP. From this experience, I gained an empathic understanding of people’s management of PD and its impact on individual’s lives. I also became better prepared for in-person research.

As the COVID-19 pandemic changed our ways of working, I had to rethink how to apply co-design-informed methods. I aimed to provide flexibility and safeguards for participants considering the COVID-19 pandemic, the variable nature of PD and people’s idiosyncratic well-being needs. Following Birkbeck’s guidelines, the third design-oriented study took place remotely, and the selected methods were adapted accordingly. This allowed me to explore and evaluate remote co-design techniques. Conducting remote research presented its own strengths and limitations.

For PwP, there have long been additional barriers to in-person research, such as increased transportation needs and not accessible physical facilities. These barriers also result in recruiting a less diverse group of participants as research may be restricted to populations within university areas. Researchers have used remote design techniques to overcome logistical issues such as travel for geographically-distant participants. However, considering our emerging understanding of best practices to support PwP in co-design practices, these approaches also pose barriers.

The first barrier is that PwPs’ experience physical symptoms such as tremor and dyskinesia. As previously indicated, they also experience on-and-off times, which can make design activities challenging to apply. Research has identified the importance of supporting embodied interaction and sensory engagement as a result of these symptoms; however, these also become more challenging in remote methods (Lazar et al., 2017). The second barrier is that, when involving PwP as co-designers, real-time interaction is important given the self-management.

For my third study, I conducted online workshops over Zoom and decided not to mail physical materials to participants before the sessions started, as described in similar design-oriented projects (e.g., Kopanoglu, 2022; Nasr et al., 2016). Instead, I used a digital probe to avoid exposing the participants to any harm (physical or psychological) while risking potential exposure to COVID-19.

When onboarding the participants to the study, I explained clearly to the participants that they could share within the limits of their comfort zone and that they could withdraw from the study at any time. When using the technology probe (see Chapter 6), participants could decide what was important to them to track. I shared information sheets and consent forms with participants before collecting any data, and I scheduled informal chats via telephone or Zoom[6] to support participants in making an informed decision. I provided my contact details as part of the consent procedures. I met regularly with my supervisory team throughout this research to discuss any issues.

3.6 Summary

This chapter outlines the epistemological underpinnings of my thesis on social constructivism and the human-centred methodology employed in this thesis. I describe the combination of qualitative and design methods used to answer my research questions. Finally, I outline ethical considerations derived from my methodological choices and how I addressed them.

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[6] https://zoom.us/

Chapter 4: Study I – Self-tracking and Individual Sensemaking in Parkinson's

Part of this Chapter has been published in the following paper:

Vafeiadou, Jenny, Asimina Vasalou, and George Roussos. "Self-tracking in Parkinson's The Lived Efforts of Self-management." Proceedings of the ACM on Human-Computer Interaction 5. CSCW1 (2021): 1-25.

4.1 Introduction to Study I

A growing body of research shows that self-tracking for disease self-management needs to be understood in the everyday context (Karkar et al., 2017; Nunes, 2015). However, as I argued in Chapter 1, self-tracking in the context of PD has often been studied from a clinical perspective. Therefore, I adopt the lens of self-tracking as *lived* (Rooksby et al., 2014),and define self-tracking as a practice. This lens can support a new understanding of how self-tracking happens in the context of self-management, because PD complex disease character makes difficult the existence of a standard practice in its self-tracking. Furthermore, to understand the value of self-tracking for self-management, it is necessary to also consider the cognitive process of disease sensemaking. Past work (Klein & Vamos, 2016) indicates that self-tracking itself is important, but not sufficient, in motivating individuals into action. Given the multidimensional character of the disease, the interpersonal differences, and the intravariability in disease manifestation, it is more important than ever to understand self-tracking as part of people's efforts to understand the different ways the disease manifests. This approach can help us to identify what information PwP value when making health decisions, contributing a more inclusive perspective on their needs, and opening future directions for self-tracking technology designed to support PD self-management.

To achieve this goal, I conducted an exploratory qualitative study of a social network dedicated to health called 'HealthUnlocked'. In line with my aim to capture the nuances of people's lived efforts to manage the disease, I clearly distinguish between self-tracking and PI. I adopt a broader definition for the concept of self-tracking that focuses on *practice* rather than on the use of PI technology. Additionally, my self-tracking definition encapsulates quantitative (e.g., motor measures) and qualitative (e.g. mood) data. Therefore, reflecting a *lived* perspective on self-tracking (Rooksby et al., 2014), I conceive of self-tracking as any *practice* embedded in everyday experience that supports an individual "to collect personally relevant information for the purpose of self-reflection and gaining self-knowledge" (Li et al., 2010). This information "could be in the form of numbers generated by wearable sensors, nominal or categorical, ordinal scales, photos, notes, etc." (Almalki et al., 2013). Given this broad definition of self-tracking, I first need to understand what PwP track and why it is important to them. Then, I move on to examine the tools used by the individuals and how they make this choice. Lastly, I use an existing framework of sensemaking for chronic disease self-management (Mamykina, Smaldone, et al., 2015) to understand how self-tracking currently fits within people's self-management, and to identify how people with Parkinson's engage in sensemaking.

This study seeks to address three research questions:

RQ1: What information do PwP self-track and why?

RQ2: What tools do PwP use for self-tracking and how they make their tool choice?

RQ3: How do PwP engage in individual sensemaking of self-tracked information and what self-tracking practices underpin sensemaking?

The contributions of this empirical study are threefold. First, the study provides a descriptive account of how PwP carry out self-tracking and sensemaking for their self-management. Second, I contextualise a previously developed framework of sensemaking for chronic disease self-management (Mamykina, Smaldone, et al., 2015) to PD self-management demonstrating that the characteristics of this chronic disease pose particular challenges during the process of sensemaking. Lastly, building on my empirical understanding of self-tracking practices and sensemaking, I identify several design considerations for self-tracking technologies aimed to support individuals with Parkinson's:

i) the need to design self-tracking tools that cut cross different domains and types of information in order to support PwPs' lived efforts to manage their health
ii) the continued need to track information that is objectively measured, but also the value of enabling PwP to engage in self-reports that capture the qualitative dimensions of the disease
iii) the importance of expanding the current scope of self-tracking for self-management to also support PwP in disease self-awareness and to facilitate iterative self-experimentation

4.2 Methodology

As I presented in the previous chapter, my overall research approach recognises experience as the starting point of the inquiry and also takes the perspective that reality cannot be separated from our human intentions or knowledge (Braun & Clarke, 2013). Therefore, in my early endeavour within my PhD research, a crucial initial step involved immersing myself in the world of PD. This familiarization process with the domain was essential to gain a comprehensive understanding of the condition, the individuals affected, and the broader context in which they navigate their lives. To achieve this, I undertook a multifaceted approach:

Informal Conversations: Leveraging my personal and academic network, I connected with individuals living with PwP. I engaged in informal conversations with PwP from diverse cultural and geographic backgrounds. These interactions provided invaluable insights into their personal experiences, challenges, and coping strategies.

Community Engagement: I volunteered with Parkinson's UK, participating in events designed to connect with the PD community. These experiences allowed me to interact with PwP, caregivers, and family members, gaining a deeper understanding of their needs and perspectives.

Clinical Observation: I shadowed a neurologist specializing in PD, observing patient consultations. This firsthand exposure to the medical context helped me comprehend the clinical aspects of PD, as well as the ways in which PwP communicate their symptoms and concerns.

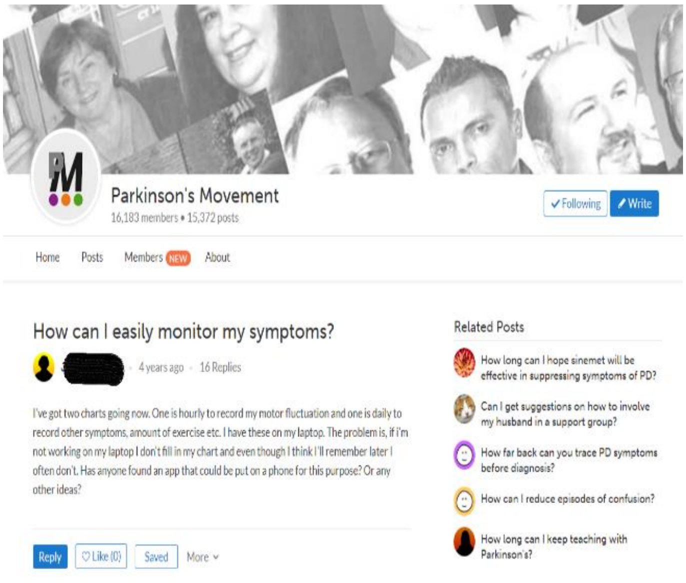
Through these experiences, I developed a nuanced understanding of the multifaceted nature of Parkinson's disease. This foundational knowledge proved invaluable as I delved into the subsequent stages of data analysis.

The data for Study I (Chapter 4) and Study II (Chapter 5) were sourced from the same OHC context. To avoid redundancy, the primary methodological approach for both studies is outlined within this chapter. Chapter 5 will further elaborate on additional methods and approaches specific to its research questions.

4.2.1 Research context, procedure, and ethics

As presented in Chapter 2, Parkinson’s is a complex neurodegenerative disease and PwP experience a range of symptoms, side effects from different medication, as well as other personal challenges related to the everyday experience of the disease. To address the challenges that arise from the disease, many PwP have an active presence online. This is reflected in the increasing number of OHCs dedicated to Parkinson’s, which operate within the major social networks for health such as PatientsLikeMe, HealthUnlocked and Myparkinson’s Team. Similar to the approach taken in a recent study aiming to understand self-tracking practices in relation to fertility care (Figueiredo et al., 2017), I take the view that OHC offer an ideal site to examine PwPs’ self-tracking practices alongside how these practices may support self-management in the everyday experience of the disease.

The context of this study is the Parkinson’s Movement, which is an OHC active within HealthUnlocked (HU). Established in 2011, and like other social networking sites, HU offers functionality for creating a personal profile, updating one’s personal status and viewing news feeds (see Figure 4.1). At present, HU includes over 700 health communities, each centred on a different condition, or health issue, with 4 million total active users (York Health Economics Consortium, 2017). While the Parkinson’s Movement community was established in the UK through a partnership with the charity ‘The Cure Parkinson's Trust’ (*About Parkinson’s Movement*, 2020), it is open to non-UK membership, and English remains the primary language of communication. Social interactions amongst members occur through threaded discussions, or private messages. In my research, I focused on member posts within the Parkinson’s Movement community in HU (14,431 members and 12,322 posts as of January 2019). Parkinson’s Movement was used as a context for capturing the self-reported practices of self-tracking and sensemaking as they relate to Parkinson’s self-management. Given that OHC, like Parkinson’s Movement, attract people who take ownership of their health, I envisioned this would result in rich posts about health self-management and in particular self-tracking. Moreover, since HU was born from a partnership with the PwP-initiated charity ‘The Cure Parkinson's Trust’, I anticipated that its members would be to some extent engaged self-advocates.



Parkinson's Movement
16,183 members • 15,372 posts

How can I easily monitor my symptoms?

[redacted] · 4 years ago · 16 Replies

I've got two charts going now. One is hourly to record my motor fluctuation and one is daily to record other symptoms, amount of exercise etc. I have these on my laptop. The problem is, if i'm not working on my laptop I don't fill in my chart and even though I think I'll remember later I often don't. Has anyone found an app that could be put on a phone for this purpose? Or any other ideas?

Related Posts

How long can I hope sinemet will be effective in suppressing symptoms of PD?

Can I get suggestions on how to involve my husband in a support group?

How far back can you trace PD symptoms before diagnosis?

How can I reduce episodes of confusion?

How long can I keep teaching with Parkinson's?

Figure 4.1: Snapshot from Parkinson's Movement Posts

The website and community forum are open to all for viewing and are made available to search engines. People who want to post are required to register; and advertising or conducting a research study requires prior permission. Following the ethical research regulations of HU, I formally requested permission to conduct research on this community. Approving my request, HU provided me with a data corpus including 5,000 randomly selected posts created between March 2011 and July 2018. Posts were anonymized by HU with each post assigned a unique identification number. A post is defined as an individual message posted by a Parkinson's Movement member, usually extracted from a longer message exchange between community members. Upon signing up to the OHC, HU members are asked to agree with the HU's terms and conditions. More specifically, among these terms and conditions, there is the option to opt in or out from the use of their posts for research purposes. The dataset obtained excluded data from those who had previously opted out. In addition to following the social network's ethical procedures, ethical approval was obtained by the Birkbeck University Ethics Committee.

More specifically, as outlined in Chapter 3, during the ethics application process, I engaged in valuable discussions with Dr. Felix Reidl at the Computer Science Department at Birkbeck. These conversations were instrumental in shaping my research practices and ensuring ethical conduct. We explored various data collection approaches, including the use of publicly accessible social media data. However, I opted for a collaborative approach with an online community that has established data handling practices and explicit consent for research purposes. This decision aligns with best practices in HCI research and prioritizes the ethical considerations of the research participants.

4.2.2 Selection of events

I uploaded the 5,000-post data corpus obtained from HU to the qualitative data analysis software Nvivo (Version 12). Since my aim was to identify discussions held by online members about their self-tracking in relation to PD self-management, I identified a set of keywords that would allow me to select appropriate events. To construct the keyword list and run the initial queries, I used a set of pre-defined keywords such as "track", "record", and "monitor" to identify self-tracking instances as well as words referring to digital and non-digital self-tracking mediums such as "diary", "watch", and "mobile". These keywords were identified by consulting previous research reporting on the tools, practices, and conceptualisations of self-tracking (Ayobi, Marshall, & Cox, 2017; Faisal et al., 2012; Lakshminarayana et al., 2017). I also extended the keyword list based on the results of a previous study on Parkinson's self-tracking in which PwP had reported what they were tracking (Stuart, 2017) (see Table 4.1). At this point, it was found that while PwP perform most of the self-tracking activities, in some cases where PwP had progressed in their disease, their carers also performed tracking activities. Such cases are outside the scope of the study and are thus excluded. In total, this process resulted in 405 posts.

Type of Information	**Frequency in PwPs' responses**
Balance Glasses of water consumed Bowel Movement/Constipation Tremor How easy was to wake up this morning	Very Common
Alcohol Consumption Morning Stiffness Speech Caffeine Intake Happiness	Common
Parkinson's on-off Pain Have I had a good day? Went toutside today Sweet treats Time Spent outside	Less Common

Table 4.1: Types of information tracked by PwP reported in (Stuart, 2017)

4.2.3 Data Analysis

Following the selection of events, I started with a familiarisation stage recommended in qualitative analysis where I read the posts extensively (Braun & Clarke, 2006). To answer the research questions, three types of analysis were conducted (see Table 4.2). I had regular meetings with supervisors to discuss the coding and the development of themes related to the data. I iteratively reworked the codes and the themes in discussion with supervisors until the coding scheme was finalized. Subsequently, I analysed the remaining dataset.

First, I analysed the posts at word level to identify the self-tracking information types mentioned in each post, as well as the tools used by PwP to track (RQ1 & RQ2). This allowed me to create a comprehensive list of self-tracking information types and tools reported by PwP across the entire dataset. Second, I iteratively analysed the entire dataset inductively with the aim to capture the meaning, experience, and practices PwP reported with respect to why, or how they collected information and used the self-tracking tools (RQ1 & RQ2). Third, I used the sensemaking framework (Mamykina, Smaldone, et al., 2015) as a conceptual framework to identify instances of PwPs' sensemaking (RQ3). For this last stage, a combined technique of deductive and inductive coding

(Fereday & Muir-Cochrane, 2006) was employed. Using the sensemaking framework, I created initial codes aligning with the framework's two modes and three phases. I then looked in the data for evidence of these pre-determined codes using them as a pre-existing coding frame (deductive analysis). If I diagnosed that the sensemaking process expressed in a post did not align with the codebook, I created new codes and incorporated them into the coding scheme (inductive analysis). This analytical process continued until no new codes were yielded. This combined deductive and inductive analysis was necessary to ensure that the sensemaking framework, informed by the characteristics of diabetes, also captured the nuances of Parkinson's. The analysis was iterative and reflexive since the selection and application of the framework was revised and updated to fit the data (Chambliss & Schutt, 2013).

Phase	**Types of analysis**	**Reported in Section**	**RQ addressed**
1st phase	Word-level analysis	Information types (Section 5.1) Tools (5.2)	RQ1 RQ2
2nd phase	Inductive analysis	Reasons for tracking (5.1) Selection of tool criteria (5.2) Self-tracking practices (5.3)	RQ1 RQ2 RQ2
3rd phase	Deductive & inductive analysis	Sensemaking in Parkinson's (5.4)	RQ3

Table 4.2: Analytic Approach

4.3 Findings

4.3.1 Information Tracked & Parkinson's Everyday Experience

This section answers the RQ1 on what PwP track and why. My findings revealed that PwP tracked a variety of information, which coalesced into four main categories based on their domain:

- **Treatment information** reflects the prescribed medicine, natural supplements, and other non-drug treatments, such as physiotherapy, that PwP use to manage their symptoms.
- **Parkinson's symptoms** (cognitive, psychological, physical/motor) capture information about the multidimensional character of the disease as it manifests for each PwP.
- **Generic health indicators** include information about general physiological measures that indicate good health.

- **Lifestyle information** captures the day-to-day well-being, habits and routine activities PwP engage in.

Tracking a combination of these diverse information types allows PwP to manage different aspects of living with the disease. Table 4.3 summarises each domain and the associated information PwP tracked.

Domain	**Information tracked**
Treatment	• Medication schedule and/or adherence • Medication side effects • Medication efficiency • Alternative/natural medicine efficiency • Overall Levodopa intake [7]
Parkinson's symptoms	• Pain experienced • Fatigue experienced • Motor symptoms (tremor, rigidity, dyskinesia, slowness, falls) • Drooling experienced • Psychology & emotions (mood, depression, panic attacks)
Generic health indicators	• Bowel movement/constipation • Blood pressure • Weight • Sugar levels • Temperature • Oxygen levels • Urine levels
Lifestyle	• Timings of meals in relation to medicine timings • Content of meals, diet, calories intake, protein intake • Physical activity and exercise • Sleep levels • Perceived quality of life • Amount of time spent on activities, e.g., chores, hobbies • Timings of the day during which PwP are productive

Table 4.3: Parkinson's tracking domains and information

Across these four domains, the information tracked was captured and represented either quantitatively and/or qualitatively. Quantitative information included tremor severity (Parkinson's

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[7] Levodopa is a synthetic substance that is converted in the brain to dopamine. It is used chiefly in the treatment of PD.

motor symptoms), medication timings (Treatment), and falls (Parkinson's motor symptoms). Qualitative information typically relied on the individual's subjective assessment; for example, quality of life (Lifestyle), fatigue (Parkinson's physical symptoms), and emotions (Parkinson's psychological symptoms). Reporting psychological symptoms and medication side effects relied predominantly on qualitative information, which posed a particular challenge to capture. To address this, some PwP maintained a log of all information considered potentially relevant. As a PwP stated characteristically: *"I made a list of all my symptoms (what is getting worse or better)".* In contrast, others recognised the limitations of self-assessment, instead choosing to track information that could be measured accurately. The following quote exemplifies this: *"Sleep, concentration, memory, and mood are the things that bother me more than tremor, but I can't measure those, except for an inaccurate card-flipping memory game I have played for many years".* A few PwP developed their own scales aiming to convert qualitative information related to their disease self-management into quantitative. This enabled them to compare health-related progress across time more easily as the following quote shows: *"Well I felt! I give myself a grade in a PD diary each day dependent on symptoms to record 'progress' (1 being awful and 5 being the best)".*

While each individual PwP chose to track different types of information, they all shared the need to use this information to make sense of their experience of living with Parkinson's. To express their lived efforts in managing Parkinson's, PwP often shared the information they tracked alongside its context, to highlight the broader complexities they experienced when living with the disease. This narrative approach to reporting self-tracking allowed PwP to pinpoint, which information was meaningful to them. It was in this context that a perceived mismatch was expressed between the lived experience of the PD and the clinical consultation. Whereas the focus of clinicians tended to be on motor symptoms and medication adherence, PwP concerns often centered on the lifestyle implications and psychological dimensions of the disease. A PwP, who worked as a teacher and felt that the disease affected immensely their ability to teach, explained the tension:

> *"Many things debar me from being able to teach: chronic fatigue, insomnia, anxiety attacks in front of classes, inability to mark pupils work, apathy, flu symptoms etc. My specialist wouldn't really know about these more subtle aspects of my situation, and I always get the feeling that clinicians place too much stress on motor skills. I sort of resent that my specialist holds the key hand in a situation that I am the best judge to know what I'm capable of, not he."*

4.3.2 Self-tracking Tools and the Criteria for Tool Selection

This section focuses on RQ2: answering the question what tools PwP use, and what informs their choice of tools. My analysis revealed that PwP did not have a single self-tracking tool, nor was there a standard set of preferred tools. When they decided to track information, PwP usually made use of tools that were embedded in their daily routine. Table 4.4 captures the range of tools used. Whilst non-digital tools were employed, it is evident that a range of digital tools were also in use. These included self-reporting tools such as online forum posts, blogs, and digital notes, reminders, activity trackers, and data representations. As reported in the previous section, the variety of digital tools employed shows the diversity of quantitative and qualitative information tracked. Most notably, several of the online forum posts analysed were in themselves self-reports of self-tracking as the example below illustrates:

"7.00am – get up, shower, breakfast, take requip, azilect, omeprazole and multi vitamins, get dressed and off to work

8.00- am at work (luckily just round the corner) look at E-mails, ring IT dep't to see if they have resolved my dragon software issue (the security systems and Dragon don't get on)…"

Non-digital tools	**Digital tools**
Mental tracking	Digital notes applications
Notes	Making graphs
Journal/diary	Alarm clocks
Watch	Videos
	Use of online health forums
	Blogs
	Vlogs
	Wii-Fit
	Digital Watch

Table 4.4: Tools of self-tracking

The selection of a particular self-tracking tool and its continued use was influenced by three criteria namely familiarity, access and the flexibility to fit with the specific goal. For many PwP, the mobile phone met these criteria. The use of phones was already pervasive and thus familiar, but also phones are portable and always accessible. One of the PwP explained that familiarity with phones generated a sense of control over the process of self-tracking: *"Very relaxing, the phone gives you full control. Nothing to adjust or think about. Just press the start button in the morning when you take the medicine."* Another criterion was flexibility, with tools capturing information that could concurrently support multiple goals perceived to be useful: *"I've got two charts going now. One is hourly to record my motor fluctuation and one is daily to record other symptoms, amount of exercise etc. I have these on my laptop."*

However, depending on the self-tracking tool used, sometimes the three criteria could not be satisfied at once. In one example, a PwP valued the flexibility afforded by charts to create different types of representations; and yet, their lack of access to a laptop became a barrier to the sustainability of this practice: *"The problem is, if I'm not working on my laptop, I don't fill in my chart and even though I think I'll remember later I often don't".* Conversely, in another post, a PwP used a wearable self-tracking tool that afforded continuous access but did not satisfy their goal:

> *"… really need a watch with an "expandable" wristband. For PD folks that need two, three or more "alarms" to handle medications over a 24 hour period, I have not been able to find a watch that can do more than 1 alarm in 24 hours."*

4.3.3 Self-tracking practices

Self-tracking practices incorporating these tools differed in structure and timespan. Structural differences encompassed the frequency of tracking and the granularity of the information captured. Some PwP applied a structured self-tracking practice with regular capture of data and in a high level of detail as shown in the following quote: *"…an elimination taking out food suspects and keeping a careful diary of symptoms experienced is best".* However, tracking frequently and with high granularity implied effort and time commitment. Some PwP attempted to address the burden of self-tracking by compromising on frequency. As one PwP explained: *"As for me I keep log, but only write on Tues & Fridays".* Another approach was to focus on and analyse less frequent critical events of positive health: *"If I felt I had a good day, then I make an effort to remember what I did and what I ate over the past day and make notes".*

The timespan of self-tracking practice was shaped by the aim underpinning the desire to engage in self-tracking. For some PwP, self-tracking was an approach for maintaining consistent levels of self-management and was incorporated longitudinally in their daily routine. As one PwP explained, not only did tracking lifestyle information help to support a healthy routine for self-management, but it was also used to assess the achievement of prior goal setting: "*Exercise exercise exercise must move as much as possible best medicine. Try and keep workout diary and plan my next day or give myself goals to meet. This will help you stay motivated and focused".* Self-tracking was also a time-bound activity used to address specific problems. Accordingly, PwP engaged in personal experimentation with treatment interventions to evaluate the improvement, or deterioration, of their symptoms. One PwP, for example, reported tracking treatment across time to reach an optimal level of their medication dosage:

> *"Started wearing off March 2013 after 1.5 hours. Neuro seems stumped so I have started experimenting. For some reason my mornings are still OK - better than off-time. So now I*

> *start at noon, 1x100 Sinemet then 1x100 every hour until 8 pm, no off-time, can go 1 hr 15 min but no more. It concerns me that this may be too much for me (from 450 to 900 mg). I have tried 200 mg – no difference. It seems that it's all about experimenting till you find the right dose, it seems no doc can predict that, but may be able to keep you out of trouble."*

4.3.4 Sensemaking in Parkinson's

This section answers RQ3: how PwP make sense of their self-tracked data by using the Sensemaking Framework (Mamykina, Smaldone, et al., 2015).

Habitual and sensemaking modes

The sensemaking framework proposes that individuals perform chronic health self-management activities in two modes, the habitual and sensemaking mode. Each mode includes three interdependent processes: perception, inference, action (Mamykina, Smaldone, et al., 2015). My findings provide evidence that PwP operate in either of these modes while self-tracking.

Habitual mode. When in the habitual mode, PwP perceived new information; then their existing mental models activated to make appropriate inferences. The following quote illustrates inference in the habitual mode relating to the onset of tremor: *"My tremor usually worsens during the day until it is almost continuous during the evening. I often find that even if I don't have a tremor at tablet time, I develop one soon after taking the meds*". In a similar example, a different PwP had constructed a routine action carried out when their wellbeing was at its best: *"Mornings are generally good for me so I usually plan my exercises and physical activities during that time frame".*

Sensemaking mode. As the sensemaking framework predicts, the sensemaking mode was triggered when PwP perceived new information from self-tracking collected over a timespan, which could not be explained by previous experiences or general knowledge. Examples of this included time periods of medication efficiency and/or symptoms that are suddenly disrupted. The following illustrative quote comes from a PwP who adhered to a daily medication schedule and tracked the response to medication over time. This led them to identify a timeframe in the day during which the medication didn't work as expected combined with a negative unexplained impact on mood. This new information could not be reconciled with the existing mental model of how this medication worked, and therefore triggered the person's sensemaking mode because they did not understand their symptomatology.

> *"Why same time every day. Why do I fall apart at the same time every day. Almost every day I get depressed and my meds don't work or work poorly. It was at night about 5 or 7 pm but it has moved to mid-afternoon. I still take my meds at the same time as always. It will last for an hour or 2."*

While engaging in the inference phase of sensemaking, like the sensemaking process reported for diabetes (Mamykina, Smaldone, et al., 2015), PwP formulated initial hypotheses that offered new plausible explanations to the perceived gap.

"When it started, I thought it was low blood sugar or low blood pressure or high blood pressure. I ruled those causes out by checking my BP and Blood Glucose. It's not my thyroid either, I get that tested every 3 months. Forget menopause, long past that, anyway I had a hysterectomy at 42."

Finally, PwP proceeded to the action phase of sensemaking by testing their new inferences. This was achieved by engaging in active experimentation to evaluate the impact of their different choices. In the following example, a PwP reported on a treatment experiment with Mucuna Pruriens,[8] i.e., a tropical legume used by PwP as an alternative supplement to traditional drugs.

"I've taken MP with water, juice, hot pineapple juice as a hot beverage. That last actually worked pretty good. I'm currently testing taking MC when I first begin sensing chest fasciculations letting me know the C/L is running out, with a cup of black tea. After a few minutes it kicks in then I find I can put off taking the C/L, until a little warmth, not hyperpyrexia begins. I don't think it needs to be this complicated and I'm seeking something simple that has eluded me so far."

My analysis showed that once an action had a positive impact, PwP adopted the new activity and the new inferences developed are incorporated into the operational mode of their self-management strategies. As proposed by the sensemaking framework, once the new activities became habits, the habitual mode of self-management was restored. The quote that follows illustrates the completion of a sensemaking episode involving treatment experimentation and the activation of a new treatment habit:

"Initial success was at 4g daily several months ago. Moved to 6g daily for two weeks trying to reduce tremor. Did not affect tremor. Failure was in fine motor control and constipation return. Moved to 2g daily finding improved motor control but still constipated. I returned to the dose 4 g daily. Now no constipation and suppressed Parkinson's symptoms."

Notably, given the interconnected nature of the domains, PwP usually tracked more than one kind of information using multiple information types in order make sense of the situation. As a PwP explained, tracking different information types to build their understanding of not suitable

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[8] Mucuna Pruriens, also referred to as the velvet bean, is a legume that grows in tropical and subtropical areas across the world. Although the beans can be used as a source of food after they are boiled, MP is also a medicinal plant, used for millennia in traditional Ayurvedic Indian medicine. Because it contains 6-9% levodopa by weight. MP has been investigated for counteracting parkinsonian symptoms. There is no regulatory body that controls standardization of the MP products (Gilbert, 2019).

medication dosage: "*I keep track of food, timing, and doses. Adding symptoms, blood pressure readings and temperature to this journal has helped me identify my body's signals of overdose*".

The Distinctive Character of Sensemaking in the Context of Parkinson's

While my findings concurred with the sensemaking framework for chronic disease, there are also features of PD that shaped the sensemaking process in distinguishing ways. In particular, during the perception stage of sensemaking, *comorbidity, disease progression* and *self-management best practices* triggered particular gaps in understanding.

Comorbidity. The majority of PwP tend to be older than 50 (NHS, 2019a) and thus, are often affected by more than one chronic condition that needs to be managed. My findings show that comorbidity posed a challenge for many PwP whilst they sought to identify cause and effect as part of the sensemaking process. In the illustrative quote below a PwP shared the difficulty they faced in disambiguating whether sleep and weight problems are triggered by Parkinson's, or hypertension medication (statins).

"Statins I have just read a very interesting article due to be published in Wednesday's Daily Mail about statins and sleep. It appears the statin Simvastatin has been linked with causing both sleep disturbance and weight gain. I am on this statin and suffer from both these things. I would be interested in hearing whether anyone else, taking this statin, has either, or both, of these problems. My sleep and weight problems have been put down to meds I am taking for Parkinson's. Maybe this is not right."

PwP often employed self-tracking to disambiguate their circumstances by exploring what the cause-and-effect relationship of their symptoms might be. Since comorbidity is a common phenomenon in aging, it was difficult to assess if an observation was the implication of PD, or of a comorbid disease. For example, in the following quote, a PwP explained how their blood pressure was tracked in relation to their PD medication regime. Their aim was to understand if the doctors' diagnosis of hypertension was correct, or if the elevated blood pressure was the result of their PD medication.

"My doctors all wanted me to get back on one of the blood pressure meds but I was sure my problem wasn't hypertension but instead was triggered by levodopa issues. I was proved right…The point here is that in the nearly two years that I was closely monitoring my bp I saw a definite linkage between the BP readings and the levodopa in my system – – low readings midway between pills, readings going up as I approached the time for a new pill, peaking at pill time, and going down as the new pill took effect."

Disease Progression. The progressive nature of PD and its changing symptoms (NHS, 2019a) are reported across many of the posts analysed. New gaps in understanding triggered the sensemaking mode because PwP often could not explain why new symptoms occurred, and if they indicated disease progression. In the following quote, a PwP described the frustration caused by a new and recent symptom, which created a gap in their understanding:

"Since my last visit with my PD Dr. in Oct. my legs keep giving out on me and I fall, if I bend to pick up anything, my body doesn't stop but rolls right down to the floor. I have no warning sign before my legs give out.....it just happens."

PwP relied on self-management routines that had become part of their habitual sensemaking mode. However, as the disease progressed, these longstanding strategies are no longer effective. For example, one PwP explained how an effective, stable, and longstanding treatment plan was not feasible to maintain as the disease progressed, resulting in a gap in understanding. Thus, the impact of the disease progression on the effectiveness of their treatment plan sparked a gap in understanding.

"I have worked along with the same plan for the last 5yrs and it seemed to be working fine, however my condition had deteriorated, and I had not considered a change in the way I do things."

Self-management best practices. For some PwP the knowledge of disease progression created a sense of vigilance, whereby routine actions in self-management are continuously questioned and revised. Rather than relying on the habitual mode until new information would trigger a gap, the sensemaking mode was always active, and PwP were in constant search for new actions they could evaluate both in relation to their current symptom relief and in slowing their disease progression. Therefore, the sensemaking mode was not always triggered by a gap in understanding, but by the invariable need to continuously identify possibilities for new actions to manage health. As one PwP explained: *"Treatment won't be the same over the course of the disease. Many PwP are always in the look of new supplements, treatments or lifestyle changes that can alleviate the symptoms such as new types of exercise or different diet".* The sensemaking framework for chronic disease self-management (Mamykina, Smaldone, et al., 2015) posits that self-tracking is an action-oriented activity aiming to ultimately reach a successful self-management routine. This example suggests that PwP constantly seek to optimise their self-management and this motivation acts as the trigger to the sensemaking mode.

Awareness-oriented Sensemaking

In contrast to the sensemaking framework, I found that PD self-tracking was sometimes awareness-oriented and did not involve the action phase. To this end, PwP used self-tracking to understand the manifestation of their disease: how their treatment worked, or if a particular disturbance they experienced was associated with PD. The illustrative quote below came from a PwP who tracked the impact of the weather on their symptoms. Rather than sparking a self-management action, they reported an increased awareness of how the weather influenced their symptoms: "*What about the weather? I personally find that my symptoms get worse during hot weather. I'm curious, how does weather impact my symptoms?*".

This awareness-oriented approach to sensemaking often occurred soon after PwP were diagnosed and were seeking to understand the nature of the disease. For example, a PwP explained how they kept a chart to track their symptoms soon after their diagnosis: *"Sometimes it can be impossible to truly know the cause and effect but in the early days I kept a chart to get my head around it".*

Another newly diagnosed PwP kept a list of his symptoms with the aim to understand the range of PD symptoms:

"My Symptoms:

Frozen Shoulders

Rigidity in my joints and muscles

Tremors in my hands, face and legs

Terrible balance (I stand up I lose my balance, while walking if I suddenly turn I lose my balance ect.)

Anxiety…."

Awareness gained through self-tracking also enabled PwP to maintain a sense of control over the disease and their life more broadly. As a PwP explained, by continuously planning and tracking their time spent on activities, they knew that they could make things happen:

"All of it has challenged my morale, confidence, self-esteem and at times it has felt impossible. But that's it, it has felt impossible but in another strange way it isn't. I bang on about making a plan all the time, and I know it seems geeky but it so works. On my plan I make sure I have equal amounts of stuff, and I make sure that PD only accounts for around 40% of my available time."

4.4 Discussion

My study set out to identify the everyday experience of Parkinson's self-tracking with respect to the information tracked, the tools employed, as well as the characteristics of the practice. Moreover, I wanted to explore how PwP build on these practices to engage in sensemaking to manage their disease. In this section, I discuss these themes to present Parkinson's sensemaking particularities in relation to PwPs' day-to-day self-management. I interpret my findings from a design lens, and I aim to identify design opportunities for digital self-tracking designed to support the everyday experience and lived character of self-management (summarised in Table 4.5).

4.4.1 Self-tracking tools for Sensemaking

In agreement with Faisal et al., (2012) who argue that people with a chronic disease value diverse information, my findings show that PwP track information types across four interrelated domains. Reflecting the multidimensional character of Parkinson’s (Iansek, 1999; Politis et al., 2010) the symptoms tracked ranged from motor symptoms to emotions or pain experienced. Furthermore, my findings support Mamykina et al. (2015) who characterize the self-management of chronic disease as a process that makes sense of the *“chaos of the lived experience.”* The four domains captured in the study highlight the significance of making associations – or generating cause-and-effect hypotheses – between symptoms (e.g., dyskinesia), treatment (e.g., medication efficiency), and outcomes/quality of life (e.g., sleep levels) as part of the sensemaking process in self-management. The findings, therefore, suggest that self-tracking technology *designed to support sensemaking* for the purpose of self-management could support this goal by enabling the tracking of a more diverse set of phenomena. Moreover, PwP expressed their desire to increase clinicians’ awareness about the implications of the “practical, routine, or banal aspects that characterise daily life with a chronic condition” (Nunes & Fitzpatrick, 2018), which could be facilitated through the tracking of the different domains and types of information that concern PwP.

Toward this goal, this research poses a number of implications for the design of technology that can support self-management through self-tracking. First, I show that PwP seek to track information that is both objectively measured as well as self-reported. While PwP perceived the tracking of measurable information to be effortless, when it came to self-reports, they expressed a lack of efficacy in having to define and to also measure qualitative dimensions of their disease across time. Some PwP addressed this challenge by creating scales based on their own words and metrics to capture their felt experiences, a practice also employed by people with Multiple Sclerosis (Ayobi, Marshall, Cox, et al., 2017). Thus, technology that may support the pre-configuration of information types and custom scales could provide motivation and scaffold for the tracking process of qualitative aspects of the disease.

Second, I found that PwP used digital and non-digital self-tracking tools ranging from diaries, to reminders, or Vlogs, echoing findings also reported by Matthews et al. (2017) who showed that people with bipolar disorder (a chronic psychological condition) used a mix of semi-automated and analogue self-tracking tools. PwP experienced difficulties in finding a tool that satisfied their needs, further corroborating the lack of a widely accepted technological tool for the purposes of Parkinson’s self-tracking and self-management. The diversity of information types tracked, and the effort required to bring these together into the sensemaking process, had an impact on how PwP chose self-tracking tools. Therefore, PwP valued tools that were already familiar and available within their everyday activities, in addition to tools that allowed for flexibility to define different time measurements and alarms. These three criteria – familiarity, access, and flexibility – support the future design of self-tracking technology more broadly, while specifically suggesting the value of building upon already adopted, portable technology.

4.4.2 The Particularities of Parkinson's Sensemaking

When applying the sensemaking framework (Mamykina, Smaldone, et al., 2015) to understand the self-management of Parkinson's disease, the findings generally converged with the model. PwP performed self-management in a habitual mode, or in a sensemaking mode. Moreover, there was evidence of the three interdependent activities across both modes: perception, inference, and action. For instance, one PwP identified that their general wellbeing was better during the morning, leading to a decision to plan exercises and physical activities during that timeframe. In this example of the habitual mode, the information of feeling poorly later in the day (perception) was explained by activating an existing mental model (inference) followed by the effortless application of a self-management activity (action). In a different example of the sensemaking mode, a PwP observed that their medication had stopped working the same time every day (perception), which created a gap in understanding as the perceived responsiveness to the medication did not match with their existing mental model.

Within the sensemaking mode, my findings also suggest that there can be loops between the inference and action phase, whereby PwP experiment with new self-management practices. For example, a PwP performed an experiment with different medication dosages by making a hypothesis about these different dosages (inference) and then testing them to evaluate the impact on their motor symptoms, and their constipation. While some of the current self-tracking tools support existing self-management practices, such as medication adherence to a prescribed treatment plan, they usually do not account for the need to experiment. This finding fits with Karkar et al. (2017) and Ayobi et al. (2017) who have already identified the importance of explicitly supporting self-experimentation in the design of self-tracking for other chronic diseases.

On the whole, the findings show similarities in sensemaking between diabetes and PD. However, there are also core differences, which derive from PD disease characteristics. Young and Miller (2019) have previously argued for the need to refine the sensemaking framework to account for chronic diseases with unknown or complex causal mechanisms. My study offers empirical support for this claim. As presented in Chapter 2, Section 2.2, there is not a single symptom profile of PD, as there are significant differences in disease manifestation among PwP. The sensemaking process of PwP was in part shaped by their disease characteristics.

This study shows that *comorbidity* creates ambiguity, causing difficulty for PwP to ascertain whether a gap in understanding is related directly to PD, or if it is caused by a different condition. Ancker et al. (2015) explained the hidden “illness work” people with multiple conditions incur when tracking. My findings suggest that this ‘work’ can be exacerbated through the variety of information PwP need to track, alongside disease characteristics such as comorbidity. For example, a PwP was experiencing very high blood pressure at specific times during the day which was initially attributed to hypertension. By self-tracking over a period of time, the PwP discovered that their Parkinson’s medication was the cause of this symptom. Mishra et al. (2019) have previously highlighted the importance of supporting PwP to disambiguate what constitutes a symptom through the design of self-tracking. My findings additionally show the need for designers to further consider the ambiguity introduced between what constitutes a Parkinson’s symptom (or side effect) and what may be part of another disease. Moreover, previous work has found that treatments plans for people with multiple conditions can create conflicts in self-management in cases where a disease symptom worsens the disease manifestation of a comorbid condition, or when medication for different conditions interact (Caldeira et al., 2020). Drawing on the findings, I argue that self-tracking could offer a potential strategy to disambiguate what the trigger is in these cases and what specific elements of the disease or the treatment are interconnected. Thus, self-tracking can facilitate sensemaking toward resolving these conflicts.

Moreover, PwP can require additional time to identify that a new symptom is persistent, as they need to distinguish between intraindividual variability and disease progression. In this study, *disease progression* created a gap in understanding, triggered by the often unpredictable and progressive nature of PD symptoms, in turn leading PwP to engage in a prolonged sensemaking period. For example, a PwP started to experience a new physical symptom, which created a gap in their understanding as there was not an obvious connection between the symptom manifestation and what triggered the new symptom. Moreover, disease progression disrupts the established self-management routine creating a gap in understanding as the long-lived treatment plan is not effective anymore. In summary, the triggers for the sensemaking mode in the context of PD are closely connected with comorbidity and the unpredictable, as well as progressive, nature of symptoms. This characteristic of PD sensemaking contrasts with diabetes where the opportune moments for sensemaking predominantly relate to tracking blood glucose, where low/high reading is the most common trigger of sensemaking (Mamykina, Smaldone, et al., 2015).

Although the sensemaking framework proposes that people enter the sensemaking mode once new information creates a gap in understanding, the present findings show that sensemaking was sometimes initiated even though there was no information gap to trigger this mode. This was because PwP recognized the degenerative nature of the condition and thus the need to continue identifying best practices for self-management that may improve their quality of life, such as treatment regime or lifestyle changes. This is in line with what has been found in relation to Multiple Sclerosis, another progressive neurodegenerative disease, which includes a range of physical and cognitive symptoms. Past work has shown how people with Multiple Sclerosis track to improve their quality of life and potentially even delay the disease progression (Ayobi, Marshall, Cox, et al., 2017).

Knowledge of the disease progression, therefore, acted as a constant trigger for PwP to seek out new routines. The non-linear nature of sensemaking suggests that technology designed to support self-management must be flexible and allow users to have different entry points into sensemaking. Moreover, given the social context of the OHC in which the posts of my dataset are originally shared, it is possible that PwP engage in information sharing with their community to inform the development of these new routines. Future work may want to explore if and how the community serves as a catalyst to a collective sensemaking whereby social interaction facilitates the individual approaches PwP take to their disease self-management.

Finally, in contrast to the framework which postulates sensemaking to be an action-orientated process, my findings showed that sensemaking was also awareness-orientated, particularly in the early stages of PD. This means that PwP track with the aim to build a conceptual understanding of their disease rather than to inform an action (Ancker et al., 2015), similar to ‘diagnostic’ tracking reported in past work (Rooksby et al., 2014). An exemplary case was a PwP who tracked a stream of their symptoms to understand the nature of the disease soon after diagnosis. A previous study shows that diseases with a high level of unpredictability can create the need for individuals to retain a sense of control throughout the course of the disease; and this, can be fostered through self-tracking (Schroeder et al., 2018). Similarly, the awareness-oriented approach to self-tracking and sensemaking observed in my study could derive from PwP’s need to address the uncertainty that comes with the diagnosis of a chronic and neurodegenerative disease, and thus the need to restore control.

As the findings demonstrate, self-awareness could foster an understanding of the disease and its different dimensions. In order to reach successful self-management, further research may seek to establish how self-tracking can support self-awareness for people with progressive diseases and complex symptom profiles throughout the course of the disease. In the context of Multiple Sclerosis, some supporting evidence from Ayobi et al. (2017) shows that self-awareness and self-management may operate synergistically. In their study, self-tracking was found to develop people's self-awareness, and also to support the individual in exploring how self-discovery could inform the adaptation of their current behaviour to their new circumstances. To this end, this study also showed that PwP tended to weave together the information they tracked in a self-reflective narrative, which enabled them to make sense of how the phenomena captured through self-tracking interacted. I, thus, argue that self-tracking technologies designed to facilitate this narrative aspect may be able to facilitate self-discovery during the sensemaking process.

Design Implications from Study I
Sensemaking could be facilitated through the design of technologies, which can track different domains and types of information that concern PwP.
Familiarity, access, and flexibility are the three proposed criteria for designers who wish to design PD self-tracking technologies.
Pre-configuration of information types and custom scales could provide motivation and scaffold for the tracking process of qualitative aspects of the disease.
Self-tracking technologies should include features that help PwP to disambiguate what the trigger of their disease manifestation is and what specific elements of the disease or the treatment are interconnected.
PD technologies designed to facilitate a narrative aspect in self-tracking may be able to facilitate self-discovery during the sensemaking process.

Table 4.5: Summary of Design Implications

4.5 Conclusion

Previous research on self-tracking technologies designed for Parkinson's has tended to take a clinically-oriented approach to improve the quality of clinical consultation, or outcomes. This approach predominantly investigates "pushed" self-tracking (Lupton, 2016), which consists of providing PwP with self-tracking technology to use for a period of time, as opposed to capturing the everyday ways in which PwP practice self-tracking. On the other hand, this study investigated self-tracking and sensemaking in the context of PD everyday experience. I found that PwP track a variety of information while choosing their self-tracking tools based three criteria: familiarity, access, and flexibility. Depending on PwP's self-tracking goal, the practice differs in terms of timespan and structure. Moreover, this study identified some particularities of PD sensemaking that derive from comorbidity, disease progression and self-management best practices. Finally, I discussed how self-tracking technologies can be designed to facilitate sensemaking, in order for PwP to be supported in two underrepresented dimensions of sensemaking: disease self-awareness and iterative self-experimentation.

Chapter 5: Study II – Investigating PD Self-tracking Beyond Self: A Social Sensemaking Approach

5.1 Introduction to Study II

Self-management of chronic conditions requires the individual's active engagement in their self-care activities, and as demonstrated in Study I, self-tracking and sensemaking of the data tracked becomes a critical way to engage in self-management. Nevertheless, as presented in Chapter 2, previous work shows that people cannot always make sense of their data independently and often, as a result, share it with others (O'Kane et al., 2016). In line with this, I adopt the lens of self-tracking as a social practice in this study. This lens can support a new understanding of how self-tracking is used in a social context.

As demonstrated in Chapter 2, when participating in an OHC, people share a range of personal information, including self-tracked information (Bussone et al., 2017) and engage in social sensemaking (Mamykina, Nakikj et al., 2015; Otiono et al., 2019; Patel, 2021). OHC is a critical context to examine social sensemaking and to understand the role of self-tracked data in this process. Specifically, in the context of PD, OHCs are part of PwPs' self-management as the disease's complexity and progressive nature mean that PwP need to "solve a puzzle" to create personalised self-management, which often mobilises them to participate in OHC (Nunes et al., 2018).

In this research, I adopt the definition of social sensemaking as "the back-and-forth negotiation of meaning" (Mamykina et al., 2015: 3220). Specifically, I investigate social sensemaking as created and situated in the micro-practices of interactions (Allard-Poesi, 2005) by studying online discussions where social constructions of meaning occur through written communication in the form of posts. This approach highlights that social sensemaking is a process shaped by the *interactions* within the social context and, underlines the importance of understanding how social sensemaking is mediated in the interaction micro-practices.

As argued in Chapter 2, unlike other diseases such as diabetes, PD, is underexplored in peer-to-peer social sensemaking. Therefore, in my effort to examine the role of self-tracking in social sensemaking, I first need to reify how social sensemaking happens among PwP in an OHC. It is important to explore this because if we better understand how people try to make sense of their disease together within an OHC, then we can better support PwP to make sense of their condition collaboratively and get help regarding data interpretation.

I conducted an empirical, qualitative study examining posts from the same OHC of Study I. Whereas Study I was concerned with investigating the cognitive aspect of PD self-tracking about disease self-management, and how people make sense of their self-tracked data individually, this study investigates how OHC serves as a catalyst to peer-to-peer disease sensemaking, and further, how sensemaking becomes a social practice in the context of PD self-management. Figure 5.1 visualises the intersection of the study's different elements and the focus of this research.

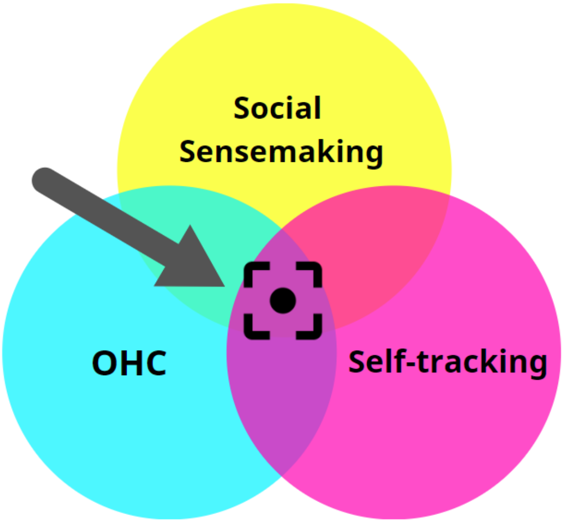

Figure 5. Focus of Study II

In summary, this study tries to answer the following question:

RQ4: What is the role of self-tracking in PwPs' peer-to-peer social interactions within the OHC, and how it contributes to social sensemaking?

By answering this question, Study II makes three contributions. First, it offers a descriptive account of social sensemaking among PwP within an OHC, and dissects the micro-practices of interactions, which enable the different dimensions of social sensemaking. This adds to the existing literature on social sensemaking by focusing on a less explored population. Second, this study presents a novel instantiation of using the social sensemaking approach as an analytical lens for PD self-tracking. Specifically, it depicts how PwP use social sensemaking to understand their PD and self-tracking data. Third, it reveals several design implications for self-tracking technologies and OHCs including:

i. the importance of expanding the current scope of self-tracking for self-management to support self-tracking as a social practice and account for PwPs' need to share their data with peers
ii. the need to build on existing communication practices and introduce features which facilitate the different dimensions of social sensemaking in OHCs
iii. the need for designers to explore ways of designing self-tracking technologies that can facilitate both individual and peer-to-peer social sensemaking.

5.2 Methodology

5.2.1 Research Context and Procedure

As explained in the previous section, I study the patterns of written interactions within an OHC to examine social sensemaking. I use an OHC as my research context to collect the data in this study. Specifically, my data come from the OHC Parkinson's Movement community embedded in the social network HealthUnlocked. This community is focused on PD, and it includes 14,431 members and 12,322 posts at the time of the data collection. PwP at different stages, as well as carers of PwP, participate. HealthUnlocked did not provide specific demographics of the community. In this study, I use the term community members to refer to PwP participating in the OHC. When reporting the findings, I use the convention – P(number) to indicate the individual PwP who posted a message. As explained in Chapter 3, Section 3.4, I selected this specific community as it was born from a partnership with the PwP-initiated charity 'The Cure Parkinson's Trust'. Based on this, I anticipated that it would yield rich data as its members would be actively engaged to some extent in their self-management and willing to share their experiences with other members. Finally, and similarly to Study I, while I acknowledge that carers are involved in the conversations, it is outside the scope of the study to examine how they contribute to social sensemaking and thus, their posts were excluded.

5.2.2 Data Collection

This study includes 65 relevant threads, averaging 58 posts per thread and 129 unique users. All replies, as well as the initial message, are individual posts that constitute the thread.

Now, I will describe how I identified this data. The data collection occurred in two stages. Firstly, the starting point of this study is the dataset of 405 anonymised posts published in the OHC Parkinson's Movement embedded on the HealthUnlocked website (see Chapter 4, Section 4.2.1 for details on how these data were collected). As stated in Chapter 1, PD self-tracking is the anchor point of this thesis, and subsequently, the field of interest for this research remains the same. Therefore, this framing guided the data collection, and it explains why the starting point of this study is a data set including only posts referring to PD self-tracking.

Starting from this dataset, I employed maximum variation sampling, a form of purposeful sampling (Patton, 1990). More specifically, maximum variation sampling aims to collect a wide range of cases to cover the spectrum of different dimensions of the phenomenon of interest, in my case, self-tracking (Given, 2008). In this research, this sampling approach was informed by what I learnt about PD self-tracking from Study I. PwP do not have a single self-tracking tool nor a standard set of preferred tools (see more in Chapter 4, Section 4.3.2). At the same time, they also track a wide variety of information depending on the disease manifestations (see more in Chapter 4, Section 4.3.1). Therefore, I included a range of posts reflecting the diversity of PD's self-tracking, a total of 100 posts.

Since my RQs aimed to understand the social sensemaking process in the context of a Parkinson's OHC, I examined "the back-and-forth negotiation of meaning", which is my working definition of social sensemaking. This could be observed at the level of the thread by investigating the relationship between different posts within the same discussion. An OHC thread is defined as an ongoing discussion of related messages that grow from one post and "consists of an initial message where a member starts a new discussion by asking a question, describing an experience, or requesting advice, and other members contribute by posting replies" (Smedley & Coulson, 2018:78).

To obtain the threads, I started from the post in my original dataset and then used a customised Google search to identify the entire thread. I ensured that the selected threads included only posts from people who had given consent to HealthUnlocked for their data to be used for research purposes (see Chapter 4, Section 4.2.1). To achieve this, I cross-referenced all the posts within these selected threads with the data corpus of 5000 posts provided by HealthUnlocked (see Chapter 4, Section 4.2.1 on how these were obtained). Posts made by community members who were not identified as part of the data corpus provided by HealthUnlocked were excluded.

In the initial stages of exploring the data, I identified that threads with multiple interactions aligned with my working definition of social sensemaking. Thus, I removed threads with fewer than five posts.

5.2.3 Analytic Approach

After defining the set of threads relevant to the study, the threads were uploaded to the qualitative analysis software NVivo. I subsequently started with a familiarisation stage recommended in qualitative thematic analysis by reading the whole data set several times (Braun & Clarke, 2006). Then, I read the threads repetitively in an active way (searching for meanings and patterns) to the extent that I became familiar with the depth and breadth of the content (Braun & Clarke, 2006). Familiarisation is important for “systematic and deep engagement, to develop a rich and complex account beyond the obvious meanings in the data” (Clarke & Braun, 2013).

During the familiarisation, I used the conceptual framework of social sensemaking (as presented in Chapter 2, Section 2.7) to “draw attention to important features of social interaction and provide guidelines for research in specific settings”(Bowen, 2006: 16). The different dimensions of social sensemaking (common ground, challenging ideas, and knowledge sharing), as identified in the framework, worked as sensitising concepts which “provided an analytic frame, serving as a point of reference and a guide in the analysis of data” (Bowen, 2006: 15). This way of working provided a framework for analysing empirical data and helped me to better understand the social phenomenon.

To answer my research question, three types of analysis were conducted (Table 5.1). For the RQ4 “How does social sensemaking happen in the context of a Parkinson’s OHC?”, I used a combined technique of deductive and inductive coding (Fereday & Muir-Cochrane, 2006). Initially, I conducted a deductive thematic analysis using the aforementioned conceptual framework of social sensemaking to create initial codes aligning with the framework’s three dimensions: common ground, challenging ideas, and knowledge sharing. I then examined the data for evidence of these pre-determined codes using them as a pre-existing coding frame (deductive analysis). If I diagnosed that the sensemaking process expressed in a thread did not align with the codebook, I created new codes and incorporated them into the coding scheme (inductive analysis). This analytical process continued until no new codes were yielded. This combined deductive and inductive analysis was necessary to ensure that the conceptual framework captured all the themes. The analysis was iterative and reflexive since the selection and application of the framework were revised and updated to fit the data (Chambliss & Schutt, 2013).

Next, I iteratively analysed the entire dataset inductively to capture the micro-practices of interactions and created codes describing how social sensemaking happens at the interaction level. For example, I created the code “validation of experience” to describe when a community member validated somebody else’s experience or previously shared information. The unit of analysis was the thread. The coding was carried out iteratively, with initial codes generated broadly and then organised to search for and generate themes.

Phase	Type of analysis	Reported in section
1st Phase	Deductive & Inductive Analysis	5.3
2nd Phase	Inductive Analysis	5.3
3rd Phase	Inductive & Deductive Analysis	5.4

Table 5.1: Analytic Approach

Reflecting my interest in exploring how self-tracking mediates social sensemaking and how it contributes to the different social sensemaking dimensions, I ultimately wanted to answer "What is the role of self-tracking in PwPs' peer-to-peer interactions within the OHC, and how does it contribute to social sensemaking?". Though the unit of analysis was maintained as the thread, this time, the focus was the instances of self-tracking and their role in the sensemaking process. I employed a deductive thematic analysis using the codes from the previous phase as predefined codes to identify how self-tracking contributes to the different dimensions of social sensemaking. If I identified that the interaction in the event did not align with a pre-existing code, I created new codes and incorporated them into the coding scheme (inductive analysis).

Notably, as it is essential to establish the trustworthiness of the coding process, the literature suggests that having several people involved in the coding process is one way to achieve this (Skjott et al., 2019). Following this best practice in coding, I initially identified meaningful units of discourse in the threads and assigned them codes. This was followed by collaborative coding during the supervision meetings. In the latter, my supervisors and I discussed the development of the themes related to the data and whether the meaning conveyed in the threads was interpreted accurately. This collaborative process aimed to provide a sound interpretation of data in response to the challenge of managing subjectivities when analysing qualitative data. I kept iteratively reworking the theme and codes in discussion with my supervisors until the coding scheme was finalised. As Campbell et al. (2013) explain, this approach is especially useful for situations where a single knowledgeable coder will code all the data once the coding scheme has been established.

5.3 Findings

One overarching finding from the data was that PwP who engage in social sensemaking have three different approaches to their self-management. There were PwP who took a medicinal approach, others focusing more on lifestyle adjustments, including nutrition and exercise, and lastly, PwP who were willing to try anything. PwPs’ self-management approach informed how they engaged in social sensemaking and the type of information they shared.

It should also be noted that similarly to what has been observed in other OHCs (Papoutsaki et al., 2021), some of the information shared by community members did not always seem to align with the established clinical treatment and PD clinical understanding. However, it was out of the scope of my expertise to evaluate the clinical validity of the community members' discussions, for example, around the use of alternative treatments. Instead, I focused on examining the social sensemaking process and how different interaction micro-practices enact the different dimensions.

5.3.1 Social Sensemaking in the Context of a Parkinson’s OHC

This section presents how social sensemaking happens in the context of a Parkinson’s OHC. Overall, my findings align with the conceptual framework of social sensemaking, initially presented in Section 2.7, capturing the three dimensions (common ground, challenging ideas, and knowledge sharing) of social sensemaking but also unearthing a fourth one, namely, transforming ideas. I also describe which interaction micro-practices facilitate each social sensemaking dimension in this section. The summary of codes is presented in Table 5.2.

Codes	**Social sensemaking dimensions**	**Interaction micro-practices**
	Establishing common ground	Finding the point of connection
		Disambiguating communication
	Challenging ideas	Questioning of information shared
		Expressing justified disagreement
	Transforming ideas	Reframing the problem
		Building on others’ ideas
	Knowledge Sharing	Sharing different types of knowledge
		Interrelated social sensemaking dimensions

Table 5.2: Summary of codes for Social Sensemaking in PD

a) Establishing Common Ground

As argued in Section 5.1, I define social sensemaking as “the back-and-forth negotiation of meaning” (Mamykina et al., 2015: 317). The analysis showed that sometimes common ground was established at the starting point of this negotiation of meaning, while in other instances, it occurred later in the discussion. In the first case, common ground was based on pre-existing ideas or experiences and initiated the back-and-forth negotiation of meaning. In the latter, it took several back-and-forth for common ground to be established in online communication. For example, the latter happened when a community member embraced another member’s way of reasoning at a later point in the conversation regarding why they were experiencing a particular symptom, as the following quote exemplifies: *“You are right! That's the word: agitation. And that's why the tremor intensified.”* (P10).

In their pursuit of making sense of the disease, community members established common ground by finding points of connection in their experiences and ways of reasoning. This included shared experiences regarding how their symptoms manifested, what treatment they were getting, and/or how they responded to medication. For example, a community member identified that their medication was off at the same time every day, creating a gap in their understanding. This post triggered a shared experience with another member:

> (P20 – Initial Post): “*Why do I fall apart at the same time every day? Almost every day, I get depressed, and my meds don't work or work poorly. It was at night, about 5 or 7 pm, but it has moved to mid-afternoon. I still take my meds at the same time as always. It will last for an hour or two. Does this happen to you?”*
>
> (P17 – Response): “*Yes, it used to be around noon'ish, now it's 4'ish*.”

This was also observed when a PwP created inferences to explain a situation, including why a symptom/side effect or a medication was not working, and another community member validated their assumption. For example, a PwP was confused about getting cramps, and other community members were trying to explain why this was happening. There was common ground in how this can be addressed through self-management.

> (P62 – Initial Post)*: “Also, look into the calcium/magnesium balance. If you get huge calcium pills and not enough magnesium, you can get cramps.”*
>
> (P61 – Response): *“You are correct [name]; I strongly believe that PD is related to magnesium and Folic acid deficiency. Please take foods rich in magnesium and folic acid. Regards…”*

Establishing common ground was important in social sensemaking as PwP have individual differences in disease manifestation, side effects, treatment efficiency and/or comorbidities, which can cause a high level of ambiguity. This ambiguity created gaps in their understanding of the disease, as it was often not clear what part of their experience was attributed to PD, what was "normal" about PD progression or why something was not working as it was expected. For example, a member of the community asked for social support as their symptom manifestation had significantly and suddenly worsened, but they could not understand what had triggered this:

"*My tremors have increased and are now on my right side as well. Sometimes, my whole body - head to legs shakes. I'm just looking for input or something if anyone can. Are my PD symptoms advancing, or is this something else? I didn't know who else to ask while my PD Dr. is away. Any input is appreciated"* (P63).

In this context, community members tried to tackle this by making sense together of what was happening through collaborative and ongoing efforts to find points of connection, aligning their perspectives and attending to the (often embodied) complexities of the disease. To this end, community members validated somebody else's experience by replying that they had also shared a similar experience, or alternatively, they confirmed that this was a common or known experience in PD. The following quote shows an example of a PwP experiencing a side effect from a common PD medication and another member validating their experience by confirming they had the same side effects:

(P56 – Initial Post): *"When I tried to take Sinemet last month, I got very high blood pressure spikes about once a day. Has anyone else experienced this?"*

(P69 – Response): *"Interesting. I have been on Sinemet for about eight years and have been dealing with uncontrollable high BP spikes for quite a while. My neuro has never said the meds may be the culprit. Thanks, I will look into this."*

Disambiguating Parkinson's

Ambiguity comes from PD intervariability as PD symptoms manifest differently to every PwP. Consequently, community members conceptualised the disease in varied ways or used the language differently to describe their disease experience. Hence, it was important for community members to *disambiguate* what other members meant when they used related concepts, practices, and metrics to describe PD. For example, a PwP was asked to rate their PD before they started a new alternative treatment called Ibogaine. However, the community member did not understand how others expected them to rate their PD, as the following quotes show:

(P60 – Initial Post): *"On a scale of 0-10, how much was your general condition score before starting Ibogaine and how much is now? 0 worst and 10 best."*

(P5 – Response): *"Scoring is difficult. I don't know what 10 represents. Is it as bad as I have experienced, or is it as bad as I think it might be?"*

As community members exchanged experiences and self-management practices by commenting on each other's posts, they helped each other realise that they might not have optimally approached their self-management or communicated their self-management activity very accurately. For example, a PwP reported a dosage that did not make sense to other community members, and they identified it as an issue. The initial poster admitted that this was a mistake in reporting their medication regime, and they subsequently aligned with the information shared by fellow members, as the following quotes show:

(P4 – Initial Post): *"That's not really Dr. Costantini's protocol at 8 grams/day. From what he has told me, that dose could potentially worsen symptoms in some PWPs!"*

(P9 – Response): "*I'm sorry, I goofed... I took 4 grams a day (8 tablets each with 500 mg Thiamine HCL. I dropped to 6, or 3 grams this last week because it just seemed to permeate my body, urine, etc*."

b) Challenging ideas

The findings showed that community members did not always agree with each other regarding the best way of managing or making sense of the disease. Previous research has found that the diversity of opinions, experiences, and approaches can result from the complex and multifaceted disease character (Gopalakrishnan & Alexander, 2015). The diversity of experiences contributed to people having different conceptualisations of the disease and different self-management approaches, sometimes leading to people challenging each other's perspectives and ways of reasoning. However, this diversity has also been found to contribute to the social sensemaking process (Mamykina et al., 2015).To this end, the study findings showed that communicating different ideas and opinions allowed members to explain their reasoning and present a counterargument. At the interaction level, challenging each other's ideas was achieved by firstly questioning the information shared, and secondly expressing justified disagreement. It should be mentioned that some of the information shared can be considered.

Questioning of Information Shared

More specifically, different perspectives were shared regarding a problem which had triggered a gap in disease understanding. Then, community members tried to make sense of the situation together while questioning each other's ideas by examining the soundness and rigour of the shared information. For example, they initially shared how they struggled with medication efficiency, and a community member suggested focusing on exercise and fast walking to get better results with their symptoms. However, another PwP questioned the information shared:

> (P66 – Initial Post): *"Hi [name]. Take comfort from what I am about to tell you.*
> *1. There is no medication on the market that does anything to slow down the progression of PD. Why is this comforting? It means that you are looking in the wrong place to do something to help you with your PD.*
> *2. The only way I know to reverse the symptoms of PD is to start doing Fast Walking. Why? Because fast walking has been proven to reverse the symptoms of PD. See this - bu.edu/neurorehab/files/201..."*
>
> (P40 – Response): *"[Name], you are still using an old 2008 reference; surely, if you are right about your claims for fast walking, we can see something more recent. It does not say fast walking has been proven to reverse the symptoms of PD. It does say: The findings SUGGEST the dose-dependent benefits of exercise and that HIGH-INTENSITY exercise can normalise corticomotor excitability in EARLY PD."*

Expressing Justified Disagreement

Moreover, community members directly challenged others' beliefs, ideas and information shared by expressing their disagreement. Such interactions advanced the social sensemaking process when members justified their disagreement with the initial statement and provided evidence for their counterargument. Evidence was provided in the form of accredited sources backing up their point (e.g., a scientific article or a website from an accredited organisation), or it was a concrete example based on their experiential knowledge. As a community member put it, experiential knowledge is also a valid form of evidence: "*I want evidence; it doesn't have to be rigorous scientific experiments but people's experience" (P40).* The following post exemplifies a disagreement regarding the efficiency of cycling in alleviating PD symptoms:

> (P66 – Initial Post): *"Cycling is gooooood exercise, but because it is not weight-bearing, it does not do much for the PD. But if that's what you want to do, then do it and enjoy!"*
>
> (P12 – Response): *"[Name], that is just not true that cycling doesn't work. Fast-paced cycling (80-90 rpm) at least three times per week has shown through research at the Cleveland Clinic and*

elsewhere to reduce PD symptoms by an average of 35% after just eight weeks. I do much more than that and have almost no symptoms after nine years. I'm 71 and finished my sixth ride across Iowa last July. Walking at a good clip is good, but it's not the only thing that works."

These interactions were inherently different to disagreeing with someone's opinion and challenging their perspective without evidence, which did not facilitate social sensemaking as the following quote shows: "*No response required, I am not looking to argue over your pill taking, that is just another diversion*" (P40). An evidence-based approach to communication in the OHC is thus essential as it is a form of fact-checking that can potentially prevent wrong information from being shared or mislead community members.

c) Transforming Ideas

Findings showed that community members did not always directly disagree with each other, as presented above. Instead, they introduced a new element not previously considered, taking the conversation in a different direction or using a previous post as a conceptual base to extend a previously shared idea. At the interaction level, this social sensemaking dimension was achieved by firstly reframing the problem and secondly building on other's ideas.

Reframing the Problem

By presenting a new idea PwP are able to *reframe the problem* and ultimately transform the initial idea. For example, a PwP shared that they had been diagnosed with diabetes because of the medications they received. Then, a fellow community member questioned whether the blood glucose levels were in fact elevated by the PD drugs, making a distinction between two different possible phenomena that might be occurring:

(P4 – Initial Post): *"I am wondering if anyone else is taking Madopar and have been told that they are now Diabetic. Apparently, the drug can alter blood glucose levels, but how much I am unable to find out."*

(P13 – Response): *"I would like to ask whether your ACTUAL blood glucose levels are up or whether it affects the readings? Surely, if it affects the readings, then it may be giving a false positive result for diabetes, and then people may be treated for something they do not have. On the other hand, if it is actually triggering diabetes, then that is a whole other issue, and doctors ought to be aware of it."*

Building on Others' Ideas

The findings, moreover, suggest that the transformation of ideas also happened as community members built on each other's ideas. More specifically, when community members used previous posts as a conceptual base and added a new element to the discussion, this reconfigured the initial idea. For example, a PwP shared their problem with the conflicting times of their medication regimen and the meal timings in their care home. A fellow community member identified two different variables as problematic: the meal's content and the intake of laxatives (a type of medicine to treat constipation). Next, another PwP built on this comment to argue for the importance of calculating the levodopa intake, as the following quotes show:

(P25 – Initial Post): *"I take one 50/200 CR plus one half of 25/100 IR every 4 hours. Also, amantadine, 100 mg twice per day. Also, 10 mg methylphenidate once per day. The CR + IR at 2,6,10 am and 2,6,10 pm. I am still in a rehab facility wherein PD meds and meal-served times are almost always in conflict. 7.45 am and 11.45 am are the most effective times for breakfast and lunch. Each time is midway between two times for Sinemet cr + ir. Well-timed food servings are rare in the large rehab facility. Alternative dose patterns would be appreciated."*

(P27 – Response): "…*The half-life of CR is higher than 4 hours, so it must be adding up during your day (my neuro says one tablet every 12 hours). At that dose, CR sounds sensible if it avoids dyskinesia, but you must be getting a high when the CR starts adding up. It will be distorted by what you eat - maybe try to avoid milk as that competes. Just a thought - if you are on laxatives (standard nursing procedure!), then you may have a quickened transit time in your gut (gastric hurry), which is not good for slow absorption meds…"*

d) Knowledge Sharing

The findings showed that community members recognised the importance of knowledge sharing and invited others to share their knowledge regarding a specific topic. PwP with less experience and PwP who experimented more with their self-management practices were the two sub-groups of community members who usually asked for others' contributions more often. For example, a recently diagnosed PwP wanted to experiment with Mucuna Pruriens, i.e., a tropical legume used by PwP as an alternative supplement to traditional drugs and invited others to share their treatment protocols: "*I'm new to the forum and was diagnosed in September. I'd like to know if anyone has experienced taking the powdered form of mucuna, what your daily dosage is and what supplement you're taking with it* "(P111). At the interaction level, knowledge sharing is achieved by sharing firstly different types of knowledge, and secondly interrelating different social sensemaking dimensions.

Sharing Different Types of Knowledge

Notably, there was not a single type of knowledge that PwP shared. Knowledge sharing in the OHC addressed the issue of not all PwP having access to relevant scientific, clinical, and experiential knowledge. In sharing knowledge, community members often provided **information coming from experts.** This included healthcare professionals, such as doctors or nurses, and resources from the academic community, such as journal articles. For example, a PwP asked about spikes in blood pressure, and a community member shared a tip from the PD nurse regarding the issue: *"A nurse told me to drink more water. Two glasses before getting out of bed"* (P32).

While expert knowledge was mainly based on scientific and clinical sources, community members also shared their **experiential knowledge,** including self-management practices that led to a desired outcome and practices that did not improve or alleviate their current disease manifestation. In doing this, they sometimes reshared previous post-reports from other members as valid experiential knowledge. For example, there was a thread focused on thiamine where community members tried to identify ways of maximising the benefits of this supplement[9]. In the following example, a PwP highlighted a post which another member shared in an earlier thread: *"There's a protocol that a member of this site worked out that works well for some folks. I use it. So far, so good. Here's the link to the post, you have to scroll down to see [name] protocol..." (P123).*

Interrelated social sensemaking dimensions

Knowledge sharing supported common ground, transforming, and challenging ideas. For example, when community members established common ground by validating each other's experience, they usually shared their experiential knowledge. Thus, it becomes apparent that the different social sensemaking dimensions are not always discrete but interrelated. The following interactions show how PwP dealt with problem issues, established common ground, and shared their experiential knowledge on coping strategies.

(P71 – Initial Post): *"I'm having MAJOR sleep issues. I'm currently taking 75 mg of Amitriptyline and 75 mg of Neurotin."*

(P56 – Response): *"I found a mixture of meds that work for me with my special issues. At bedtime, I take Klonopin (restless legs), Mirabegron (incontinence), CataplexG (B vitamin - relaxation), and Melatonin (sleep). This combo has helped me sleep for every night for the past few years."*

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[9] Thiamine or Vitamin B1 is an over-the-counter dietary supplement. No research studies have proven so far that this supplement can treat PD but some PwP keen to try it anyway. https://www.michaeljfox.org/news/thiamine-vitamin-b1-and-parkinsons

Moreover, when challenging each other's idea, this often involved knowledge sharing as PwP provided scientific or experiential knowledge as evidence to support their counterargument, as the following quotes show:

> (P2 – Initial Post): *"Based on my personal research, I have developed an action plan for myself. Follow along if you want to, but beware, I am not a physician. I welcome any input from my friends up here. I'm not putting down the doses; this will vary based on numerous factors such as body mass, severity of disease, how crazy you are, etc..."*
>
> (P56 – Response)*: "I would also be concerned about vitamin E - there is a lot of controversy about its supplementation - some studies show that it might be increasing inflammatory cytokines in some genotypes:*
> *"In healthy control subjects, the effect of α-tocopherol supplementation on the production of inflammatory cytokines appears to be dependent on an individual's genotype. These genotype-specific differences may help explain some of the discordant results in studies that used vitamin E."ncbi.nlm.nih.gov/pubmed/225..."*

5.3.2 Self-tracking Enacts Social Sensemaking

Next, I describe the different ways that members use self-tracking in their online interactions and how sharing self-tracked information contributed to the different dimensions of social sensemaking, establishing common ground, challenging ideas, transforming ideas, and knowledge sharing. I identified four themes which showed how self-tracking contributes to social sensemaking: a) being the point of connection, b) promoting an evidence-based approach, c) facilitating problem reframing, and d) underpinning experiential knowledge. Table 5.2 summarises the codes used to answer RQ4.

	Social sensemaking dimensions	**Interaction micro-practices**	**Role of self-tracking in social sensemaking**
Codes	Establishing common ground	Being the point of connection	Shared self-management practice
			Shared sensemaking practice of disease manifestation
			Shared experimentation practice
	Challenging ideas	Promoting an evidence-based approach	Evaluating the self-tracking practice
			Evaluating self-tracking findings
	Transforming ideas		Reconfiguring self-tracking

		Facilitating problem reframing	Self-tracking as a proposed solution
	Knowledge Sharing	Underpinning experiential knowledge	Supporting others’ self-tracking efforts
			Raising Awareness for self-tracking
			Contributing to collective experiments

Table 5.3: Summary of codes for RQ4

Self-tracking as a Point of Connection

As described in Section 5.3.1, common ground was fostered despite the different disease trajectories and interpersonal variabilities in community members’ disease manifestation. This was accomplished by identifying points of connection in their experiences and ways of reasoning. Findings show that self-tracking became the point of connection as a shared practice when two or more PwP realised they used self-tracking as a self-management practice. It also functioned as a point of connection in PwPs’ reasoning when PwP shared self-tracking as a practice to make sense of disease manifestation or to experiment with similar lifestyle and treatment options.

Many PwP used self-tracking as an approach to their day-to-day self-management which helped them follow a specific regime, including treatment, diet, exercise, hydration, etc. Despite their different regimes, some PwP established common ground through sharing information about their self-tracking as a way of self-management. For example, one PwP who tracked their medication and mealtimes shared how the non-adherence to specific meal timings can affect the efficiency of their medication. In response, another community member also shared their self-tracking reporting how they track their response to medication about food intake:

> (P25 – Initial Post*):* *“I take one 50/200 CR plus one-half of 25/100 IR every 4 hours. Also, amantadine, 100 mg twice per day. Also, 10 mg methylphenidate once per day. The CR + IR at 2,6,10 am and 2,6,10 pm. I am still in a rehab facility wherein PD meds and meal-served times are almost always in conflict. 7.45 am and 11.45 am are the most effective times for breakfast and lunch. Each time is midway between two times for Sinemet CR + IR.”*
>
> (P39 – Response*): “I take one 25/100 IR and one 25/100 ER four times a day at 6,10, 2, and 6. I try to eat 30 minutes to an hour after my doses. If I am in a meeting and cannot eat at 11 or so, my 2 pm doesn't work well most of the time.”*

Notably, establishing common ground through self-tracking sometimes extended the benefits for social sensemaking to other community members who did not actually track themselves but had the opportunity to identify the role of self-tracking in PD self-management. For example, another member of the community who contributed to the thread presented above, did not self-track but acknowledged the role of self-tracking in self-management by embracing the other members' ideas: "*I find it interesting that you all are so in tune with what causes what and how you are able to remain so focused on your regiment of drugs and lifestyle, especially you [name].*" (P16).

Findings also show that self-tracking was not only a shared practice in maintaining their routine but a point of connection in their reasoning. Specifically, PwP established common ground by tracking their symptoms to make sense of their disease manifestation. Furthermore, PwP who tracked their symptoms found points of connection in their experiences. The example below shows that a PwP tracked their tremor every morning, and then another community member validated their experience by confirming they had identified the same symptom.

(P55 – Initial Post): "*How is your tremor first thing in the morning? Mine is a lot less if I test it as soon as I wake up, and I'm still groggy. I recently posted about 20 days ago that my tremor disappeared, and I stopped doing everything and was trying to test things one by one. It was gone for about 2 weeks. It has come back, and I'm still trying to identify what it was. My best guess is that I was being more consistent with over 1 hour per day exercise.*"

(P74 – Response): *"I have the same symptoms you posted. Curious to know how you're now doing? Most of my problems seem to have been low iron causing low oxygen, which I can see with a $15 pulse oximeter."*

Furthermore, PwP used self-tracking to employ a form of lay research and as part of their self-experimentation efforts to identify which lifestyle choices and treatment options provided desired outcomes and to what extent. It should be mentioned that some PwP were willing to do experiments which did not conform to clinical guidelines. When PwP established common ground by sharing and comparing their experiments, self-tracking of these experiments often became a collaborative practice suggesting "a form of science developed and enacted by the citizens themselves" (Irwin, 2002). The example below illustrates how two PwP compared their experiential knowledge from experimenting with Mucuna Pruriens:

(P124 – Initial Post*)*: *"Interesting!!!. I have been taking Kapikachu (Indian Mucana) from Vaidyaratnam, Kerala, INDIA, since 2012, but max ON time I have been able to get is only 3.5 Hrs, generally average 2.5 Hrs full ON time… If you are getting 7 Hrs ON time, it's really great!!! Please let me know in detail how do you take??"*

(P72 – Response): *"I'm sure the difference lies in the amount of l-dopa in what you are buying versus what I am buying. Also, the eighth of a teaspoon that I have been using weight is roughly .36 grams so 3/8 is almost 1.1gram."*

Self-tracking as an Evidence-based Approach to Experiential Knowledge

As described in Section 5.2.2, when PwP made sense together of their condition within the OHC, they didn't always agree with each other but instead challenged each other's ideas. This happened by questioning previously shared information or by expressing a justified disagreement. Community members promoted a form of fact-checking by sharing their self-tracking practices with others and reporting findings from their experiments within the OHC. They tried to enhance an evidence-based approach when experiential knowledge and lay experiments were shared.

Within the OHC, PwP reported self-tracking practices to understand and monitor disease manifestation and self-experimentation. The experiments were intended to test different treatment options and lifestyle changes. This involved first determining a hypothesis about a limited number of variables and a specific cause-and-effect relationship between them. Social sensemaking often included community members questioning how fellow PwP performed experiments, and in particularly, the rigour of these experiments. Being rigorous meant being systematic about what was tracked, how they collected the information, and how long PwP tracked specified variables that measured their suspected cause and effect. Community members looked for this information to understand how a specific hypothesis was formed and confirmed and, furthermore, whether the reported findings from their self-experimentation were valid. Thus, challenging ideas took the form of evaluating lay practices of self-tracking.

For example, a PwP shared their experiment with ibogaine and reported reduced symptoms. In reply to this post, a fellow PwP questioned how long they were doing this experiment, which achieved the desired outcome of reduced symptoms. The excerpt below shows the interaction:

(P92 – Initial Post): "*I had a permanent reduction of symptoms after I completed a micro dose course. I am going to start another micro dose course to see if I can achieve another reduction of symptoms next month*."

(P5 – Response): *"I actually meant, how LONG were you taking it for? Like, was it a couple of months before you saw this "permanent" change in symptoms? Or shorter/longer?"*

Self-tracking facilitates Problem-reframing

As presented in Section 5.1.3, findings showed that community members did not always directly disagree with other PwP, but instead reframed the initial idea. This happened in two ways: introducing a new element in the conversation that was not previously considered or using a previous post as a conceptual base to extend an idea. Sharing self-tracking practices and its findings sparked the social sensemaking process among PwP, often inviting other PwP to expand the initial idea shared. More specifically, community members often shared the details of their self-tracking practice and the findings from their practice that had sparked a gap in their understanding. Based on this sharing, community members could see how the PwP had reasoned interpreted the information, further enabling the reframing of the initial enquiry of the post.

In the following example, a PwP began a thread sharing with the OHC a surprising outcome of tracking their food and its relation to their disease manifestation. The original poster could not explain the link between their unhealthy eating and reduced symptom manifestation. They were evidencing a gap in their understanding. Sharing their self-tracking with the community instigated social sensemaking and ultimately allowed others to redefine the initial idea. More specifically, a PwP reframed the initial hypothesis that healthy food should aggravate the disease manifestation and introduced a new variable important in forming a cause-and-effect hypothesis. Specifically, the PwP implied that stress is triggered by trying to maintain a rigid, healthy diet and the disease manifestation.

(P21 – Initial Post): *"…Two days ago, I got down in the dumps and fell off the wagon and had two days of comfort eating (most of it secretly away from the family) …I give myself a grade in a PD diary each day, dependent on symptoms, to record 'progress' (1 being awful and five being the best). Well, I haven't had 5 for ages, until I went on my junk food bender. Funny, ridiculous, unpredictable and frustrating. What a disease this is*!"

(P125 – Response): *"I think it shows just how much a decrease in stress can benefit us!"*

PwP sometimes created a new inference that bridged their initial understanding gap, but they sometimes could still not restore their routine action about PD self-management. Community members could often help them with alternatives by *reframing the initial problem* and helping them to restore action through self-tracking. For example, a PwP had a problem with their medication efficiency (gap in understanding), and they identified the problem of protein interfering with their medication (inference). However, they found it difficult to cut off protein from their diet (difficulty in restoring action). Based on their experiential knowledge, a fellow PwP reframed the problem of the protein intake about their self-management; it is not about cutting off the protein but instead monitoring the timings of the protein intake. This is shown in the following interaction:

(P29 – Initial Post): *"I know about food containing protein blocking the absorption of Sinemet, but I seem to have a high degree of need for protein in my diet. How should I best manage this problem? Protein does interfere with my Sinemet, but I have tried just eating vegetables and fruit during the day, but it does not hold me, and I get weak from not having protein. Catch 22, I know!"*

(P22 – Response): *"My suggestion is to get a Pebble watch or schedule your iPhone or Smart Phone alarms (to alert you to take a pill) at times that don't overlap these boundaries. I take Sinemet at 6 a.m., 2 p.m., and 10 p.m. at night and eat plenty of protein at meals at 7, noon and 7 p.m."*

Self-tracking underpins experiential knowledge

As presented in 5.3.1, knowledge sharing was the heart of social sensemaking and included different types of knowledge, such as clinical, scientific, and experiential. Self-tracking is predominantly associated with experiential knowledge. Findings show that community members invited other members' contributions of experiential knowledge, and self-tracking was mainly introduced as part of two topics: PD daily self-management and self-experimentation.

In the first case, PwP dealt with lots of ambiguity regarding their self-management, and this was a common trigger for social sensemaking. As shown in Chapter 4, self-tracking is among the issues that cause ambiguity, as it is not a well-defined and clearly structured activity in PD self-management. While it was acknowledged that self-tracking is a recommended practice by health professionals, it was still hard to figure out what to track, when and how. For example, a PwP complained about the number of factors that affect PD: *"I just can't seem to get a handle on it, there are just too many variables that come into play" (P16);* while another community member was looking for a better tool that would help them track: *"Anyone knows of alarm watches that would meet these requirements?"* (P22).

To this end, PwP often shared their experiential knowledge on the self-tracking practice to help others on how to do it but also bring awareness on the importance of self-tracking as part of self-management in general. For example, when a community member complained about issues with their blood pressure, another PwP stressed the importance of tracking this health indicator: "*PD progressions are unannounced and often overlooked. Take your pressure frequently and at different times of the day. Even a "normie" has many fluctuations. The key is learning when and attributing it to why or what." (P128)*. The community also shared their experiential knowledge which derived from the self-tracking practice, showcasing what one could learn from self-tracking. For example, a PwP shared what they learned from tracking their sleep:

"*I have used smart alarmHD on my iPad. It is a useful tool to assess how much sleep and the types of sleep you are getting. There are shortcomings, but I found it interesting to see the unusual sleep cycles I have, and also to listen to the recording of noises I made during the night*" (P124).

In the second case, it was common practice for community members to experiment, trying new treatments and lifestyle alterations to alleviate symptom manifestation. Whereas earlier I showed that sharing their self-experimentation led to challenging the rigour of the practice, community members valued other PwPs' tracking of self-experimentation as it was the primary way to construct knowledge together: "*The more people who do their own research on this topic and report back, we may eventually get to some modicum of truth*" (P4). Sharing the experiential knowledge from self-tracking and self-experimentation gave a sense of credibility to the individual experience. A PwP explained why they value experiential knowledge in the following quote: "*Although scientific assessments are the ultimate, I find it stimulating to read others' experiences and try the most promising out myself"* (P41).

As PwP shared their experiential knowledge of different treatment protocols, more community members were motivated to change their disease management and optimise their treatment and lifestyle. For example, a community member was motivated by others' reporting of experiments and started their experiment: "*I just received my first dose of ibogaine HCL and am ready to embark on a trial micro-dosing over the next few weeks. I will keep you updated on my progress here!"(P122)*. Furthermore, by tracking their experiments and sharing their findings, PwP could contribute to collective experiments, findings comparisons, and ultimately validation of treatment options. For example, a PwP shared their experiment with ibogaine[10] and asked other members with a similar experience to input so they could compare notes. Other PwP also joined this collective endeavour:

(P5 – Initial Post): *"I started a low-dose regime of ibogaine a few days ago, and the results are remarkable in just a few days. My neurologist is aware that I am doing this and was supportive. I wondered if anyone else is trying it (or has tried it). I was hoping to compare notes. I am taking two 20 mg doses per day (approximate because of the difficulties in accurately measuring such a small dose)."*

(P90 – Response): *"Yes, I resumed taking ibogaine around the first of May. I'm taking 20mg twice daily, and the results are good, better than before. I'm not sure why the ibogaine HCL I have now seems more potent than I had before. It may be more pure, or it could be just the cumulative effect (more neurons)…."*

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[10] Ibogaine (12-methoxyibogamine, NIH 10567, Endabuse) is one of the psychoactive indole alkaloids found in the West African shrub, Tabernanthe iboga (Popik & Skolnick, 1999). No scientific research has yet established positive outcomes for PD symptoms.

Notably, PwP kept reporting back to the community throughout their experiments. For example, a PwP kept updating the community about how they tracked their progress during the experiment:

“*Improvement has either plateaued or is too slow to be noticed. I am going to try to come up with a set of tasks or measures to make weekly comparisons to find out which it is, a plateau or incrementally slow*.” (P5).

To summarize, I have demonstrated the different dimensions of social sensemaking, how the interaction micro-practices mediate the social sensemaking process, and lastly how self-tracking contributes to the different dimensions of sensemaking.

5.4 Discussion

5.4.1 Social Sensemaking in a Parkinson’s OHC

Building on previous work that has shown that OHCs are social sensemaking spaces where people with chronic conditions engage in collaborative practices around their health (e.g., Kane et al., 2016; Mamykina et al., 2015; Mamykina, Nakikj, et al. 2015; Papoutsaki et al., 2021), this study contributes a new analytical lens for viewing PD self-tracking in the context of self-management. It lays the foundation for new directions for the design of Parkinson’s OHCs and self-tracking technologies, which I will present below. I identified the different dimensions of social sensemaking, echoing findings from other chronic conditions, and further described how social sensemaking happens through PwPs’ interaction micro-practices in the context of a Parkinson’s OHC.

Firstly, findings suggested that PwP actively engaged in social sensemaking regarding a diversity of health information, including their individual symptoms, lifestyle choices, treatment options, and the overall character of the disease. The progressive and complex nature of the disease and the high interpersonal variability in disease manifestation and treatment response often created a gap in PwPs’ sensemaking regarding the nature of the disease and how to approach their self-management. The findings also showed that PwP sought others with similar experiences and got validation regarding their experience, which helped them establish a common understanding of what experiences were part of living with PD. Furthermore, due to the progressive nature of PD as well as interpersonal differences, social sensemaking was often operationalised through symptom or treatment **benchmarking,** which helped PwP understand what was “normal” in a given situation. This is in line with previous work, which has shown that people develop a common understanding of their disease self-management through sharing and aligning their personal histories and opinions (Huh & Ackerman, 2012). It also confirms the importance of common ground when people seek validation in the “normalisation” of their experience (O’Kane et al., 2016).

Moreover, the findings showed that communicating different ideas and opinions allowed members to explain their reasoning and present a counterargument. To achieve this, they employed an evidence-based approach. Specifically, community members challenged each other and evaluated the soundness of the information shared. For example, supported by a scientific article, a PwP recommended fast-walking to reduce symptoms, while another community member challenged this idea by checking the resources shared. Challenging each other’s ideas and promoting an evidence-based approach has proven to be important because OHCs are places where harmful advice or unproven interventions can spread (e.g., Níet al., 2022). Moving forward, this theoretical understanding of social sensemaking can guide designers to build on existing interaction micro-practices and introduce features which reinforce fact-checking by community members to minimise the spread of misinformation. There remains an ongoing challenge in the space of OHCs attempting to avoid legitimising harmful or potentially dangerous self-management practices. This study has highlighted how people with complex and progressive diseases might be even more prone to risky behaviours due to the limitations of the current treatments. Moving forward, OHCs could facilitate this process by introducing reflective prompts to PwP when sharing suggestions and probing critical feedback from their peers.

Furthermore, experiential knowledge sharing can influence PwP's individual understanding. For example, PwP found common ground in timing their meals in relation to their medication intake. Then, a community member who did not track realised that monitoring certain variables was an important aspect of self-management. Even though PD has interpersonal variability and PwP can have very different disease experiences, the date shows that they still manage to relate to each other and build their understanding. This reflects what Nakikj (2019) argued about the relationship between individual and social sensemaking in a diabetes OHC. Specifically, he found that how an individual makes sense of the information contributes to the social sensemaking process, and as social sensemaking happens, it influences the individual sensemaking. The interplay between individual and social sensemaking introduces design considerations that warrant further exploration, particularly in the context of chronic disease and the intervariability presented in diseases such as PD.

5.4.2 Facilitating Disease Sensemaking for Complex and Progressive Conditions through Self-Tracking

To answer the RQ5: **"What is the role of self-tracking in PwPs' social interactions with the OHC, and how does it contribute to social sensemaking**?", I initially build on previous work, which has shown that self-tracking often becomes a social practice (Chung et al., 2017; Ayobi et al., 2018) and people make sense together of their self-tracked information (Puussaar et al., 2017a). In the chronic disease context, self-tracking has been widely studied in different conditions, including diabetes (Kane et al., 2016). However, the way that people with complex and progressive diseases embed their self-tracking information in their social interactions within an OHC and how this contributes to social sensemaking has not been adequately investigated. In the case of PD specifically and to the best of my knowledge, the social aspect of self-tracking has not been studied before. To this end, I described how PwP shared their self-tracking practices and data, facilitating the social sensemaking process. Based on the findings, I present relevant design implications for future OHCs and self-tracking tools.

Like other OHCs (Figueiredo et al., 2017; Young & Miller, 2019), the findings indicated that PwP attempted to address the complexity of their condition by engaging in social sensemaking to understand causal relationships and further identify self-management best practices based on their self-tracking or someone else's data. PwP established **common ground** about self-management by sharing their self-tracking practices and findings. Despite the diversity in PD manifestation (van der Marck & Bloem, 2014), the fact that community members used self-tracking in similar ways (e.g., to monitor disease manifestation, track their experiments) driven by shared motivations (e.g., having a better understanding of their disease manifestation, testing different lifestyle and treatment options) created a shared experience, and the emergence of common ground in the community. Notably, even people who did not self-track could understand, based on other members' shared practices and **experiential knowledge,** that it is important for their self-management. In other words, sharing made self-tracking visible and therefore introduced new ways to perform self-management, and energised others, new to managing their disease, to begin self-tracking. This aligns with previous research in the context of diabetes, where Huh and Ackerman (2012) found that people with diabetes could identify solutions for a newly encountered problem by sharing one another's experiential knowledge.

As shown in 5.3.2, PwP **challenged each other's ideas** and employed an evidence-based approach to findings from experimentation. For example, there were instances of PwP sharing their experiential knowledge while tracking their experiments. However, others identified that more or different factors at play affected the causal relationship between the variables (treatment and disease manifestation) in their hypothesis. This corroborates findings from Mamykina, Nakikj, et al. (2015), who had examined the patterns of communication within an online diabetes community and found that perspective negotiation, a core element of sensemaking, happened as members of the OHC often interrogated each other's perspectives, weighing evidence, and presenting and critiquing new arguments and evidence.

Self-tracking was often part of treatment self-experimentation. Based on these findings, OHCs could collaborate with clinical staff to facilitate N-of-1 studies safely and meaningfully for PwP. As there is an increased interest in personalising medicine and N-of-1 studies in the context of PD (Riggare et al., 2017), this could introduce scientific rigour to the approaches PwP already employ. Currently, there is an increased interest in leveraging the individual data of people's lay experiments in chronic disease self-management. For example, in the context of endometriosis, a woman's health condition, McKillop et al. (2018) built a self-tracking tool, which supports self-experimentation and citizen science. Building on the findings and previous literature, a potential design approach for Parkinson's OHCs could include a dedicated space for social self-tracking which would facilitate reporting collective experiments in their platform. To ensure that experiments would happen in a safe way, the dedicated space could be moderated by a clinical professional.

Finally, the findings indicated that improving how self-tracking technologies support collective engagement can improve disease understanding and self-management. PwP found value in sharing their self-tracking with others to determine the normalcy of their information and to get informational support on their self-management practices. These aspects suggest that self-tracking technology in PD self-management should also account for the need to share the data with others and facilitate social sensemaking. Current research on PD technologies has focused on sharing data with doctors to support clinical practice (e.g., Hemmerling & Wojcik-Pedziwiatr, 2022; Wang et al., 2020) but has not looked at how PwP can learn from each other's self-tracking. Building on the learnings about the role of self-tracking in social sensemaking, I suggest designers accommodate PwPs' need for PD self-tracking to be a peer-to-peer social practice. More specifically, they should consider incorporating social features and support different data modalities to facilitate peer-to-peer interactions within PD self-tracking technologies and support different dimensions of social sensemaking.

5.5 Conclusion

In this study, I focused on peer-to-peer interactions from an OHC as it is still less explored how PwP make sense together of their disease and discuss their self-tracked data. Initially, I introduced social sensemaking as an analytic framework to describe the different dimensions of PwPs' social sensemaking and to unpack the interaction micro-practices that enact this process. Moreover, I found that self-tracking contributed to the different dimensions of social sensemaking and identified the role of self-tracking in facilitating these dimensions. Finally, I presented design considerations and opportunities for PD self-tracking technologies and OHC.

Chapter 6: Study III – Sensemaking-Driven Design Exploration through Data Visualisation

6.1 Introduction to Study III

The overarching goal of this PhD thesis has been to stimulate how one might approach designing self-tracking technologies embedded in everyday experience for PD. This thesis includes three studies contributing to this goal, and this chapter will present the last one.

Using a sensemaking framing, this study investigates new design possibilities for PD self-tracking and explores how data visualisation can contribute to this process. Previous literature on PD technology has indicated that the available PD technologies that collect data do not always show data visualisations to PwP (Nunes et al., 2019), and when they do, the data visualisations are not always designed for non-experts to interpret (Boving et al., 2021). Furthermore, recent research has called for self-tracking technologies to centre the output of self-tracking around peoples' needs and preferences (Cajamarca et al., 2020) and this study aims to address this gap.

Before I present this third study, I will set its context by explaining how the previous two empirical chapters led to this point. As shown in the background section (Chapter 2), this thesis takes a *lived* perspective on self-tracking, and self-tracking is conceptualised as any practice embedded in everyday experience that supports an individual "to collect personally relevant information for self-reflection and gaining self-knowledge" (Li et al., 2010). Study I (reported in Chapter 4) showed how PwP self-track and make sense of this information in the context of their everyday experience. I found that PwP track diverse information while choosing their self-tracking tools based on three criteria: familiarity, access, and flexibility. Depending on their self-tracking goal, the practice differed in temporal patterns (e.g., short-term vs. longitudinal tracking) and structure. Moreover, this first study concluded that during the perception stage of sensemaking, comorbidity, disease progression, and self-management best practices triggered gaps in how PwP understand their PD.

Study II (reported in Chapter 5) investigated how PwP, as part of an OHC, made sense of their disease together and used their self-tracking data during this social sensemaking process. The findings of this study evidenced that self-tracking is a social practice in the context of PD self-management as PwP shared their data with their peers. PwP attempted to address the complexity of their disease by engaging in social sensemaking and specifically, trying to understand causal relationships regarding various types of health information, including their symptoms, lifestyle choices, and treatment options. Further, they tried to identify self-management best practices based on their self-tracking or someone else's data. When examining the role of self-tracking in social sensemaking, I found four main themes regarding the contribution of self-tracking in social sensemaking: i) being the point of connection, ii) promoting an evidence-based approach, iii) facilitating problem reframing, iv) underpinning experiential knowledge.

While the first two studies were empirical, this is design-oriented. Combining qualitative research and design methods has been well documented in the literature (Ayobi, 2020; Ibrahim, 2020). This study extends the findings of the first two empirical studies by building on the concepts of Study I (self-tracking as an individual practice and individual sensemaking) reported in Chapter 4 and Study II (self-tracking as a social practice and social sensemaking) reported in Chapter 5, while introducing another dimension of self-tracking: data visualisation. Specifically, this study draws from Study I to design a technology probe and explore how we can approach the design of a flexible self-tracking practice while accommodating different temporal patterns (short-term vs. longitudinal tracking). Leveraging the insights from Study II, which highlighted the social context of sensemaking, the methodology of Study III was built upon this understanding. Throughout this chapter, I will highlight when these ideas are incorporated into each phase of the study.

In summary, this study tries to address the following question:

RQ5: How can a sensemaking-driven approach motivate new ways of designing for PD self-tracking?

The contributions of this study are three-fold. First, by acknowledging the social and situated nature of self-tracking, this study's approach provides a methodological contribution to adapting existing design approaches for motivating the design of alternative PD self-tracking technologies. The second contribution is offering a set of new design principles, which researchers and designers can use in the future when designing self-tracking for PD in the context of PwPs' everyday experience. A third contribution of this study is a design concept that illustrates the sensemaking- driven approach by utilizing data visualisations to support both individual and social sensemaking.

Collaborations

To achieve the objective of this study, apart from myself, the PhD researcher, acting as the design researcher, a few other people were involved: a developer, a postdoctoral researcher/designer, and my supervisors. I will outline here how my collaborators contributed to each phase of this study. During Phase 1, I led this work by drawing on the findings from the previous studies and framing the design engagement. Regarding the work carried out by my collaborators, the developer and the designer supported me with the technical and visual requirements of the probe. Specifically, the designer helped to translate the design recommendations of Study I into the design of the technology probe, and the developer built the technology probe needed as part of the preworkshop task. During this phase, I also met regularly with my supervisors to discuss the design and use of the technology probe.

To fulfil the goal of Phase 2, conversations with the designer and my supervisors took place to define the design principles that would inform the artefact. Similar to Phase 1, the postdoctoral researcher/designer supported me with the visual elements of the artefact and the production of the mock-ups.

6.2 The Role of Data Visualisation in Making Sense of Self-tracking

In this section, I review the literature on data visualisation and make the argument that visualisations are an important but less explored component in PD self-tracking motivating its use in this study.

As mentioned in section 2.1, I conceptualise self-tracking as a *practice* and examine its characteristics. Through visualisations, many PI technologies make self-tracking data available to the end users. Thus, I focus on data visualisation, which I define as the visual representation of quantitative or qualitative data coming from self-tracking practice and supports disease sensemaking. These representations are anchored on “visual encodings such as position and colours” (Lor & Backonja, 2020: 120) and “leverage[ing] the human visual system to support the process of sensemaking” (Heer & Agrawala, 2008: 49). Notably, there are different types of visualisations, from the more conventional ones, such as tables (Alshehhi et al., 2023) and graphs (Niess et al., 2020), to pictorial ones (e.g., Ayobi et al., 2020). Also, visualisations can have different temporal dimensions ranging from daily to weekly, monthly, and annual.

Previous research has focused on data visualisation to help people make sense of their data by creating visual associations between individual data values and revealing trends or connections between data points (Samal et al., 2011). For example, Epstein et al. (2014) designed different types of visualisations to represent cuts, i.e., subsets of collected PI data with a shared feature, such as the time spent at home per day of the week. Design choices in the visual encoding of personal data can strongly influence how data-driven self-knowledge is shaped. Choosing a specific type of visualisation can create a particular perspective on data. According to a recent systematic review (Lor & Backonja, 2020), there is the potential for data visualisations to bolster positive health outcomes for users. However, further research is required to focus on the use of visualisation to support people with chronic disease to self-manage. Another recent systematic review on data visualisation for chronic neurological and mental health self-management revealed that few studies directly addressed research questions related to data visualisation preferences (Polhemus et al., 2022). The systematic review also showed that "visualisations are not "one-size-fits-all", and it is important to engage with potential users during visualisation design to understand when, how, and with whom the visualisations will be used to manage health"(Polhemus et al., 2022: 106).

In the context of PD, previous research has mainly focused on the use of visualisations for supporting medication adherence (e.g., Daley et al., 2014; de Barros et al., 2013) and thus has focused on predefined metrics such as motor symptoms and medication schedule (e.g., Memedi et al., 2018). Riggare et al. (2019) investigated the experiences of PwP with self-tracking in Sweden and they found that some PwP created visualisations from their self-tracking by using, for example, Microsoft Excel to make graphs or other visual representations of their data. The authors further argued that we need to design and develop self-tracking technologies to allow PwP to visualise trends or measure the effectiveness of their lived efforts of self-management and what they have identified as their current priorities.

In addition, Grosjean et al. (2022), in a recent co-design study of PD technology, found that incorporating a holistic approach to the disease is meaningful which considers a PwP's general well-being and medical and social needs. Hence, we need to consider this when designing technologies to support PD self-management, and data visualisation should reflect this range of information. Building on this point, this thesis further argues that data visualisations should account for the PD's complex disease character and aim to support PwP in making sense of the diversity of information included in PD self-management.

To fully support sensemaking, visualisations should also support social interaction. Heer & Agrawala (2008) argued that artefacts, namely visual representations, can facilitate establishing common ground as part of social sensemaking. It is noteworthy that previous research on sharing data visualisations with others has shown the importance of users having control over who sees their data (Epstein et al., 2014; Potapov & Marshall, 2020). Higher-level visualisations are more likely to be shared online and "get social feedback [while] not reveal[ing] private or overwhelming details"(Epstein et al., 2014: 675).

To address the current gaps in self-tracking technologies in terms of offering visualisations meaningful in the context of self-management, future tools used by PwP need to provide visualisations that help PwP in disease sensemaking. To this end, this last study will further explore the role of visualisations in PD self-tracking and how they can support individual and social disease sensemaking

6.3 Methodology

The methodology implemented in this study was based on the fundamental principles of engagement, respect for lived experiences, collaboration, and creativity (Sanders & Jan Stappers, 2008). Inspired by the notion of co-creation and by studying how knowledge is constructed, in this case by inviting PwP to the “design table” to discuss the challenge at hand, this co-design-informed approach distributes the generation of knowledge. Specifically, this happens by acknowledging and problematising the importance of involving end users in the design process and conducting research *with* them rather than for them. These principles align with the overall epistemological position of this thesis, namely social constructivism (as presented in Chapter 3).

Building on Study II (Chapter 5) and following the work of others who have highlighted that the situated and social nature of self-tracking (e.g , Epstein et al., 2015; Taylor et al., 2015), this study aimed to capture how PwP who track their PD interact in a social setting. To achieve this, a focus group methodology was employed. This approach allowed for observation of how PwP discuss and interpret their self-tracked data, providing insights into how social interactions and shared experiences shape individual sensemaking. The focus group served as a lens through which to explore the interplay between individual and social sensemaking.

It should be noted that that the self-tracking data collected during the study was not considered as primary research data, but rather as a process to sensitise participants to some of the themes of the study, encourage self-reflection in the participants. This approach is similar to previous design-led methods in HCI, which foster experimental engagement with personal data (Elsden, Chatting, et al., 2017; Ståhl et al., 2009). More specifically, we drew from work on designing documentary informatics (Elsden, Durrant, et al., 2017) that explores documentary uses of quantified data to support reminiscing and sense making about oneself. In retrospect, this data was more like a boundary object or ‘tickets for talk’ (Elsden et al., 2016)

6.3.1 Participants

Three criteria guided the recruitment of participants: people a) at the early/mid-stage of PD, b) with basic digital literacy, c) members of an OHC and/or people who self-tracked. I advertised the study through a PD Facebook group and the charity Parkinson’s UK. The participants were recruited through the charity, and they did not know each other or live in geographical proximity. Based on methodological learnings from previous research, the aim was to engage a group of four to five participants. During McNaney's (2016) design-oriented workshops with PwP, it was found that the group size of seven was too large to facilitate the participation of all members. As this project required a time commitment over several weeks, I envisioned that some participants might drop out because of the required time commitment and effort. Therefore, I recruited eight people, more people than the intended number of which, three dropped out for various reasons. In the end, five PwP took part in this study (as shown in Table 6.1). Out of five participants, four were female and one male; all had been living with PD for more than five years, and their ages ranged from 51 to 65 years old. Lastly, two out of five participants had self-tracking experience, while four out of five were members of a Parkinson's community.

Pseudonym	**Years since Diagnosis**	**Age**	**Self-tracking experience**	**Parkinson's Community Member**
Paola	6	Not provided	No	Yes
Rania	12	65	Yes	No
Nick	8	51	Yes	Yes
Alice	8	63	No	Yes
Cecily	12	54	No	Yes

Table 6.1: Participant Information

6.3.2 Phases & Objectives

This research was conducted in two phases (Table 6.2) and took place across five weeks. The objective of the first phase was to support participants in exploring the role of visualisations with different temporal patterns during their individual and social sensemaking. This objective was anchored in the findings of Study I (reported in Section 4.3), which showed that PwP use different temporal patterns in their self-tracking, employing short-term vs. long-term self-tracking. This phase included a preworkshop task, where participants tracked their data for a week with a technology probe and two online workshops that built on this task. Specifically, during workshop 1, we considered visualisations of participants' daily data. In workshop 2, we focused on visualisations of their weekly data to explore how the different temporal patterns impact sensemaking.

The objective of the second phase was to design an example of a new self-tracking technology artefact. Based on the findings from workshops 1 and 2, weTRACK was designed as a self-tracking tool for PwP.

Study Phase	Description	Timeline	Notes
Phase 1	Preworkshop Task – Use of technology probe	Week 1	N/A
	Online Workshop 1	Week 2	N/A
	Online Workshop 2	Week 3	N/A
Phase 2	Designing of the Artefact	Week 4	N/A
	Online Workshop 3	Week 5	Not in scope of the thesis

Table 6.2: Summary of Study Activities

Procedure & Ethics

As a preliminary step, I conducted informal discussions with potential participants. During these sessions, I began by explaining the voluntary nature of the study and outlined its structure and format. Participants were given ample opportunity to ask questions, and once their inquiries were addressed, they were provided with an informed consent form to review and sign at their leisure.

To address the potential challenges participants might face in visualizing a new technology or discussing abstract concepts (Lindsay et al., 2012), I incorporated a pre-workshop task into Phase 1. This task aimed to facilitate more productive discussions during the two workshops.

As discussed in Chapter 3, Section 3.5, to prioritise participant safety during the Covid 19 Pandemic, I opted for a digital probe instead of mailing physical materials, a common approach in similar design-oriented projects (e.g., (e.g., Kopanoglu, 2022; Nasr et al., 2016). This decision, reached in consultation with the Ethics officer and my supervisors, prioritised participant well-being while balancing the methodological needs of the study. Alternative options, such as sending disinfected physical kits, were considered but ultimately deemed to carry an unnecessary risk of exposure.

Each workshop lasted approximately one hour and was conducted with the five PwP participants through the online communication platform Zoom. These workshops involved an iterative knowledge translation process, and therefore, initially generated ideas could be further developed (and fed back on) by participants in the subsequent workshops. To achieve this, each workshop started with a recap of the previous week's key insights. This process was facilitated by the visual online platform Miro. Throughout all three workshops, I ensured active participation and psychological safety for all the participants. Participants were encouraged to share only up to the point they felt comfortable, acknowledging that some PD topics might be sensitive. This was also reiterated when participants expressed that a particular issue was hard to talk about in a social context. For example, one of the information types tracked included constipation, which a couple of participants identified as a topic that is better discussed privately. I explained that they could share as much as they felt comfortable, respecting their personal boundaries.

The self-tracking data collected during the study as well as the recoding from the sessions were stored in a password protected cloud file and they could be accessed by myself , the study collaborators, and my supervisors.

Phase 1

Preworkshop task: self-tracking with a technology probe

A self-tracking technology probe was designed and incorporated into the process to help participants ground their conversations about self-tracking in their data. The technology probe functioned as a prompt for participants, assisting them in articulating how self-tracking worked for them in the process of individual and social disease sensemaking. This enabling them to provide design input in a more relatable way. Jarke and Gerhard (2018) found that probes helped participants share their perspectives and supported them in understanding others' perspectives. This created a shared understanding of the phenomenon and a shared vision of the technology design outcome. Technology probes have been previously used to design technology with PwP (e.g., Bourazeri & Stumpf, 2018). In this thesis, the technology probe also helped me to evaluate some of the design assumptions and recommendations from the qualitative studies reported in Chapters 4 and 5.

An initial one-to-one briefing discussion was arranged with each participant, where the technology probe and pre-workshop task were introduced. During this short discussion, I explained the study's rationale and structure. Once I made sure that participants were familiar with the concepts of the study and had no further questions, I introduced the pre-workshop task, which asked the participants to track information types relevant to them for a week using the technology probe. More specifically, I presented them with a list, from which to choose 12 information types across four domains (shown in Table 6.3). This list was based on the findings from Study I (Section 4.3.1), where it was shown that PwP tracked a wide range of qualitative and quantitative information based on the expression of their PD. After selecting the information types, they wished to track, participants were shown how the technology probe worked step-by-step, and they had the opportunity to clarify any confusion about the probe. Finally, I explained that we would schedule the three online workshops after completing the preworkshop task.

Following this initial briefing, I sent the participants an email summarising the discussion and the weblink to access the technology probe. The email also highlighted that participants could contact the researcher at any time if there was a need for additional support. To pre-emptively address any technical issues with the technology probe, I contacted the five participants via email at the midway point of the week. At that time, a couple of participants reported difficulty using the technology probe. Therefore, I also created short how-to videos addressing the most common questions as a reference point.

Domain	**Information tracked**
Treatment	• Missing meds • Medication inconsistency • Side effects
PD symptoms	• Pain • Fatigue • Tremor • Rigidity • Dyskinesia • Slowness • Falls • Drooling • Low mood
Generic health indicators	• Constipation • Blood pressure • Sugar levels • Temperature
Lifestyle	• Poor diet • Protein intake • Inactivity • Insomnia • Poor sleep • Temperature

Table 6.3: List of information which participants could track

Technology probe design and functionality

To design the technology probe, I drew from an existing state-of-the-art self-tracking app, “uMotif”(Lakshminarayana et al., 2017), which represented PwP’s tracking of different information in the form of a flower-like figure (shown in Figure 6.1). This flower-like shape allowed different information types to be presented in one visualisation and used the same predefined scale for all the metrics. Also, this design was expected to be received positively as it was visually appealing. The probe was informed by the findings of Study I (Chapter 4). More specifically, four points underpinned the design of the technology probe, as summarised in Table 6.4.

Figure 6.1: UMotif's self-tracking visual

Findings from Study I	Corresponding Probe Design Features
PwP tracked a variety of information types. I identified 24 information types merged into four main categories based on their domain. Each PwP combined information types from these four domains (as reported in section 4.3.1) based on their version of PD.	The technology probe's flower-like visual allowed participants to track up to 12 information types from these four domains (Figure 6.3).
PwP devised their own scales to quantify their experiences (as reported in section 4.3.1).	Based on my recommendations from Study I (see 4.4.1), the technology probe had a predefined scale to facilitate the tracking practice (as shown in Figure 6.3).

Self-tracking practices incorporating these tools differed in timespan (as reported in section 4.3.3).	The probe allowed participants to track for several days, enabling the production of the PwPs' daily and weekly.
PwP weaved together the different information types in a self-reflective narrative, enabling them to understand the interaction of the phenomena captured through self-tracking (as reported in section 4.3.1).	Below the flower-like visual, the technology probe included a reflection text box allowing users to input their reflections underneath their self-tracked data. The reflection box allowed participants to capture qualitative accounts of their experiences. It also served as a prompt for them to provide the context of their self-reporting and further make associations, or generate cause-effect hypotheses, between symptoms (e.g., dyskinesia), treatment (e.g., medication efficiency), and outcomes/quality of life (e.g., sleep levels) as part of the sensemaking process.
PwP selected their self-tracking tools based on familiarity and accessibility (as reported in section 4.3.2).	The technology probe was a web-based application designed for laptops or tablets, which are already familiar technologies.

Table 6.4: Technology probe design rationale and links with Study I

It should be clarified that the goal of this technology probe was not to assess the efficacy or feasibility of the prototype but to yield insights around self-tracking and feed the conversations amongst the PwP involved in the workshop.

I will now describe the steps participants followed when using the technology probe. The first time they used the probe, participants had to select the 12 information types we discussed during our 1-1 chat. After selecting the information they would track, participants could begin the self-tracking. Every day, they needed to type their name, email, and day of tracking (as shown in Figure 6.2) and then their pre-sets would appear. When they proceeded to the next screen, they would see a colourful flower-like visual, including the date within the central circle of the flower (as shown in Figure 6.3). Each petal represented one of their preselected information types, with predefined levels (low, medium, high). They first had to click on each petal to track the specific information type and then use the buttons "+" and "-" to select the appropriate level. Finally, once they had finished tracking, they could add their notes in the reflection box, which included the prompt “*Today, I felt...*”. Once they completed, they had to submit their entry.

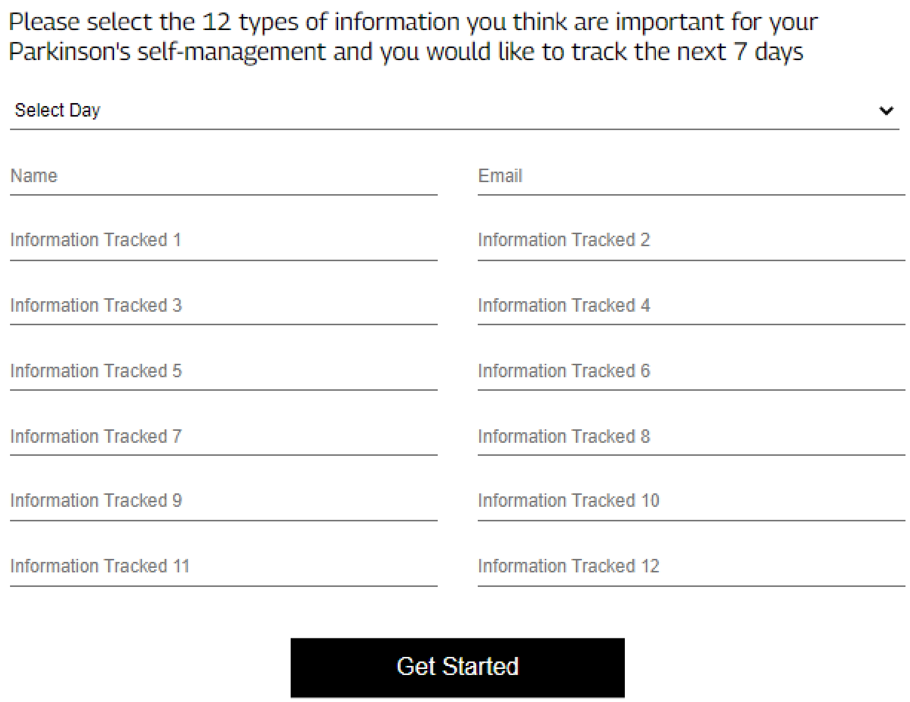
Please select the 12 types of information you think are important for your Parkinson's self-management and you would like to track the next 7 days

Figure 6.2: Technology probe: Sign-in form

Figure 6.3: The technology probe featuring three levels of tracking (low, medium, high) and a self-reflection notes box

Online Workshop 1

The objective of this first phase was to support participants in exploring the role of visualisations with different temporal patterns during their individual and social sensemaking. The temporal patterns were reflected in daily and weekly visualisations. In this first workshop, I examined how participants made sense of their **daily** data visualisations. To frame the design engagement (following Harrington et al., 2019), I started the first workshop with an explanation of the overall study purpose: the participants were here to help me - the doctoral researcher - learn from their lived experiences and design some form of self-tracking tool, which would support how PwP carry out their self-management. I selected this articulation of the goal to emphasise the desire to capture participants' lived efforts of self-management and their role in directing my understanding rather than vice versa.

At the beginning of the first workshop, emphasis was given to participants getting to know each other and building rapport. To this end, the workshop started with each participant introducing themselves and answering some icebreaker questions. I then reminded them of the study's structure and explained the key concepts I wished to explore, such as social sensemaking. During this first workshop, each participant was asked to share within the group one of their daily visualisations (Figure 6.4 visualises an example from Paola) and explain why they had chosen this one. Then, they were asked to reflect on their daily visualisation and how they felt that day. The group was encouraged to discuss each other's visualisations and any questions which derived from self-tracking and interacting with the data visualisations. This sharing aimed to spark the social sensemaking process within the group. At the end of the workshop, participants were reminded that the focus of the next workshop would be on weekly data visualisations. When these weekly visualisations were shared with them via email, they were asked to reflect on their visualisations before the workshop.

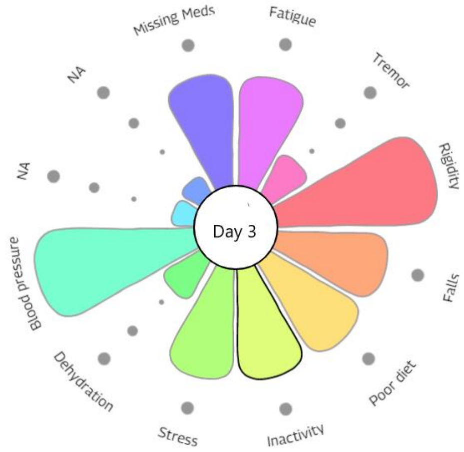

Figure 6.4: Data visualisation - Paola Day 3

Online Workshop 2

This workshop examined how participants made sense of the weekly data visualisations and the role of weekly data visualisations in individual and social sensemaking. Five days before the workshop, participants were sent weekly data visualisations for each information type/petal they had tracked during the preworkshop task. Figure 6.5 illustrates an example from Nick, who had tracked his dyskinesia across the week. Participants were asked to reflect on their weekly visualisations and select the one they wanted to share with the group. During the session, I facilitated a conversation between participants, who were again encouraged to converse based on the visualisations. I tried to unpack the factors that facilitated social sensemaking and could hinder the process.

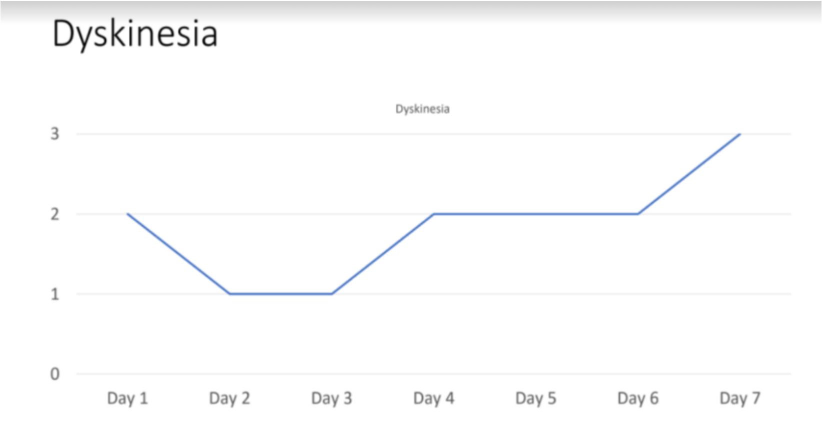

Figure 6.5: Weekly data visualisation – Nick's week

Phase 2

Designing the artefact

The objective of Phase 2 was to design the final artefact based on the insights generated during workshops 1 and 2 and, finally, for participants to critically examine the artefact during workshop 3. During the first two online workshops, participants shared their self-tracking experiences and the lived efforts of practising self-management using the technology probe. A list of design principles was drawn from these discussions. In preparation for the third workshop, visual mock-ups were produced based on the design and technical feasibility of the participants' ideas and preferences.

Methods and Insights not reported on within the thesis

In keeping with the co-design orientation of the study, I also conducted a third workshop with the participants. During this workshop, participants were presented with mock-ups of the artefact. While presenting the mock-ups to participants, I explained the design decisions based on what had been discussed in the first two workshops. This connection between the design decisions and participants' traces of engagement aimed to address our epistemological commitment to designing *with* PwP and honour this study as a collaborative dialogue rather than exclusively promoting the research agenda (Harrington et al., 2019). Participants shared their perspectives and collectively discussed the features that worked well, what was missing, and what could be improved. However, in line with the overarching goal of the thesis to focus on stimulating how one might approach designing for PD self-tracking embedded in everyday experience, it was beyond the scope of the study to analyse how PwP responded to the design artifact.

Data collection and Analysis

The three online workshops were part of the data collection. Video recordings were made of the three online workshops, and written notes regarding the role of visualisations in individual and social sensemaking were taken during the workshops that later supplemented the video analysis. In total, three hours of video recordings were collected and analysed. The data also comprised 20 visualisations per participant (including seven daily visualisations, one weekly overview visualisation, and twelve weekly visualisations featuring one information type across the week) created as part of the preworkshop task. The data was securely stored in password-protected cloud storage, accessible only to me and my supervisory team.

The video, text, and picture files were imported into Dovetail[11], a qualitative data analysis software tool. The summary of the data collection is presented in Table 6.2. An iterative analysis (summarised in Table 6.5) facilitated data collection throughout the process. More specifically, analysis happened between workshop 1 and workshop 2. This analysis was summarised as a set of '*lessons learned*' and '*what's next?*' points, which were then discussed with the participants at the beginning of the next session to validate the main points as the project progressed. Also, before workshop 3, the analysis focused on the reflective field notes aiming to inform the design of the proposed concept. I analysed what ideas and preferences participants shared and how the final design result bears traces of their participation.

When the data collection was completed, I employed inductive thematic analysis to understand how technology can facilitate PD self-tracking and further support individual and social sensemaking. My analysis was also informed by the role self-tracking can play in facilitating different dimensions of social sensemaking.

The data included the video recordings, the researcher notes, and the visualisations. The inductive thematic analysis was underpinned by a social constructivist theoretical perspective aligning with the methodology of the whole thesis (Braun & Clarke, 2006). This recognised that knowledge was co-constructed and situated within the context the data was generated. A flexible coding process was used whereby codes were iteratively generated and developed in an immersive process of repeatedly watching and listening to the data. These coded patterns were gradually developed into themes. Throughout this process, I analysed the data and kept meeting and discussing with my supervisors until the analysis was finalised to ensure rigour.

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[11] https://dovetailapp.com

Type of Analysis	**Study Phase**	**Data analysed**
Lessons Learnt & Next Steps	Data collection - Phase 1	Visualisations, reflective study notes
Lessons Learnt & Next Steps	Data collection - Phase 2	Visualisation, reflective study notes
Inductive Thematic Analysis	After data completion	Video recordings, visualisation and reflective study notes

Table 6.5: Summary of Analytical Activities

6.4 Findings

Section 6.3.1 – 6.3.4 report on the emergent themes from Phase 1 of the study, as generated from the two online workshops, 1 and 2. Section 6.3.5 reports on the design principles derived from workshops 1 and 2. These principles informed Phase 2 and informed the design of a proposed concept named weTRACK. Section 6.3.6 reports on the details of the proposed design idea.

6.4.1 Diversity and Flexibility as Design Elements in Parkinson's Visualisations

The technology probe included a data visualisation in the form of a flower. This gave an overview of all the information participants tracked daily, allowing the participants to view the different **information types** together. Most participants related this visualisation to the diversity of information types they usually tracked to carry out their self-management. This corroborated the findings from Study I, showing that PwP tracked various information types. A couple of participants identified the usefulness of having different visualisations, one that presents all the information tracked together in one visual and another that focuses on a single information type across time. For example, Nick said: *"I think it kind of helps to have different presentations, so that is a good overview, but also, probably the earlier charts you got looking at single issues*." More specifically, he explained how previous experiences made him realise that tracking across time is essential to get a clearer picture of what works and what does not with his PD medication regime, as the following quote shows:

"I was on 150s. Reduced it to 100, and initially it was good, you know, because you think yourself the drugs are 24 hours acting for us in that system and probably faster than that, in theory, but some […] So I was able to drive a car relaxed, you know very nice, do not go around and, I reduced it to 100, and that was nice but about six days later, my digestive system just ran into a halt, which so, you know, you were not supposed to discover that in 24 hours."

Based on this experience, when needing to understand his response to treatment, weekly data visualisation of a single information type was more informative when compared to a visualisation of the combined daily data. This shows how PwP need their visualisations to reflect different temporal patterns depending on their sensemaking needs.

Flexibility was also reported to be important when it comes to the information types tracked across time. As participants were in different stages in their PD journey, they discussed the shifting of priorities in PD self-management over time and how tracking and visualisations must be adjusted accordingly. Alice, for example, explained that her health changed over time: she selected specific information types to track based on the most pressing issue she experienced at that time. This is reflected in the quote below:

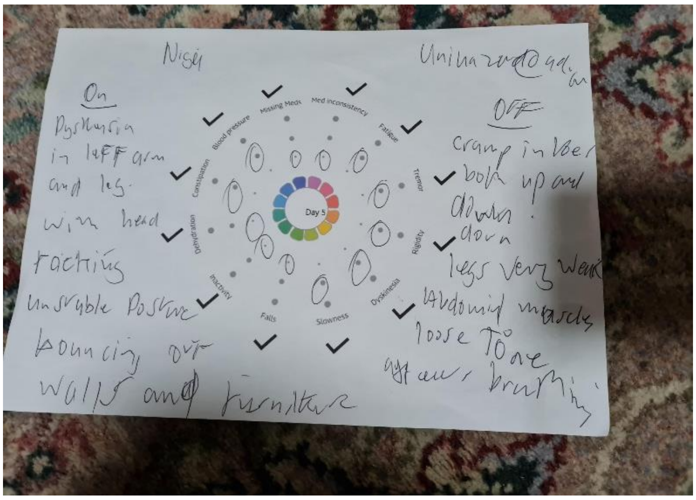
"Say that you track this for six weeks, and then suddenly something else becomes more important. I put blood pressure. OK, because that was at a time when my blood pressure wasn't very good, and it was particularly troublesome."

These findings corroborate Study I, which showed that flexibility was an essential characteristic of the self-tracking practice carried out by PwP. This finding extended the understanding of visualisations in PD self-tracking. Furthermore, it highlighted the importance of design flexibility on visualisations: what can be tracked and how it can be visualised with different types of visualisations.

6.4.2 The Role of Data Visualisation in Individual Sensemaking

Creating inferences

Similar to what was reported in Study I, during the workshops, I also observed that participants used the probe to engage in **individual sensemaking** of the relationship between different information types. All the participants tried to create inferences by generating **cause-effect hypotheses** between symptoms (e.g., dyskinesia), treatment (e.g., medication), and outcomes/quality of life (e.g., overall feeling) as part of the sensemaking process for self-management. For example, when sharing his visualisation, Nick explained how he understood his disease manifestation and the factors that affect it*: "One would be a correlation, wouldn't it? I mean, not that correlation tells you everything, but if the medication is working in the morning and then dyskinesia and tremors are different in the afternoon, and you wonder what affected, that kind of thing."*



Nick

[illegible]

On

Dyskinesia in left arm and leg with head racking unstable posture bouncing off walls and furniture

OFF

Cramp in [illegible] both up and down! down legs very weak Abdominal muscles loose tone [illegible] bruising

Figure 6.6: Data visualisation with reflective notes from the participant - Nick's Day 5

Moreover, the probe's visualisations helped participants to validate or contradict an **initial hypothesis**. When Alice shared her visualisation (as shown in Figure 6.7), she explained that she had initially thought missing medications caused her to feel unwell. However, through tracking and inspecting the visualisations, she realised that the initial hypothesis she had formed was not correct, and that, in fact, another factor – poor diet – caused the worsening effect:

"What was quite interesting about this was the missed medicines; I thought they were causing me to be very drowsy, slow, etc., in the afternoon if I miss them, but in actual fact, what I have realised is that my diet has got something to do with this, and when I have a really poor diet that's when I get very tired, very drowsy; and what I did find was more the diet than the missed meds…So that was quite interesting."

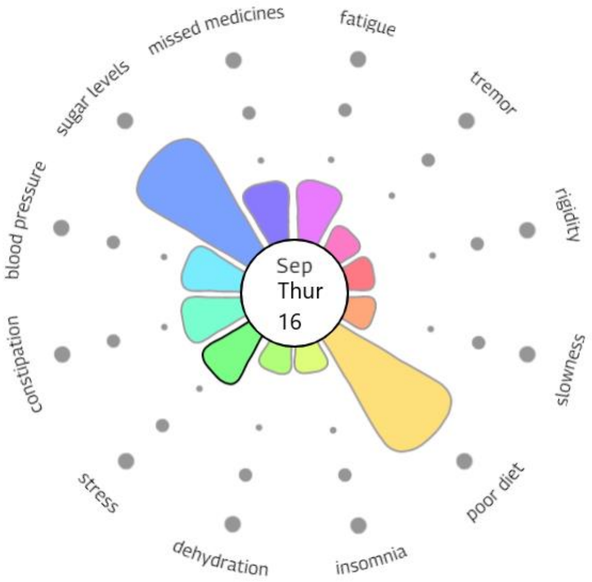


Figure 6.7: Data visualisation - Alice's Day 4

While participants mentioned that those visualisations generated from the technology probe were helpful, some also pointed out that it was not easy to understand what happened without the context of their everyday experience. More specifically, they identified the importance of their notes. Rania, for example, said, "*But your notes would be necessary because if you look back at the charts, perhaps not so meaningful if you don't have a commentary*."

Moving to action

As presented in Chapter 3, experimentation is mapped to the action phase of the sensemaking framework. Some participants called for visualisations to help them move to action by testing their inferences through self-experimentation. For example, Cecily mentioned that she appropriated her data visualisation to support her experimentation as part of her efforts to understand what makes her feel better and improve her PD self-management: "*I added some components, especially on the intervention side. So, what are other types of intervention that I can do or can track to see if it adds to my experience?".* In this quote, Cecily refers to information types as "components" of her tracking and asks for information types that she can experiment with*.* This corroborates findings from Study I, which showed that PwP perform self-tracking to experiment with their self-management practices.

6.4.3 Sharing Data Visualisation In a Social Context

Study II demonstrated the significance role of social context in self-tracking. In line with this, participants acknowledged the benefit of sharing visualisations with peers in this study. In their view, the same visualisation bolsters individual and social sensemaking, thus serving different purposes. Rania explained that visualisations benefit peer-to-peer communication as they function as conversation starters: "*something in front of you that you can perhaps show and share rather than sort of sit there and think about what to say. [it helps] the communication process, as well as understanding what's going on [with your own health]*". An instance of social sensemaking occurred during the workshop when Rania shared her visualisation which indicated low water consumption. Rania and Alice actively engaged in a back-and-forth, trying to understand this information in the context of Rania's life. Alice started by asking Rania: "*I have a question about dehydration and how this affects you. Do you know if it affects you?*". In the workshop, I observed a few instances when participants engaged in social sensemaking when viewing each other's visualisations. This involved discussing the meaning of data and the person's circumstances, sharing relevant knowledge and offering advice.

Three out of four components of social sensemaking were observed during the workshops. Firstly, data visualisations helped participants to establish **common ground**. As Alice explained, the visualisations helped her see that, although PwP have different disease manifestations, there are overarching themes, which connect their experiences: "*The visualisations, I think what they did for me was they helped me to realise that sort of, from everybody's perspective, that we were all sort of on the same page, if you see what I mean".* The visualisations also allowed the group to **reframe each other's identified problems**. This was observed when one participant shared a hypothesis about their health, and another participant identified a different factor causing the identified issue. As reported previously, Alice mentioned that she thought a poor diet was causing her symptoms to worsen. However, Nick reframed her problem and introduced another factor about Alice's medication schedule, i.e., the timing of meals. Elaborating on this, Nick introduced protein as a factor affecting medication efficiency and, thus, symptom manifestation: *"But what is the relationship between when you take your medication and when you eat: to absorb the medication content, proteins in particular?".*

In both workshops of this study, each participant shared one visualisation and verbal explanation of their self-tracking with the technology probe. This enabled each participant to share their experiential knowledge on different aspects connected to the lived efforts of self-management. This corroborates that self-tracking often underpins **experiential knowledge** previously shown in Study II (Chapter 5). The rest of the group learned through peers about the factors that affected their disease manifestation and self-management best practices. For example, Nick mentioned that he realised sleep was one of the things he should have tracked after other participants presented their visualisations: "*listened to the other people when they were talking about the sleep side of things and probably it should have been there [in the technology probe]*". This example shows how the social context can influence the sensemaking process.

While sharing visualisations facilitated sensemaking, during the sessions, a couple of participants also referred to some sensitive information which they had reported when self-tracking with the technology probe. It is thus important to recognise that PwP may track symptoms or lifestyle information they would not feel comfortable sharing at all or prefer to share with some people (e.g., only female PwP). For example, Alice shared that constipation falls into this list of topics, as the following quote shows: *"I wouldn't want to discuss my constipation, for instance, with somebody else*."

6.4.4 Data Granularity in Parkinson's Visualisation & Challenges for Sensemaking

The technology probe offered a standardised way of self-tracking by including preconfigured information types and predefined levels. In Study I, the findings showed that some PwP created scales based on their own words and metrics to capture their felt experiences. This study shows the nuances of standardising the tracking through the flower-like visual, and how PwP responded to the same preconfigured levels of the information tracked. While most participants embraced the concept of standardisation, some identified the limited data granularity of these predefined levels in their data visualisation. For example, Rania highlighted that the technology probe's three levels (low, medium, high) might not show distinctly the nuances of her experience through just three preconfigured levels. As she explained in the following quote, she would find it easier to accurately capture her experience by having more levels: *"The tremor in some days it is sort of medium, but if I put a number to it may be slightly less or slightly more. It would make me visualise more the intensity of it if I had a few more levels on a tracking like that".*

During the workshops, the participants described more dimensions of the information types represented in the technology probe. For example, while measuring symptoms such as tremor, Cecily explained different dimensions, including characterising a) the intensity of the symptom, b) the frequency (how many times during the day), c) the duration (for how long the symptom manifests) d) the position of the symptom manifestation (right vs. left leg). All the participants used the reflective notes incorporated in the technology probe, to document these additional dimensions. Also, a couple of participants explained that the different dimensions apply to information types capturing lifestyle, such as sleep and diet, including more than one data point (quality vs. quantity). As Rania explained, the quality of her diet was fine, but she realised that the portions were not ideal: "*It is not exactly poor diet. It is just the quantity of food. I eat enormously*." These examples show that information types are multidimensional and depend on each PwP's lived experience.

In addition to the challenges described in the section above regarding the effect of predefined levels of individual sensemaking, the design feature also caused challenges in the process of social sensemaking. Several participants explained that these predefined levels could be interpreted differently depending on how each PwP experienced their disease. For example, Alice explained that although blood pressure might be, in theory, an objective measure, it becomes subjective in the context of chronic disease self-management. In other words, the interpretation of the blood pressure through the data visualisation depends on someone's circumstances and symptomatology (hypotension vs. hypertension): "*Level three blood pressure to me would be if my blood pressure was* *low, but level three blood pressure, for somebody else, maybe if it was high. Yeah, blood pressure for other people could be excellent if high*”.

6.4.5 Designing Data Visualisations for PD Self-tracking

In summary, workshops 1 and 2 validated the importance of self-tracking for personal and social peer-to-peer sensemaking, providing important insights that corroborated the empirical studies reported in the previous chapters. Moreover, these two workshops expanded the understanding of the specific role of visualisations in PD self-tracking. Through observing the use of the technology probe, the first two workshops reported in this chapter inform six PD-specific design principles for designing new PD technologies for individual and social sensemaking.

Table 6.6 summarises the principles. Intended to bolster both individual and social sensemaking, the principles also reflect the main characteristics of PD: the multidimensional character of the disease, the interpersonal variability and the intravariability of disease manifestation (see Chapter 2.3).

Design Principle	**Description**	**Origin**
Supporting a diversity of information types	The disease character of PD is multidimensional, and the disease manifestation includes a range of symptoms. Thus, PwP need to track a range of information, from motor symptoms to emotions or pain experienced. Given the interconnected nature of the domains, PwP should be supported to track multiple information types and use them together to make sense of their PD.	Study I Study III
Allowing for the flexible use of information types	Because of their interpersonal differences, it is essential to allow PwP to track the most relevant information types that align the most with their own version of PD. Moreover, the intravariability in disease manifestation and the progressive character of PD means that PwPs’ self-tracking needs can change over time. Thus, flexibility should be extended to allow PwP to change their information types at different points in time.	Study I Study III
Supporting contextualisation of data visualisation	Visualisations, on their own, are not facilitative to individual and social sensemaking, because PwP tend to weave together the information they track in a self-reflective narrative. This enables them to capture the context of the specific information captured. Enabling this can help them later remember what happened at a specific time, which can add nuances from the everyday experience.	Study I Study III

Facilitating cause-and-effect relationships	PwP are constantly making associations or generating cause-effect hypotheses between symptoms (e.g. dyskinesia), treatment (e.g., medication efficiency), and outcomes/quality of life (e.g. sleep levels) as part of their sensemaking process for self-management. Visualisations showing the different information together can foster these connections, and other features could be explored to support PwP in understanding how different factors are interconnected.	Study I Study III
Supporting a structured self-tracking practice	PwP developed their own scales to convert qualitative information related to their disease self-management into quantitative. When they use predefined scales, they help them make their practice more systematic and facilitate sensemaking. Self-tracking technology should offer predefined scales to bolster sensemaking.	Study I Study III
Offering different temporal patterns	Depending on their goals, PwP structure their self-tracking practice in different temporal patterns (e.g., daily, weekly, or more long-term), and they need a different level of data granularity. Visualisations can facilitate this process and offer both fine-grained and coarse-grained data.	Study I Study III
Enabling self-tracking data share	PwP share information with their peers to learn from each other and inform the development of their self-management best practices. Self-tracking data can positively contribute to the social sensemaking process among peers. Therefore, self-tracking technology designed for PD self-management should also account for the need to share and regulate the disclosure of different data types (including visualisations) with peers, to facilitate this social sensemaking.	Study II Study III

Table 6.6: Design Principles

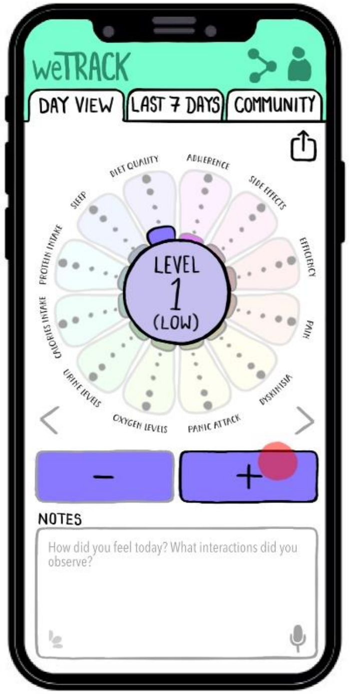
6.4.6 The Proposed Design Concept "weTrack"

I will now illustrate these design principles through a proposed design idea. More specifically, in this section, I present *weTRACK*, a self-tracking tool designed to be embedded in an OHC, leveraging data visualisations to support PwPs' individual sensemaking and peer-to-peer, social sensemaking. I also demonstrate how the principles informed the design of specific functionalities and features of weTRACK by including the corresponding *design principle* in brackets.

weTRACK is drawing on the existing solution of the technology probe used in the pre-workshop tasks. It uses a flower-like figure to present users with different information types, which enabled them to track these daily information types daily (*supporting a diversity of information types*). Users can track these information types on five levels (Figure 6.8). After inputting their tracking through the flower-like figure, users can capture any qualitative information in the reflection box under the visualisations. Here, they can reflect on the nuances and the context of the disease manifestation and any further details (for example, a tremor appearing in the right hand). Users can also use the tagging functionality to interlink their notes with the relevant information type (Figure 6.9). When users tag a petal to a specific part of their note, this appears in the same colour as the relevant petal. This helps the user to connect their visualised data and their notes, giving the context of the data visualisation (supporting contextualisation of data visualisation).

In turn, the input from daily tracking presents users with a daily visualisation (Figure 6.10) and two weekly visualisations. Depending on their self-tracking needs, the user can choose to see the daily visualisation, which offers a fine-grained view of the data and/or get the bigger picture of their data from the weekly visualisations *(allowing for the flexible use of self-tracking, offering different temporal patterns).* Specifically, the users can see all their information types in the flower-like figure, which presents them with a holistic view of their data: their weekly average and the aggregate of all their data (Figure 6.11). The users can also view a linear graph showing one information type across the last seven days, allowing them to see what changes might have happened during that period. Users can further customise their weekly graphs by tapping the petals to select which ones they want to view together in a linear graph. This enables them to see two or three information types across the last seven days (Figure 6.12). In addition to accessing two or three information types together, users can also identify cause-and-effect relationships *(facilitating cause-and-effect relationship*). Notably, there is a gap in the graph to avoid distorting the data when a user skips a day (Figure 6.12).

weTRACK also allows PwP to share their data with peers as part of an embedded Parkinson’s OHC with PwP who all self-track (Figure 6.13). This feature helps users who want to make sense of their data, as part of their self-management, to participate in a wider PD community where they can learn from each other’s data and make sense of it together. Users can therefore embed their data visualisations in their community posts when they ask questions and share insights based on self-tracking (Figure 6.14). There is also a customisable sharing feature (enabling self-tracking data share*,* allowing for the flexible use of information types), which empowers the user to control their privacy, enabling them to share information with a smaller and specific audiences, particularly when PD raises discomforts around sharing personal information (Figure 6.15).



How did you feel today? What interactions did you observe?

Figure 6.8: Daily tracking

I forgot my medication this morning and found that I suffered side effects like a numb left knee and shortness of breath.

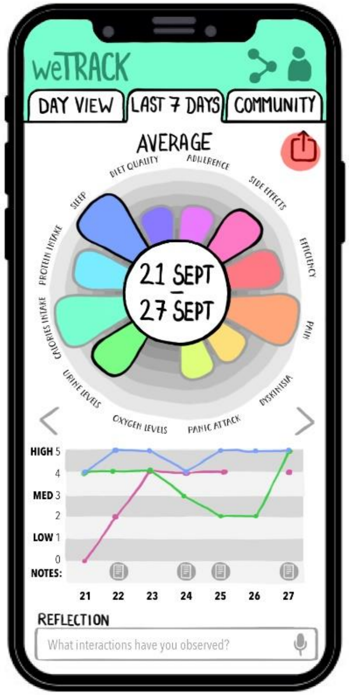
Figure 6.9: Tagging Functionality

I forgot my **medication** this morning and found that I suffered side effects like a **numb left knee and shortness of breath**.

Figure 6.10: Daily visualisation

What interactions have you observed?

Figure 6.11: Weekly average



What interactions have you observed?

Figure 6.12: Weekly linear graph

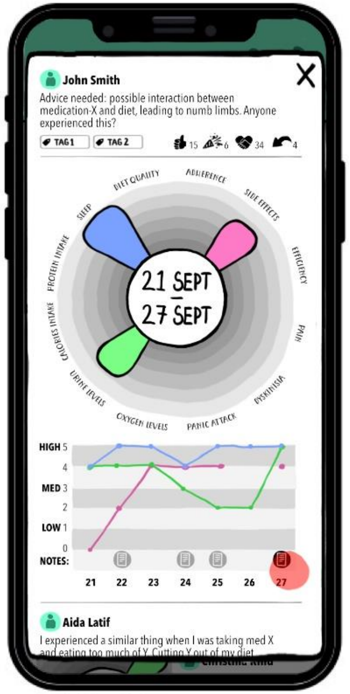
John Smith
Advice needed: possible interaction between medication-X and diet, leading to numb limbs. Anyone experienced this?

Jane Doe
I switched things up over the past 3 weeks and look what happened! What an improvement in so many areas. However, the one th…

Michael Baker
I had such a great day today!

Christina Kind

Figure 6.13: weTRACK community



John Smith
Advice needed: possible interaction between medication-X and diet, leading to numb limbs. Anyone experienced this?

Aida Latif
I experienced a similar thing when I was taking med X and eating too much of Y. Cutting Y out of my diet

Figure 6.14: weTRACK example post

CREATE NEW COMMUNITY POST

CAPTION OR QUESTION

Pose a question to the community or give your post some context…

Choose a tag / topic to make your post easier to find (optional)

CHOOSE WHO TO SHARE WITH

○ COMMUNITY ○ FRIENDS ONLY

CHOOSE CONTENT TO SHARE

Only the petals that you have currently selected will be shared.

○ LAST 7 DAYS ONLY
○ LAST 14 DAYS
○ LAST 21 DAYS
○ LAST 28 DAYS
☐ INCLUDE NOTES OF THE DAY
☐ INCLUDE REFLECTIONS

PREVIEW IMAGE

○ FLOWER ○ GRAPH

Figure 6.15: Sharing customisation feature

6.5 Discussion

This study consists of a sensemaking-driven exploration of PD self-tracking leveraging data visualisations with different temporal patterns (daily and weekly to sensemaking. I used the learnings from workshops 1 and 2 to outline a set of design principles for future PD self-tracking technologies. Based on these principles, this study offered a proposed design concept of an alternative design illustrating a PD self-tracking could look like if these principles were applied. Specifically, I presented weTRACK, a self-tracking tool embedded in an OHC, leveraging data visualisations to support PwPs' individual sensemaking and peer-to-peer, social sensemaking.

This discussion section reflects on the findings regarding the role of data visualisations in PD self-tracking and the considerations when designing visualisations of PD self-tracking, which support both individual and social sensemaking. I further discuss the learnings which came up after applying the design principles presented in 6.3.5 and how they can be useful for researchers and designers wanting to develop PD self-tracking technologies.

6.5.1 Revisiting Data Visualisations in Parkinson's Self-tracking

Prior research in PD self-tracking and the use of visualisations has been traditionally framed from a clinical point of view (e.g., Mentis et al., 2017). Although technologies allow for data entry and visualisation of information, most PD technologies include fixed logging on a single or small set of predetermined activities and symptoms, such as medication regimens or (motor) symptoms, to assess PD progression in clinical settings and domestic environments (e.g., Stamate et al., 2018; Pan et al., 2015). This lack of variety restricts the data visualisation to a subset of PD self-tracked data, subsequently affecting how PwP make sense of their disease. This means that the needs of PwP may not be fully supported in how data is visualised. In line with this, Riggare et al. (2019) argued that self-tracking technologies that allow PwP to visualise the effect of their lived efforts of self-management and to identify their current priorities need to be designed and developed.

This study has addressed this issue by focusing on the role of visualisations in PD self-tracking as part of everyday life and explored how we might design them. Specifically, it has addressed the gap caused by a limited understanding of design needs when it comes to the output of self-tracking around peoples' needs and preferences (Cajamarca et al., 2020). The findings have shown that people value the flexibility of being able to choose the information types from different domains relevant to their PD version. This aligns with Study I (Chapter 4), where I demonstrated that participants need to track various information types across different domains and that a holistic approach to the disease is meaningful for PwP (Grosjean et al., 2022). Taking a holistic approach to self-tracking meant that data visualisation was approached in new ways, exploring how different information types can come together in one visualisation and how this impacts people making sense of their data visualisations.

It is also noteworthy that while it is important for the design to be visually appealing as it increases engagement in the self-tracking practice (Abtahi et al., 2020), the findings also unearthed an interesting case where one of the participants, Cecily, highlighted that the design of the flower-like visual felt counterintuitive (the flower-like figure looked bigger and more visually appealing when higher levels of symptomatology were reported; an outcome that was not deemed positive in the context of chronic disease management). This shows how some design elements can have contradictory effects on some users and add to the emotional labour of self-tracking (Knittel et al., 2021). Consequently, it is important to note that designers need to explore how visualisations can be engaging but also in line with users' mental models.

Moreover, findings indicate that tracking specific information types should be **flexible** across time as PwPs' needs change throughout their life with PD and further offer different **temporal patterns** of the tracked information. This is because the intravariability in disease manifestation and the progressive character of PD means that PwPs' self-tracking needs can change over time. Flexibility should be extended to allow PwP to change their information types at different points in time, and a variety of visualisations capturing different levels of data granularity should be embedded in the self-tracking tools. While we should maintain a single way to input data in the self-tracking technology by PwP, researchers and designers can focus on offering different outputs of temporal patterns of data and granularity through various visualisations. Depending on their self-tracking needs and visualisations, users can interact with a different visualisation to see an overview of their health, identify cause-and-effect relationships or understand how an information type changes across time. Finally, it must be recognised that this flexibility in self-tracking can create other challenges in the design of self-tracking visualisations. For example, designers need to explore ways of introducing a functionality enabling users to modify the information types they track over time while ensuring that long-term data visualisations remain meaningful, and users can interpret their data effectively at different points in time.

6.4.2 Considerations when Designing for Sensemaking

While Study I (Chapter 4) and Study II (Chapter 5) focused on individual sensemaking and peer-to-peer social sensemaking, respectively, this study examines these two processes together and, thus, goes beyond designing *only* to support individual cognitive accounts. This approach extended my understanding of PD self-tracking as centred on the needs of PwP in everyday life and also unpacked some of the **tensions** that come up when attempting to cater for both. For example, predefined levels in self-tracking were included in the study, aiming to facilitate the self-tracking practice and PwP's disease sensemaking. Nevertheless, peers can interpret the same visualisations differently because of their distinctive personal circumstances since PD manifestation differs among people (Parkinson's UK, 2017). Thus, it can pose a risk to the way social sensemaking happens. In other words, even though the process is well intended, it might create misalignments in interpreting the same data and steer the social sensemaking process in the wrong direction. This is a challenge that researchers and designers may want to pay attention to.

Furthermore, visualisations could help participants manage their PD by identifying patterns in their PD manifestation, and that can be further supported when they have access to the context of what happened during the given period of self-tracking. This aligns with similar research showing people having difficulties understanding and engaging with data derived from automatic self-tracking (Kanis et al., 2015) and further highlights the importance of complementing the quantifiable data with context and qualitative accounts. In this study, I found this was beneficial for the social sensemaking process, as peers also needed to understand someone else's circumstances and the context within which the data was generated.

While PwP valued sharing their data with peers and acknowledging the role of visualisations in the social sensemaking process, there was also the need to have the flexibility to choose with whom to share their data and which information types they feel comfortable sharing. Since each member selected their self-tracking domains in this case, the study has shown that there can be tension between the social sensemaking process and the nature of some information types, which can be considered quite personal. The findings are in line with Heer & Agrawala (2008) who argued that visual representations can facilitate establishing common ground as part of social sensemaking. They further also corroborate previous research on sharing data visualisations with others, which has shown the importance of users having control over who sees their data (Ayobi et al., 2018; Potapov & Marshall, 2020).

Finally, while the study participants acknowledged social sensemaking as a valuable process, which complements individual sensemaking, I found that they also felt the need to associate the community with an established and recognisable organisation to set the foundation of a trusted and safe space where social sensemaking can happen.

6.6 Conclusion

This chapter presented a sensemaking driven design exploration examining the role of visualisations in PD self-tracking and adapting existing methods to motivate a new way of framing and designing PD self-tracking. Informed by previous findings on PD self-tracking and the needs of everyday life, a probe was developed to help us explore the design space of self-tracking with embedded visualisations. I conducted online workshops with PwP to examine the role of data visualisations with different temporal patterns (daily vs. weekly) in PD self-tracking to supports sensemaking. Based on the two previous empirical studies and complemented by the findings of this study, I identified design principles for PD, which researchers and designers can use in the future when designing for PD self-tracking in the context of PwPs' everyday experience. This study also proposed a designed idea which demonstrates how data visualisation of PD self-tracking could support the interaction between individual and social sensemaking. weTRACK is the output of our sensemaking driven design exploration, an example of a self-tracking technology design that leverages data visualisations to support sensemaking. Lastly, I discussed the learnings and tensions that arise when designing for individual and social sensemaking of PD self-tracking.

Chapter 7: General Discussion

The overarching goal of this thesis has been to stimulate how one might approach designing for PD self-tracking embedded in everyday experience. I drew on qualitative and design methods to investigate this goal. The key steps I took in each chapter are summarised briefly below to set the context for the following general discussion of this thesis.

The thesis began by setting the background of this PhD work (Chapter 2) surrounding self-tracking in PD, a complex and progressive chronic disease. The literature review provided insights into how existing work has studied self-tracking in chronic disease self-management more broadly and then, specifically in PD. I described PD's essential disease characteristics and unpacked the symptom manifestation's complexity and diversity. As the disease character largely shapes how people manage their disease, unpacking the disease characteristics and bringing specific nuances to self-tracking informed my analytical focus on the studies presented in this thesis. Next, I provided an overview of health technologies designed for PwP, which showed that previous research has focused on improving the clinical assessments of the disease. By presenting this work, I highlighted a gap in HCI work regarding Parkinson's self-tracking, the lived efforts of self-management, and the nuances of everyday experience. To address this gap, I suggested an alternative perspective for investigating this research area and introduced a sensemaking approach to examine self-tracking in the context of PD self-management.

Furthermore, in the background investigations (Chapter 2), I situated PD self-tracking within the context of Online Health Communities (OHC) as they comprise an essential part of their self-management. Previous research has shown that people with chronic diseases share their data with peers within this context. Then, I introduced social sensemaking as a conceptual framework to understand how self-tracking informs PwPs' online peer-to-peer interactions. Next, I presented the overarching methodology (Chapter 3) of the PhD work a) to situate my thesis in the epistemological paradigm of Social Constructivism, and b) to justify the selection of my exploratory approach and the combination of qualitative and design methods.

The thesis consists of three studies presented in their individual chapters. Study I (Chapter 4) is an exploratory qualitative study of Parkinson's Movement, an OHC dedicated to PD, investigating a) what information PwP track and why, b) the tools that PwP use and the criteria of their choice, c) how PwP engage in sensemaking of self-tracked information in the context of PD self-management. Study II (Chapter 5) is an empirical, qualitative study examining posts from the same OHC as Study I but this time employing a social sensemaking approach and examining the role of self-tracking in peer-to-peer online interactions. Study III (Chapter 6) is a design-oriented study, building on the concepts of the two previous studies by using the concepts of Study I (self-tracking as an individual practice and individual sensemaking) and Study II (self-tracking as a social practice and social sensemaking) to introduce data visualisations, the output of self-tracking.

Having presented and discussed the findings of the three studies compromising this thesis in their individual chapters, in this final chapter, I consolidate the overarching contributions made with this thesis, positioning each of them in relation to previous work and within the research field of HCI. I also reflect upon the implication of this work for HCI and relevant disciplines as well as the transferability of my findings in other chronic diseases. I conclude with the limitations of this thesis and offer possible avenues for other researchers to build future work.

7.1 Thesis Contributions

Drawing from my findings, I will focus on my thesis's three substantive contributions to HCI and CSCW, Digital Health and Person-centred Outcomes Research, and Health Education. I indicated in brackets which studies support these contributions.

1) **A lived approach to self-tracking**: The thesis offers empirical insights on how PD self-tracking happens in everyday life, informing how researchers can approach PD self-tracking in a theoretical and design level (Study I and Study II).
2) **A holistic approach to PD self-management**: The thesis offers empirical insights on how PwP make sense of their data individually and socially and the interplay between these two processes as part of their PD self-management (Study I, Study II, and Study III).
3) **Sensemaking driven design exploration:** This thesis offers a new methodological approach by building upon existing research and design practices to explore sensemaking while leveraging data visualisations to motivate alternative designs for PD self-tracking (Study III).

7.1.1 Contribution 1 – A Lived approach to PD self-tracking

Impact on HCI & Digital Health

Digital Health and HCI research in this area have focused on the clinical aspects of PD self-tracking and how self-tracking can support the clinical requirements of assessing PD. To address this, the central concern of this thesis has been to stimulate a different approach for PD self-tracking by contextualising it in everyday life. Studying **self-tracking as a practice** helped methodologically to get a *lived* perspective on its role in everyday life and to go beyond its use in clinical tools. This thesis offered a descriptive account of the everyday experience of Parkinson's self-tracking with respect to the information tracked, the tools employed, and the characteristics of the practice (Chapter 4.3). The thesis findings showed that PwP track twenty-five information types across four interrelated domains that reflect the multidimensional character of PD (Iansek, 1999; Politis et al., 2010) and the variety of physical and emotional symptoms and lifestyle information that affect the PD self-management. PwP experienced difficulties finding a tool that satisfied their needs, further corroborating the lack of a widely accepted technological tool for Parkinson's self-tracking and self-management. These findings showed the need to design PD self-tracking tools that cut across different domains and types of information to support PwPs' *lived* efforts to manage their health. Moreover, while PwP perceived the tracking of measurable information to be effortless regarding self-reports, they expressed a lack of efficacy in defining and measuring qualitative dimensions of their disease across time. Some PwP addressed this challenge by creating scales based on their own words and metrics to capture their felt experiences, a practice also employed by people with MS (Ayobi et al., 2017).

This empirical understanding of PD self-tracking in **everyday** life led to a few potential considerations for the design of future self-tracking technologies aimed at supporting individuals with Parkinson's. By offering a better understanding of the PwPs' needs for self-tracking technology, the thesis can inspire designers to rethink the assumptions that underline the development of current technologies, including which information is meaningful to PwP. This thesis contributed several design considerations and opportunities for self-tracking technologies: (i) the need to design self-tracking tools that enable the tracking of a more diverse set of phenomena cutting across different domains and types of information to support PwPs' lived efforts to manage their health; (ii) the continued need for tracking information that is objectively measured, but also the value of enabling PwP to engage in self-reports that capture the qualitative dimensions of PD. These considerations give a direction to the design of self-tracking technologies and contribute to overarching questions regarding the role of digital health in PD (e.g . van Wamelen et al., 2021).

Impact on Person-centred Outcomes

PD research, including new treatment options and clinical interventions for PD, needs to be assessed by scientifically robust outcomes. Previous health science literature (e.g., Espay et al., 2019) and health policies (e.g., Ipsos MORI & The Strategy Unit, 2018) have shown that **person-centred** outcomes are equally important in the case of clinical research as clinical trials can more efficiently capture the needs of PwP, and potentially benefit the PD community(Feeney et al., 2020). The clinical research policy guidance now suggests that researchers should inform and evaluate the direction of clinical intervention outcomes by considering how *meaningful* these outcomes are to PwP (Parkinson's UK, 2018). Person-centred outcomes can guide PwP-clinician communication by clarifying PwP-defined success in self-management and treatment (Nisenzon et al., 2011). My thesis findings speak to these questions about the meaningfulness of outcomes for PwP. In my findings, PwP expressed their desire to increase clinicians' awareness about the implications of the "practical, routine, or banal aspects that characterise daily life with a chronic condition" (Nunes & Fitzpatrick, 2018). The findings captured 25 information types, coalescing in four domains (treatment, Parkinson's symptoms, generic health indicators, and lifestyle) that are *meaningful* to PwP in everyday life and important to track for PwP. Researchers can use this wide range of information types to further develop person-centred outcomes and broaden the set of criteria by which clinicians and clinical researchers evaluate the impact of PD on PwPs' lives. For example, this thesis's findings can be used to support personalized medicine by facilitating ongoing conversations among PwP and their clinical team to define what PwP need from their treatment and care plans, how they can use self-tracking to inform the outcomes that are right for them, and how they can achieve these outcomes. Also, by expanding our understanding of person-centred outcomes, this thesis informs the principles that technologies and technological interventions should be based upon to deliver personalised medicine successfully.

Impact on Health Education

Ancker et al. (2015) explained the hidden "illness work" people with multiple conditions incur when tracking, and indeed, one of the disease characteristics is that PD very often co-exists with at least one other condition (Santiago et al., 2017). Ayobi (2020) has previously highlighted the importance of providing structure for the self-tracking practice in MS and guiding people on how they can include self-tracking in their own unique circumstances of self-management. As presented in Chapter 4.3, living with a multidimensional disease and the need to track a wide range of information types has many complexities exacerbating this "illness work" and calling for a comprehensive Health Education for PwP, which will support practically PD self-management and alleviate this work. Considering the disease characteristics including disease progression, intravariability, and comorbidity, this thesis shows the importance of systematically introducing PD self-tracking as an essential aspect of self-management and supporting PwP to self-track. It specifically calls for incorporating information as part of Health Education for PwP. Specifically, health education practitioners need to educate PwP on the existence of self-tracking tools and how they can use them. They should also explain the role of self-tracking in facilitating disease sensemaking and how self-tracking can be used at different stages of the disease journey (using self-tracking after initial diagnosis compared to using self-tracking as the disease progresses). Finally, health practitioners can support PwP to adopt evidence-based sensemaking by using a systematic self-tracking practice which will help them to make informed decisions about their treatment and care plan.

7.1.2 Contribution 2 – Holistic approach to PD self-management

Impact on HCI & CSCW

This thesis's empirical approach draws new insights into the lived efforts of chronic disease self-management by taking a **holistic** approach to PD self-tracking in the context of self-management. A holistic expands the way researchers approach and theorise self-tracking to include individual and social sensemaking. I started by studying the individual aspect of sensemaking (Chapter 4), then focused on its social dimension (Chapter 5), and lastly brought them together (Chapter 6), by investigating the interplay between them.

By contextualising a previously developed framework of sensemaking for chronic disease self-management to PD (Mamykina, Smaldone, et al., 2015), this thesis instantiates the framework for PD. This is important because researchers would first need to understand self-tracking as part of people's efforts to make sense of the different ways their PD manifests before moving on to designing meaningful self-tracking technologies for PwP. Findings support Mamykina et al. (2015), who characterise chronic disease self-management as a process that makes sense of the *"chaos of the lived experience"* (Chapter 4.4.1). The four information domains captured in Study I highlight the significance of making associations, or generating cause-effects hypotheses, between symptoms (e.g., dyskinesia), treatment (e.g., medication efficiency), and outcomes/quality of life (e.g., sleep levels) as part of the sensemaking process for self-management (Chapter 4.3.4). The findings suggest that self-tracking technology should be *designed to support sensemaking* for self-management.

More specifically, when applying the sensemaking framework (Mamykina, Smaldone, et al., 2015) to understand the self-management of Parkinson's disease, the findings generally converged with the model (Chapter 4.3.4). PwP performed self-management in a habitual or a sensemaking mode, and there was evidence of the three interdependent activities across both modes: perception, inference, and action. However, the findings also demonstrated that the characteristics of PD pose particular challenges during the sensemaking process. While the sensemaking framework proposes that people enter the sensemaking mode once new information creates a gap in understanding, this thesis's findings showed that sensemaking was sometimes initiated even though there was no information gap to trigger this mode. This was the result of PwP recognising the degenerative nature of the condition and, therefore the need to continue identifying best practices for self-management (such as treatment regime or lifestyle changes) to improve their quality of life. Also, within the sensemaking mode, my findings suggest that there can be loops between the inference and action phases whereby PwP experiment with new self-management practices. Finally, the findings highlighted that sensemaking can be awareness-oriented, in the early days after diagnosis. This thesis calls for a broader scope of self-tracking for self-management including supporting PwP in disease self-awareness and facilitating iterative self-experimentation through self-tracking.

Regarding the theoretical implications for this work in HCI, this thesis empirically contributes to the argument that researchers need to refine the sensemaking framework to account for chronic diseases with unknown or complex causal mechanisms (Young & Miller, 2019) by specifically identifying the challenges and nuances of PD, one of the most prevalent complex and progressive chronic diseases.

After examining PwP’s individual sensemaking, this thesis studied peer-to-peer social sensemaking (Chapter 5), a previously overlooked approach for Parkinson’s self-tracking. The thesis contributes a conceptual framework to HCI and CSCW, describing how social sensemaking happens among peers within the OHC context and provides evidence of the different dimensions of the process. The findings suggested that PwP actively engaged in social sensemaking about individual symptoms, lifestyle choices, treatment options, and the overall character of the disease (Chapter 5.3.1). They corroborated the existence of four dimensions of the social sensemaking process: establishing common ground, challenging ideas, transforming ideas, and knowledge sharing. The findings also showed how these dimensions are enabled at the interaction level (Chapter 5.3.1), how they co-exist and, in fact, how they are interrelated in an overarching process: social sensemaking. My thesis has ultimately shown that self-tracking contributes to this process. PwP found value in sharing their self-tracking with peers to determine the normalcy of their data and get informational support on their self-management practices (Chapter 5.3.2). Findings demonstrated that sharing self-tracking information facilitated the social sensemaking process and supported its different dimensions (Chapter 5.3.2). My thesis contributes to HCI and CSCW by expanding the way we theorise and conceptualise self-tracking and sensemaking in PD.

Impact on Digital Health

In the final phase of my PhD, my investigation culminated in a sensemaking driven co-design exploration of PD self-tracking studied within a social context (Chapter 6). Acknowledging the role of peers and the social aspect of PD self-tracking, this thesis motivates a new way of designing for PD, which goes beyond designing *only* to support the individual cognitive accounts of human practice. This approach extends our understanding of PD self-tracking in everyday life by indicating that improving how self-tracking technologies support collective engagement can improve disease understanding and self-management. My findings suggest that self-tracking technology in PD self-management should also account for the need to share the data with peers and facilitate social sensemaking. My thesis contributes a novel approach to PD self-tracking, combining the individual and peer-to-peer social sensemaking processes informing Digital Health for PD and suggesting different directions that future projects can take.

7.1.3 Contribution 3 – A Sensemaking Driven Design Exploration and Data Visualisation

This thesis also responds to an identified gap in the literature and showed that while there is the potential for self-tracking to support positive health outcomes for users, further research is required to focus on the use of visualisations to support people with chronic disease to self-manage (Lor & Backonja, 2020). The importance of data visualisations in social contexts has also been identified by Heer & Agrawala (2008b) who argued that data visualisation can play an important role in social sensemaking, acting as a visual anchor to establish common ground between people, to enable the search for relevant information, and to support shared decision-making.

My last study addressed these points, which explored the role of data visualisations in PD self-tracking to support sensemaking (Chapter 6). My thesis contributes a set of seven design principles along with a proposed design concept illustrating how these principles can be used in the future when designing for PD self-tracking in the context of everyday experience. The design concept leverages data visualisations to facilitate both individual and social sensemaking and the interplay between the two. It shows how designers can translate the design principles into features. The design principles are:

a) Supporting a diversity of information types

b) Allowing for the flexible use of information types

c) Supporting contextualisation of data visualisation

d) Facilitating cause-and-effect relationships

e) Supporting a structured self-tracking practice

f) Offering different levels of data granularity

g) Enabling self-tracking data share

Providing a design concept illustrates how the same feature, namely data visualisations may support the different dimensions of the sensemaking process. Data visualisations functioned as conversations starters, initiating the social sensemaking process. Then, they allowed participants to establish common ground, reframe their initially identified problems, and overall, promoted sharing their experiential knowledge. This output also highlighted some of the **tensions** researchers and designers can face when designing for individual and social sensemaking in a single self-tracking technology, and contributed an understanding of translating the design principles to specific technology features. While sharing self-tracking data facilitates disease sensemaking and the social sensemaking process when it comes to interpreting the same visualisations, the findings also showed that they can be interpreted differently because of the distinctive personal circumstances that PD's variable manifestation elicits (Parkinson's UK, 2017).

Data visualisations can also pose a risk to the way social sensemaking happens. Even though most peer-to-peer interactions are well intended, visualisations might create misalignments in interpreting the same data and steer the social sensemaking process in the wrong direction. This is a challenge that HCI researchers and designers may want to pay attention to. Specifically, they can explore designing mechanisms to identify and correct potential misalignments coming from different interpretations of data visualisations. The second principle – flexibility in self-tracking – also comes with challenges regarding data visualisations. These challenges include the functionality of information types that can change across time and are reflected in the visualisations. Designers may want to explore ways to strike a balance between providing the required flexibility in self-tracking and mitigating the different data captured on the data visualisations across time to maintain their meaningfulness in managing the chronic disease.

Riggare had reported that PwP want to share their data with and use spreadsheet programmes to visualise their self-tracking data (Riggare et al., 2019) showing that there is an unmet need for tools that PwP use to track and visualise their PD information and further allow them to share this data with their peers. To conclude, this sensemaking driven design exploration contributes to the visualisation research for Digital Health in PD and the proposed design concept offers an example of how the presented design principles can be used by those working on the area of PD data visualisation.

7.2 Transferability of Findings

The findings presented throughout this thesis were all drawn from research focused on PwP. In regard to the transferability (the ability to transfer insights from this thesis to other contexts) of this thesis findings, I have discussed previous literature focusing on other chronic disease (e.g., Multiple Sclerosis and diabetes) to facilitate the transferability into other domains. Researchers and designers can explore the design considerations proposed in this thesis, apply a sensemaking driven approach to design and utilise the empirically informed design principles in their own domains. Finally, researchers and designers working on MS can draw inspiration from weTRACK to explore how people with MS might benefit from sharing their data visualisations and further make sense together of these visualisations within an OHC embedded in a self-tracking tool. The specific details (e.g., the information types) might not be applicable but the broader concept of weTRACK is likely to be transferable. To sum up, while the transferability of this thesis contributions needs to be further examined, I believe that the findings are relevant to self-tracking of chronic disease, especially for diseases with similar disease characteristics.

7.3 Limitations & Future Work

This thesis presents some limitations that could be addressed in future work. First, I collected the data for Study I (Chapter 4) and Study II (Chapter 5) from an OHC. Hence, the sample consisted mainly of PwP with certain digital skills who wanted to share their experiences with others online. Some PwP may not have access to these online communities due to social, economic, and technological barriers. PwP who have access to the OHCs, but did not share their experiences, are also not represented in my samples. Therefore, Parkinson's Movement population might not be representative of all PwP. For example, it is expected that my findings will not reflect experiences from PwP in the later stages of Parkinson's due to the cognitive and physical impairments that PwP often experience as the disease progresses, and as a result making it more difficult for PwP to participate in OHCs.

Another limitation arose from the fact that the data came from Parkinson's Movement community established in the UK. Though it also operates internationally, the assumption is that PwP from English-speaking countries would be more likely to participate in this community. These PwP may not represent the broad spectrum of PwP who have different social and cultural values. Future work must be done to gain a more representative picture of how self-tracking fits this diverse population's needs and how it supports people in more advanced stages of the disease.

Furthermore, my sample included only posts from people with Parkinson's, however, community members often comprise caregivers, family, and friends. Their role has therefore not been captured in the sensemaking process. Finally, due to the lack of additional detailed contexts in online posts as well as multimodal elements such as pictures, it is possible that some issues might have been missed in the analysis.

To address these issues, sampling can include participants from hospitals, support groups, or other PwP diverse communities when trying to reach PwP that use self-tracking practices. In addition, analysing online posts may miss certain issues that PwP face daily and would not be comfortable sharing online. Thus, future studies can address the issue of self-disclosure by using direct research methods, such as interviews, while helping build trust in the research relationship. Finally, I found that carers often act on behalf of PwP in relation to self-tracking, a practice that may be more prevalent as Parkinson’s disease advances. Hence, future work should also investigate how the involvement or the absence of a carer impacts PwP’s self-tracking practices, and further should include the development and deployment of self-tracking tools to gain further insight into the needs of PwP.

Due to the inherent nature of online posts, the findings regarding the role of self-tracking in social sensemaking process may not capture the full scope of the phenomenon. For example, there are physical meetings among PwP where the role of self-tracking might be manifested in a different way. This could be because certain operationalised behaviours in person might not be observable in online posts. Therefore, future research should consider methods such as field observation to produce more robust results.

While the design considerations suggest ideas to explore during the design process, there is no way of guaranteeing that applying these principles will lead to self-tracking technologies meeting the social sensemaking needs of PwP. That remains to be evaluated in future work.

Lastly, the thesis could have taken a different direction when moving into its design phase, based on the design considerations that came up from the first two empirical studies. For example, self-experimentation as part of self-tracking was one of the identified themes in this thesis's first two empirical studies. When examining individual sensemaking in Study I (Chapter 4), within the sensemaking mode, the findings suggested that there can be loops between the inference and action phases whereby PwP experiment with new self-management practices. When studying the social sensemaking of self-tracked data in Study II (Chapter 5), there were examples of PwP sharing their experiential knowledge by tracking their experiments and peers making sense together of the validity of this approach and the results shared. While some PD self-tracking tools support self-management practices, such as medication adherence to a prescribed treatment plan, they usually do not account for the need to experiment. HCI researchers and practitioners working in the digital health space can further explore these findings on how self-tracking can be designed to facilitate experimentation at individual and peer-to-peer levels. OHCs could collaborate with clinical staff to facilitate N-of-1 studies safely and meaningfully for PwP. As there is an increased interest in personalising medicine and N-1 studies in the context of Parkinson’s (Riggare et al., 2017), this could introduce scientific rigour to the approaches PwP already employ. Also, OHCs could dedicate a particular space for social self-tracking as part of collective experiments to their platform to facilitate the process.

References

Aarsland, D., Påhlhagen, S., Ballard, C. G., Ehrt, U., & Svenningsson, P. (2012). Depression in Parkinson disease—epidemiology, mechanisms and management. *Nature Reviews Neurology*, *8*(1), 35–47. https://doi.org/10.1038/nrneurol.2011.189

Aarsland, D., Tandberg, E., Larsen, J. P., & Cummings, J. L. (1996). Frequency of Dementia in Parkinson Disease. *Archives of Neurology*, *53*(6), 538–542. https://doi.org/10.1001/archneur.1996.00550060082020

About Parkinson's Movement. (2020). HeathUnlocked. https://healthunlocked.com/parkinsonsmovement/about

Abtahi, P., Ding, V., Yang, A. C., Bruzzese, T., Romanos, A. B., Murnane, E. L., Follmer, S., & Landay, J. A. (2020). Understanding Physical Practices and the Role of Technology in Manual Self-Tracking. *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies*, *4*(4), 1–24. https://doi.org/10.1145/3432236

Almalki, M., Gray, K., & Sanchez, F. M. (2013). The use of self-quantification systems for personal health information : big data management activities and prospects. *HISA Big Data in Biomedicine and Healthcare*.

Alshehhi, Y. A., Abdelrazek, M., Philip, B. J., & Bonti, A. (2023). Understanding User Perspectives on Data Visualization in mHealth Apps: A Survey Study. *IEEE Access*, *11*, 84200–84213. https://doi.org/10.1109/ACCESS.2023.3302325

Ancker, J. S., Witteman, H. O., Hafeez, B., Provencher, T., Van De Graaf, M., & Wei, E. (2015). "You get reminded you're a sick person": Personal data tracking and patients with multiple chronic conditions. *Journal of Medical Internet Research*, *17*(8). https://doi.org/10.2196/jmir.4209

Arroyo-Gallego, T., Ledesma-Carbayo, M. J., Sanchez-Ferro, A., Butterworth, I., Mendoza, C. S., Matarazzo, M., Montero, P., Lopez-Blanco, R., Puertas-Martin, V., Trincado, R., & Giancardo, L. (2017). Detection of Motor Impairment in Parkinson's Disease Via Mobile Touchscreen Typing. *IEEE Transactions on Biomedical Engineering*, *64*(9), 1994–2002. https://doi.org/10.1109/TBME.2017.2664802

Association for Computing Machinery. (2018). *ACM Code of Ethics and Professional Conduct*.

Attard, A., & Coulson, N. S. (2012). A thematic analysis of patient communication in Parkinson's disease online support group discussion forums. *Computers in Human Behavior*, *28*(2), 500–506. https://doi.org/10.1016/j.chb.2011.10.022

Ayobi, A. (2020). *Self-Tracking by People Living with Multiple Sclerosis: Supporting Experiences of Agency in a Chronic Neurological Condition*. University College London.

Ayobi, A., Marshall, P., & Cox, A. L. (2017). Self-Experimentation and the Value of Uncertainty. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, 51–61. https://doi.org/10.1002/j.2167-4086.2013.00005.x

Ayobi, A., Marshall, P., & Cox, A. L. (2020, April 21). Trackly: A Customisable and Pictorial Self-Tracking App to Support Agency in Multiple Sclerosis Self-Care. *Conference on Human Factors in Computing Systems - Proceedings*. https://doi.org/10.1145/3313831.3376809

Ayobi, A., Marshall, P., Cox, A. L., & Chen, Y. (2017). Quantifying the Body and Caring for the Mind. *2017 CHI Conference on Human Factors in Computing Systems - CHI '17*, 6889–6901. https://doi.org/10.1145/3025453.3025869

Ayobi, A., Sonne, T., Marshall, P., & Cox, A. L. (2018). Flexible and Mindful Self-Tracking. *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems - CHI '18*, 1–14. https://doi.org/10.1145/3173574.3173602

Bacon, L., Gnani, S., Wingfield, D., Durack, C., & Khan, S. (2017). Are we stripping the care out of care plans? In *British Journal of General Practice* (Vol. 67, Issue 657, pp. 181–182). Royal College of General Practitioners. https://doi.org/10.3399/bjgp17X690377

Belcher, V. N., Fried, T. R., Agostini, J. V., & Tinetti, M. E. (2006). Views of older adults on patient participation in medication-related decision making. *Journal of General Internal Medicine*, *21*(4), 298–303. https://doi.org/10.1111/j.1525-1497.2006.00329.x

Blandford, A., Furniss, D., & Makri, S. (2016). *Qualitative HCI Research*. Morgan & Claypool Publishers.

Blandford, A., Gibbs, J., Newhouse, N., Perski, O., Singh, A., & Murray, E. (2018). Seven lessons for interdisciplinary research on interactive digital health interventions. *DIGITAL HEALTH*, *4*. https://doi.org/10.1177/2055207618770325

Blatt, R., Christianson, M. K., Sutcliffe, K. M., & Rosenthal, M. M. (2006). A sensemaking lens on reliability. *Journal of Organizational Behaviour*, *27*, 897–917.

Bloem, B. R., Henderson, E. J., Dorsey, E. R., Okun, M. S., Okubadejo, N., Chan, P., Andrejack, J., Darweesh, S. K. L., & Munneke, M. (2020). Integrated and patient-centred management of Parkinson's disease: a network model for reshaping chronic neurological care. *The Lancet Neurology*, *19*(7), 623–634. https://doi.org/10.1016/S1474-4422(20)30064-8

Boving, A. T., Shuster, C. L., Walls, T. A., & Brothers, T. (2021). Personal digital health in Parkinson's disease: Case histories and commentary. *DIGITAL HEALTH*, *7*, 205520762110619. https://doi.org/10.1177/20552076211061925

Bowen, G. A. (2006). Grounded Theory and Sensitizing Concepts . *International Journal of Qualitative Methods*, *5*(3), 12–23.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Brown, R., Ploderer, B., Da Seng, L. S., Lazzarini, P., & Van Netten, J. (2017). Myfootcare: A mobile self-tracking tool to promote self-care amongst people with diabetic foot ulcers. *Proceedings of the 29th Australian Conference on Computer-Human Interaction*, 462–466. https://doi.org/10.1145/3152771.3156158

Bussone, A. (2018). *Reflection and Personal Health Informatics for People Living with HIV*. City, University of London.

Bussone, A., Stumpf, S., & Wilson, S. (2017). The use of online forums by people living with HIV for help in understanding personal health information. *International Journal of Medical Informatics*, *108*, 64–70. https://doi.org/10.1016/j.ijmedinf.2017.10.001

Cajamarca, G., Herskovic, V., & Rossel, P. O. (2020). Enabling older adults' health self-management through self-report and visualization—a systematic literature review. In *Sensors* (Vol. 20, Issue 15, pp. 1–16). MDPI AG. https://doi.org/10.3390/s20154348

Caldeira, C., Gui, X., Reynolds, T. L., Bietz, M., & Chen, Y. (2020). Managing healthcare conflicts when living with multiple chronic conditions. *International Journal of Human Computer Studies*, *145*, 102494. https://doi.org/10.1016/j.ijhcs.2020.102494

Campbell, J. L., Quincy, C., Osserman, J., & Pedersen, O. K. (2013). Coding In-depth Semistructured Interviews: Problems of Unitization and Intercoder Reliability and Agreement. *Sociological Methods and Research*, *42*(3), 294–320. https://doi.org/10.1177/0049124113500475

Cerón-Guzmán, J. A., Tetteroo, D., Hu, J., & Markopoulos, P. (2022). "Not Sure Sharing Does Anything Extra for Me": Understanding How People with Cardiovascular Disease Conceptualize Sharing Personal Health Data with Peers. *International Journal of Environmental Research and Public Health*, *19*(15), 9508. https://doi.org/10.3390/ijerph19159508

Chambliss, D. F., & Schutt, R. K. (2013). *Making sense of the social world : methods of investigation*. SAGE.

Charmaz, K. (2006). *Constructing Grounded Theory*. SAGE Publications.

Chopra, S., Zehrung, R., & Shanmugam, T. A. (2021, May 6). Living with uncertainty and stigma: Self-experimentation and support-seeking around polycystic ovary syndrome. *Conference on Human Factors in Computing Systems - Proceedings*. https://doi.org/10.1145/3411764.3445706

Christiano Storni. (2013). DESIGN FOR FUTURE USES: PLURALISM, FETISHISM AND IGNORANCE (OR THE EPISTEMOLOGICAL AND CHRONOLOGICAL POLITICS OF DESIGNING FOR TYPE 1 DIABETES). *Nordic Design Research Conference*.

Chung, C., Agapie, E., Schroeder, J., Mishra, S., Fogarty, J., & Munson, S. A. (2017). *When Personal Tracking Becomes Social : Examining the Use of Instagram for Healthy Eating*.

Chung, C., Dew, K., Cole, A., Zia, J., Fogarty, J., Kientz, J. A., Munson, S. A., Design, H. C., & Science, C. (2016). Boundary Negotiating Artifacts in Personal Informatics: Patient-Provider Collaboration with Patient-Generated Data. *CSCW '16*, 770–786.

Clark, H. H., & Brennan, S. E. (1991). Grounding in communication. In *Perspectives on socially shared cognition.* (pp. 127–149). American Psychological Association. https://doi.org/10.1037/10096-006

Clarke, V., & Braun, V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The Psychologist*, *26*(2).

Clawson, J., Pater, J. A., Miller, A. D., Mynatt, E. D., & Mamykina, L. (2015). No longer wearing: Investigating the abandonment of personal health-Tracking technologies on craigslist. *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing*, 647–658. https://doi.org/10.1145/2750858.2807554

Coulter, Angela., & Collins, A. (2011). *Making shared decision-making a reality : no decision about me, without me*. King's Fund.

Cunningham, J., Benabdallah, G., Rosner, D., & Taylor, A. (2023). On the Grounds of Solutionism: Ontologies of Blackness and HCI. *ACM Transactions on Computer-Human Interaction*, *30*(2), 1–17. https://doi.org/10.1145/3557890

Daley, D. J., Deane, K. H. O., Gray, R. J., Clark, A. B., Pfeil, M., Sabanathan, K., Worth, P. F., & Myint, P. K. (2014). Adherence therapy improves medication adherence and quality of life in people with Parkinson's disease: a randomised controlled trial. *International Journal of Clinical Practice*, *68*(8), 963–971. https://doi.org/10.1111/ijcp.12439

de Barros, A. C., Cevada, J., Bayés, À., Alcaine, S., & Mestre, B. (2013). User-centred design of a mobile self-management solution for Parkinson's disease. *Proceedings of the 12th International Conference on Mobile and Ubiquitous Multimedia*, 1–10. https://doi.org/10.1145/2541831.2541839

Deb, R., An, S., Bhat, G., Shill, H., & Ogras, U. Y. (2022). A Systematic Survey of Research Trends in Technology Usage for Parkinson's Disease. *Sensors*, *22*(15), 5491. https://doi.org/10.3390/s22155491

Ehrlén, V. (2021). Tracking oneself for others: communal and self-motivational value of sharing exercise data online. *Leisure Studies*, *40*(4), 545–560. https://doi.org/10.1080/02614367.2020.1869289

Elm, J. J., Daeschler, M., Bataille, L., Schneider, R., Amara, A., Espay, A. J., Afek, M., Admati, C., Teklehaimanot, A., & Simuni, T. (2019). Feasibility and utility of a clinician dashboard from wearable and mobile application Parkinson's disease data. *Npj Digital Medicine*, *2*(1), 95. https://doi.org/10.1038/s41746-019-0169-y

Elsden, C., Nissen, B., Garbett, A., Chatting, D., Kirk, D., & Vines, J. (2016). Metadating: Exploring the Romance and Future of Personal Data. *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*, 685–698. https://doi.org/10.1145/2858036.2858173

Epstein, D. A., Cordeiro, F., Bales, E., Fogarty, J., & Munson, S. A. (2014). Taming Data Complexity in Lifelogs : Exploring Visual Cuts of Personal Informatics Data. *DIS*.

Epstein, D. A., Ping, A., Fogarty, J., & Munson, S. A. (2015). A lived informatics model of personal informatics. *UbiComp 2015 - Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing*, 731–742. https://doi.org/10.1145/2750858.2804250

Espay, A. J., Hausdorff, J. M., Sánchez-Ferro, Á., Klucken, J., Merola, A., Bonato, P., Paul, S. S., Horak, F. B., Vizcarra, J. A., Mestre, T. A., Reilmann, R., Nieuwboer, A., Dorsey, E. R., Rochester, L., Bloem, B. R., & Maetzler, W. (2019). A roadmap for implementation of patient-centered digital outcome measures in Parkinson's disease obtained using mobile health technologies. In *Movement Disorders* (Vol. 34, Issue 5, pp. 657–663). John Wiley and Sons Inc. https://doi.org/10.1002/mds.27671

Faisal, S., Blandford, A., & Potts, H. W. W. (2012). Making sense of personal health information : Challenges for information visualization. *Health Informatics Journal*, *19*(3), 198–217. https://doi.org/10.1177/1460458212465213

Feeney, M., Evers, C., Agpalo, D., Cone, L., Fleisher, J., & Schroeder, K. (2020). Utilizing patient advocates in Parkinson's disease: A proposed framework for patient engagement and the modern metrics that can determine its success. *Health Expectations*, *23*(4), 722–730. https://doi.org/10.1111/hex.13064

Felipe, S., Singh, A., Bradley, C., Williams, A., & Bianchi-Berthouze, N. (2015). Roles for Personal Informatics in Chronic Pain. *Proceedings of the 9th International Conference on Pervasive Computing Technologies for Healthcare*. https://doi.org/10.4108/icst.pervasivehealth.2015.259501

Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating Rigor Using Thematic Analysis: A Hybrid Approach of Inductive and Deductive Coding and Theme Development. *International Journal of Qualitative Methods*, *5*(1), 80–92. https://doi.org/10.1177/160940690600500107

Figueiredo, M. C., Caldeira, C., Tera, R., Sean, V., Kai, Z., & Yunan, C. (2017). Self-Tracking for Fertility Care : Collaborative Support for a Highly-Personalized Problem. *PACM on Human-Computer Interaction*, *1*(November).

Frias, C. M. De, Dixon, R. A., Fisher, N., & Camicioli, R. (2007). Intraindividual variability in neurocognitive speed : A comparison of Parkinson's disease and normal older adults. *Neuropsychologia*, *45*, 2499–2507. https://doi.org/10.1016/j.neuropsychologia.2007.03.022

Friedman, J. H., Brown, R. G., Comella, C., Garber, C. E., Krupp, L. B., Lou, J. S., Marsh, L., Nail, L., Shulman, L., & Taylor, C. B. (2007). Fatigue in Parkinson's disease: A review. *Movement Disorders*, *22*(3), 297–308. https://doi.org/10.1002/mds.21240

Gilbert, R. (2019, September). *Mucuna pruriens – a natural remedy for Parkinson's disease?* American Parkinson Disease Association.

Given, L. M. (2008). Purposive Sampling. In *The SAGE Encyclopedia of Qualitative Research Methods* (p. 698). SAGE Publications, Inc. https://doi.org/10.4135/9781412963909.n349

Greene, J. A., Choudhry, N. K., Kilabuk, E., & Shrank, W. H. (2011). Online social networking by patients with diabetes: A qualitative evaluation of communication with Facebook. *Journal of General Internal Medicine*, *26*(3), 287–292. https://doi.org/10.1007/s11606-010-1526-3

Greenhalgh, T. (2009). Chronic illness: beyond the expert patient. *Bmj*, *338*(march), 629–631. https://doi.org/10.1136/bmj.b49.

Grosjean, S., Bate, E., & Mestre, T. A. (2020). Designing socially acceptable mHealth technologies for Parkinson's disease self-management. In *FinJeHeW* (Vol. 12, Issue 3).

Grosjean, S., Ciocca, J.-L., Gauthier-Beaupré, A., Poitras, E., Grimes, D., & Mestre, T. (2022). Co-designing a digital companion with people living with Parkinson's to support self-care in a personalized way: The eCARE-PD Study. *DIGITAL HEALTH*, *8*, 205520762210816. https://doi.org/10.1177/20552076221081695

Guo, C., Zhang, Z., Zhou, J., & Deng, Z. (2020). Seeking or contributing? Evidence of knowledge sharing behaviours in promoting patients' perceived value of online health communities. *Health Expectations*, *23*(6), 1614–1626. https://doi.org/10.1111/hex.13146

Hajat, C., & Stein, E. (2018). The global burden of multiple chronic conditions: A narrative review. *Preventive Medicine Reports*, *12*, 284–293. https://doi.org/10.1016/j.pmedr.2018.10.008

Harrington, C. N., Borgos-Rodriguez, K., & Piper, A. M. (2019). *Engaging Low-Income African-American Older Adults in Health Discussion through Community-based Design Workshops*. https://doi.org/10.1145/13290605.3300823

Hartzler, A., & Pratt, W. (2011). Managing the personal side of health: How patient expertise differs from the expertise of clinicians. *Journal of Medical Internet Research*, *13*(3). https://doi.org/10.2196/jmir.1728

Heer, J., & Agrawala, M. (2008a). Design considerations for collaborative visual analytics. *Information Visualization*, *7*, 49–62.

Heer, J., & Agrawala, M. (2008b). Design considerations for collaborative visual analytics. *Information Visualization*, *7*, 49–62.

Heldman, D. A., Filipkowski, D. E., Riley, D. E., Whitney, C. M., Walter, B. L., Gunzler, S. A., Giuffrida, J. P., & Mera, T. O. (2012). Automated motion sensor quantification of gait and lower extremity bradykinesia. *Proceedings of the Annual International Conference of the IEEE Engineering in Medicine and Biology Society, EMBS*, 1956–1959. https://doi.org/10.1109/EMBC.2012.6346338

Hemmerling, D., & Wojcik-Pedziwiatr, M. (2022). Prediction and Estimation of Parkinson's Disease Severity Based on Voice Signal. *Journal of Voice*, *36*(3), 439.e9-439.e20. https://doi.org/10.1016/j.jvoice.2020.06.004

Henwood, F., Wyatt, S., Hart, A., & Smith, J. (2003). "Ignorance is bliss sometimes": Constraints on the emergence of the "informed patient" in the changing landscapes of health information. *Sociology of Health and Illness*, *25*(6), 589–607. https://doi.org/10.1111/1467-9566.00360

Huh, J., & Ackerman, M. S. (2012). Collaborative help in chronic disease management. *Proceedings of the ACM 2012 Conference on Computer Supported Cooperative Work*, 853–862. https://doi.org/10.1145/2145204.2145331

Iansek, R. (1999). Key points in the management of Parkinson's disease. *Australian Family Physician*, *28*(9), 897–901.

Ibrahim, S. B. (2020). *Communication and Non-Speaking Children with Physical Disabilities: Opportunities and Reflections from Design-Oriented Research*.

Ipsos MORI, & The Strategy Unit. (2018). *Person-Centred Intelligence*.

Kabelac, Z., Tarolli, C. G., Snyder, C., Feldman, B., Glidden, A., Hsu, C.-Y., Hristov, R., Dorsey, E. R., & Katabi, D. (2019). Passive Monitoring at Home: A Pilot Study in Parkinson Disease. *Digital Biomarkers*, *3*(1), 22–30. https://doi.org/10.1159/000498922

Kalf, J. G., Smit, A. M., Bloem, B. R., Zwarts, M. J., & Munneke, M. (2007). Impact of drooling in Parkinson's disease. *Journal of Neurology*, *254*(9), 1227–1232. https://doi.org/10.1007/s00415-007-0508-9

Kane, A. A. O., Park, S. Y., Mentis, H., Blandford, A., & Chen, Y. (2016). Turning to Peers : Integrating Understanding of the Self, the Condition, and Others ' Experiences in Making Sense of Complex Chronic Conditions. *Computer Supported Cooperative Work (CSCW)*, 477–501. https://doi.org/10.1007/s10606-016-9260-y

Karkar, R., Schroeder, J., Epstein, D. A., Pina, L. R., Scofield, J., Fogarty, J., Kientz, J. A., Munson, S. A., Vilardaga, R., & Zia, J. (2017). TummyTrials: A Feasibility Study of Using Self-Experimentation to

Detect Individualized Food Triggers Ravi. *Proc SIGCHI Conf Hum Factor Comput Syst.*, 650–6863. https://doi.org/10.1145/3025453.3025480.Science

Kassavetis, P., Saifee, T. A., Roussos, G., Drougkas, L., Kojovic, M., Rothwell, J. C., Edwards, M. J., & Bhatia, K. P. (2016). Developing a Tool for Remote Digital Assessment of Parkinson’s Disease. *Movement Disorders Clinical Practice*, *3*(1), 59–64. https://doi.org/10.1002/mdc3.12239

Kaziunas, E. (2018). *Designing for Lived Health: Engaging the Sociotechnical Complexity of Care Work*. University of Michigan.

Klein, K., & Vamos, S. (2016). Our self-tracking movement and health literacy : are we really making every moment count ? Commentary Our self-tracking movement and health literacy : are we really making every moment count ? *Global Health Promotion*, *August 2016*, 1–5. https://doi.org/10.1177/1757975916660674

Kopanoglu, T. (2022, June 16). *Design for patient empowerment: Guidelines to design for supporting the self-management of people living with chronic conditions*. https://doi.org/10.21606/drs.2022.530

Kuosmanen, E., Kan, V., Visuri, A., Boudjelthia, A., Krizou, L., & Ferreira, D. (2019). Measuring Parkinson’s Disease Motor Symptoms with Smartphone-based Drawing Tasks. *Adjunct Proceedings of the 2019 ACM International Joint Conference on Pervasive and Ubiquitous Computing and Proceedings of the 2019 ACM International Symposium on Wearable Computer*, 1182–1185.

Lahtiranta, J., Koskinen, J. S. S., Knaapi-Junnila, S., & Nurminen, M. (2015). Sensemaking in the personal health space Information Technology & People Article information : *Information Technology & People*, *28*(4), 790–805. https://doi.org/10.1108/ITP-09-2014-0214

Lakshminarayana, R., Wang, D., Burn, D., Chaudhuri, K. R., Galtrey, C., Guzman, N. V., Hellman, B., James, B., Pal, S., Stamford, J., Steiger, M., Stott, R. W., Teo, J., Barker, R. A., & Wang, E. (2017). Using a smartphone-based self-management platform to support medication adherence and clinical consultation in Parkinson’s disease. *Npj Parkinson’s Disease*, *3*(2), 1–8. https://doi.org/10.1038/s41531-016-0003-z

Lam, C. L. K., & Lauder, I. J. (2000). The impact of chronic diseases on the health-related quality of life (HRQOL) of Chinese patients in primary care. *Family Practice*, *17*(2), 159–166.

Lazar, A., Edasis, C., & Piper, A. M. (2017). A Critical Lens on Dementia and Design in HCI. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, 2175–2188. https://doi.org/10.1145/3025453.3025522

Lee, J. M. Z., Shine, J. M., & Lewis, S. J. G. (2015). What matters to people with Parkinson’s disease living in Australia? *Journal of Clinical Neuroscience*, *22*(2), 338–341. https://doi.org/10.1016/j.jocn.2014.06.097

Li, I., Dey, A., & Forlizzi, J. (2010). A stage-based model of personal informatics systems. *Proceedings of the 28th International Conference on Human Factors in Computing Systems - CHI ’10*, 557. https://doi.org/10.1145/1753326.1753409

Li, T., & Le, W. (2020). Biomarkers for Parkinson’s Disease: How Good Are They? *Neuroscience Bulletin*, *36*(2), 183–194. https://doi.org/10.1007/s12264-019-00433-1

Liang, O. S., Chen, Y., Bennett, D. S., & Yang, C. C. (2021). Identifying Self-Management Support Needs for Pregnant Women With Opioid Misuse in Online Health Communities: Mixed Methods Analysis of Web Posts. *Journal of Medical Internet Research*, *23*(2), e18296. https://doi.org/10.2196/18296

Lieberman, M., & Golant, M. (2005). Online Support Groups for Parkinson's Patients. *Social Work in Health Care*. https://doi.org/10.1300/J010v42n02

Lindsay, S., Jackson, D., Schofield, G., & Olivier, P. (2012). Engaging older people using participatory design. *Proceedings of the 2012 ACM Annual Conference on Human Factors in Computing Systems - CHI '12*, 1199. https://doi.org/10.1145/2207676.2208570

Lipsmeier, F., Taylor, K. I., Postuma, R. B., Volkova-Volkmar, E., Kilchenmann, T., Mollenhauer, B., Bamdadian, A., Popp, W. L., Cheng, W.-Y., Zhang, Y.-P., Wolf, D., Schjodt-Eriksen, J., Boulay, A., Svoboda, H., Zago, W., Pagano, G., & Lindemann, M. (2022). Reliability and validity of the Roche PD Mobile Application for remote monitoring of early Parkinson's disease. *Scientific Reports |*, *12*(12081), 1–15. https://doi.org/10.1038/s41598-022-15874-4

Lomborg, S., & Frandsen, K. (2016). Self-tracking as communication. *Information Communication and Society*, *19*(7), 1015–1027. https://doi.org/10.1080/1369118X.2015.1067710

Lor, M., & Backonja, U. (2020). Visualizations Integrated Into Consumer Health Technologies Support Self-management of Chronic Diseases. *CIN: Computers, Informatics, Nursing*, *38*(3), 120–130. https://doi.org/10.1097/CIN.0000000000000583

Lu, X. I., Epstein, D. A., Lu, X., & Chen, Y. (2021). A Model of Socially Sustained Self-Tracking for Food and Diet. *Article*, *5*(CSCW2), 451. https://doi.org/10.1145/3479595

Lupton, D. (2014). Self-tracking cultures: towards a sociology of personal informatics. *OZCHI 2014: The 26th Australian Computer-Human Interaction Conference: Designing Futures, the Future of Design*, 1–10. https://doi.org/10.1145/2686612.2686623

Lupton, D. (2016). The diverse domains of quantified selves : self- tracking modes and dataveillance. *Economy and Society*, *45*(1), 101–122. https://doi.org/10.1080/03085147.2016.1143726

Lupton, D. (2017). Digital health now and in the future: Findings from a participatory design stakeholder workshop. *DIGITAL HEALTH*, *3*. https://doi.org/10.1177/2055207617740018

MacKrill, K., Groom, K. M., & Petrie, K. J. (2020). The effect of symptom-tracking apps on symptom reporting. *British Journal of Health Psychology*, 1–12. https://doi.org/10.1111/bjhp.12459

Macleod, H., Tang, A., & Carpendale, S. (2013). Personal Informatics in Chronic Illness Management. *Graphics Interface Conference*, 149–156.

Mamykina, L., Heitkemper, E. M., Smaldone, A. M., Kukafka, R., Cole-Lewis, H. J., Davidson, P. G., Mynatt, E. D., Cassells, A., Tobin, J. N., & Hripcsak, G. (2017). Personal discovery in diabetes self-management: Discovering cause and effect using self-monitoring data. *Journal of Biomedical Informatics*, *76*, 1–8. https://doi.org/10.1016/j.jbi.2017.09.013

Mamykina, L., Mynatt, E. D., Davidson, P. R., & Greenblatt, D. (2008). MAHI: Investigation of social scaffolding for reflective thinking in diabetes management. *Conference on Human Factors in Computing Systems - Proceedings*, 477–486. https://doi.org/10.1145/1357054.1357131

Mamykina, L., Nakikj, D., & Elhadad, N. (2015). Collective Sensemaking in Online Health Forums. *CHI 2015, Crossings*, 3217–3226.

Mamykina, L., Smaldone, A. M., & Bakken, S. R. (2015). Adopting the sensemaking perspective for chronic disease self-management. *Journal of Biomedical Informatics*, *56*, 406–417. https://doi.org/10.1016/j.jbi.2015.06.006

Mankoff, J., Kuksenok, K., Rode, J. A., Kiesler, S., & Waldman, K. (2011). Competing Online Viewpoints and Models of Chronic Illness. *CHI*.

Mantri, S., Lepore, M., Daeschler, B. E. M., Kopil, C., Marras, C., & Chahine, L. (2021). The Experience of OFF Periods in Parkinson's Disease: Descriptions, Triggers, and Alleviating Factors Descriptions, Triggers, and Alleviating Factors. *Journal of Patient-Centered Journal of Patient-Centered Research and Reviews Research and Reviews*, *8*, 232–240. https://doi.org/10.17294/2330-0698.1836

Matthews, M., Murnane, E., & Snyder, J. (2017). Quantifying the Changeable Self: The Role of Self-Tracking in Coming to Terms With and Managing Bipolar Disorder. *Human-Computer Interaction*, *32*(5–6), 413–446. https://doi.org/10.1080/07370024.2017.1294983

Mayo Clinic Staff. (2022, September 6). *Deep Brain Stimulatiion*. Mayo Clinic.

McKillop, M., Mamykina, L., & Elhadad, N. (2018). Designing in the Dark: Eliciting Self-Tracking Dimensions for Understanding Enigmatic Diseases. *ACM SIGCHI Conference on Human Factors in Computing Systems, CHI 2018*, 1–15. https://doi.org/10.1145/3173574.3174139

McLean, G., Hindle, J. V., Guthrie, B., & Mercer, S. W. (2017). Co-morbidity and polypharmacy in Parkinson's disease: insights from a large Scottish primary care database. *BMC Neurology*, *17*(1), 126. https://doi.org/10.1186/s12883-017-0904-4

Mcnaney, R., Miller, N., Walker, R., & Olivier, P. (2012). Designing for the Person Living with Parkinson's: A Focus on Wellbeing Beyond Designing for the Person Living with Parkinson's. *DIS*, 1–2.

Mead, J. (2022, April 27). Investigation into a Self-Management App for People with Postural Tachycardia Syndrome (POTS). *Conference on Human Factors in Computing Systems - Proceedings*. https://doi.org/10.1145/3491101.3516803

Memedi, M., Tshering, G., Fogelberg, M., Jusufi, I., Kolkowska, E., & Klein, G. (2018). An Interface for IoT: Feeding Back Health-Related Data to Parkinson's Disease Patients. *Journal of Sensor and Actuator Networks*, *7*(1), 14. https://doi.org/10.3390/jsan7010014

Mentis, H. M., Komlodi, A., Schrader, K., Phipps, M., Gruber-Baldini, A., Yarbrough, K., & Shulman, L. (2017). Crafting a view of self-tracking data in the clinical visit. *Conference on Human Factors in Computing Systems - Proceedings*, 5800–5812. https://doi.org/10.1145/3025453.3025589

Menza, M., Dobkin, R. D., Marin, H., & Bienfait, K. (2010). Sleep disturbances in Parkinson's disease. *Movement Disorders*, *25*(S1), S117–S122. https://doi.org/10.1002/mds.22788

Miles, M. B., & Huberman, M. (1994). *Qualitative Data Analysis : an Expanded Sourcebook* (2ne ed.). Sage.

Miller, C. K., Weinhold, K. R., & Mitchell, D. C. (2016). Using ecological momentary assessment to track goal progress toward the adoption of a low Glycemic index diet among adults with type 2 diabetes: A pilot study. *Topics in Clinical Nutrition*, *31*(4), 323–334. https://doi.org/10.1097/TIN.0000000000000083

Minar, M., Dragasek, J., & Valkovic, P. (2019). Comorbidities in Parkinson's disease – The results from national epidemiological study cosmos. *Journal of the Neurological Sciences*, *405*, 211. https://doi.org/10.1016/j.jns.2019.10.1193

Mishra, S. R., Hekler, E. B., Mangravite, L., Klasnja, P., Omberg, L., Kellen, M., & Woodburn, J. M. (2019). Supporting Coping with Parkinson's Disease Through Self-Tracking. *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, 1–16.

Murnane, E. L., Walker, T. G., Tench, B., Voida, S., & Snyder, J. (2018). Personal Informatics in Interpersonal Contexts : Towards the Design of Technology that Supports the Social Ecologies of Long-Term Mental Health Management. *Proceedings of the ACM on Human-Computer Interaction, 2 (CSCW), 127*, *2*, 1–27.

Nakikj, D. (2019). Investigating and Supporting Sensemaking within Online Health Communities. In *Columbia University*. https://search.proquest.com/docview/2194411792?accountid=17242

Nakikj, D., & Mamykina, L. (2017). A park or a highway: Overcoming tensions in designing for socio-emotional and informational needs in online health communities. *Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW*, 1304–1319. https://doi.org/10.1145/2998181.2998339

Nambisan, P., Permanente, K., & Hopkins, J. (2011). Information seeking and social support in online health communities : impact on patients' perceived empathy. *Journal of the American Medical Informatics Association*, *18*(3), 298–304. https://doi.org/10.1136/amiajnl-2010-000058

Nasr, N., Leon, B., Mountain, G., Nijenhuis, S. M., Prange, G., Sale, P., & Amirabdollahian, F. (2016). The experience of living with stroke and using technology: opportunities to engage and co-design with end users. *Disability and Rehabilitation: Assistive Technology*, *11*(8), 653–660. https://doi.org/10.3109/17483107.2015.1036469

Neal, L., Oakley, K., Lindgaard, G., Kaufman, D., Leimeister, J. M., Selker, T., ACM Digital Library., & ACM Special Interest Group on Computer-Human Interaction. (2007). *Online Health Communities*. 1256.

Neff, G., & Nafus, D. (2016). *Self-tracking*. The MIT Press.

Neuberger, J. (1999). Do we need a new word for patients? *BMJ*, *318*(June), 1756–1758.

NHS. (2019a). *Overview -Parkinson's disease*. https://www.nhs.uk/conditions/parkinsons-disease/

NHS. (2019b). *What is personalised care?* https://www.england.nhs.uk/personalisedcare/what-is-personalised-care/

Ni, Z., Qian, Y., Yao, Z., & Zhang, S. (2022). Understanding the Adoption of Dietary Interventions Within a Chinese Autism Online Community: A Diffusion of Innovations Perspective. *Health Communication*, 1–12. https://doi.org/10.1080/10410236.2022.2048469

Niess, J., Knaving, K., Kolb, A., & Woźniak, P. W. (2020). Exploring Fitness Tracker Visualisations to Avoid Rumination. *22nd International Conference on Human-Computer Interaction with Mobile Devices and Services*, 1–11. https://doi.org/10.1145/3379503.3405662

Nisenzon, A. N., Robinson, M. E., Bowers, D., Banou, E., Malaty, I., & Okun, M. S. (2011). Measurement of patient-centered outcomes in Parkinson’s disease: What do patients really want from their treatment? *Parkinsonism & Related Disorders*, *17*(2), 89–94. https://doi.org/10.1016/j.parkreldis.2010.09.005

Nunes, F. (2015). Designing Self-care Technologies for Everyday Life : A Practice Approach. *Proceedings of the 33rd Annual ACM Conference Extended Abstracts on Human Factors in Computing Systems*, 215–218.

Nunes, F. (2018). *The Everyday Life with Parkinson’s and Self-care Technologies*. http://www.ub.tuwien.ac.athttp://www.ub.tuwien.ac.at/eng

Nunes, F., Andersen, T., & Fitzpatrick, G. (2019). The agency of patients and carers in medical care and self-care technologies for interacting with doctors. *Health Informatics Journal*, *25*(2), 330–349. https://doi.org/10.1177/1460458217712054

Nunes, F., & Fitzpatrick, G. (2018). *Understanding the Mundane Nature of Self-care : Ethnographic Accounts of People Living with Parkinson’ s*. 1–15.

Nunes, F., Verdezoto, N., Fitzpatrick, G., Kyng, M., Onvall, E. G. R., & Storni, C. (2015). Self-Care Technologies in HCI : Trends , Tensions , and Opportunities. *ACM Transactions on Computer-Human Interaction (TOCHI)*, *33*(6).

O’Kane, A. A., Park, S. Y., Mentis, H., Blandford, A., & Chen, Y. (2016). Turning to Peers: Integrating Understanding of the Self, the Condition, and Others’ Experiences in Making Sense of Complex Chronic Conditions. *Computer Supported Cooperative Work: CSCW: An International Journal*, *25*(6), 477–501. https://doi.org/10.1007/s10606-016-9260-y

Østbye, T., Yarnall, K. S. H., Krause, K. M., Pollak, K. I., Gradison, M., & Michener, J. L. (2005). Is There Time for Management of Patients With Chronic Diseases in Primary Care ? *Annals Of Family Medicine*, *3*(1), 209–214. https://doi.org/10.1370/afm.310.INTRODUCTION

Otiono, J., Olaosebikan, M., Shaer, O., Nov, O., & Ball, M. P. (2019). Understanding users information needs and collaborative sensemaking of microbiome data. *Proceedings of the ACM on Human-Computer Interaction*, *3*(CSCW). https://doi.org/10.1145/3359262

Paiva, D., Abreu, L., Azevedo, A., & Silva, S. (2019). Patient-centered communication in type 2 diabetes: The facilitating and constraining factors in clinical encounters. *Health Services Research*, *54*(3), 623–635. https://doi.org/10.1111/1475-6773.13126

Pan, D., Dhall, R., Lieberman, A., & Petitti, D. B. (2015). A Mobile Cloud-Based Parkinson’s Disease Assessment System for Home-Based Monitoring. *JMIR MHealth and UHealth*, *3*(1), 1–15. https://doi.org/10.2196/mhealth.3956

Pantzar, M., & Ruckenstein, M. (2017). Living the metrics: Self-tracking and situated objectivity. *DIGITAL HEALTH*, *3*, 205520761771259. https://doi.org/10.1177/2055207617712590

Papoutsaki, A., Shapiro, B., Epstein, D. A., So, S., & Kenderova, G. (2021). Understanding Delivery of Collectively Built Protocols in an Online Health Community for Discontinuation of Psychiatric Drugs. *Proc. ACM Hum.-Comput. Interact*, *5*. https://doi.org/10.1145/3479564

Parkinson’s Europe. (2017). *Rating Scales*. https://www.parkinsonseurope.org/about-parkinsons/symptoms/rating-scales/

Parkinson’s Foundation. (2020). *Statistics*. https://www.parkinson.org/Understanding-Parkinsons/Statistics

Parkinson’s UK. (2017). *The incidence and prevalence of Parkinson’s in the UK*.

Parkinson’s UK. (2018). *Patient and Public involvement Guidance for researchers*. https://www.parkinsons.org.uk/sites/default/files/2018-11/PPI%20Guidance%20for%20Researchers.pdf

Patel, D. (2021). Online Health Communities as a resource for collective sensemaking for men who experience fertility difficulty. *The 24TH ACM Conference on Computer Supported Cooperative Work and Social Computing Workshop: The Future of Research on Online Health Communities: Discussing Membership, Structure, and Support*.

Patel, D. (2022). *Online Information-Seeking Behaviours of Men Experiencing Fertility Difficulties*.

Patel, D., Shawe, J., Stephenson, J., Blandford, A., & Warner, M. (2019). *“I feel like only half a man”: Online Forums as a Resource for Finding a “New Normal” for Men Experiencing Fertility Issues*. https://doi.org/10.1145/3359184

Patton, M. (1990). Qualitative Evaluation and Research Methods. *Qualitative Evaluation and Research Methods*, 169–186. https://doi.org/10.1002/nur.4770140111

Pichon, A., Schiffer, K., Horan, E., Massey, B., Bakken, S., Mamykina, L., & Elhadad, N. (2021). Divided We Stand: The Collaborative Work of Patients andProviders in an Enigmatic Chronic Disease. *Proceedings of the ACM on Human-Computer Interaction*, *4*(CSCW3), 1–24. https://doi.org/10.1145/3434170

Polhemus, A., Novak, J., Majid, S., Simblett, S., Morris, D., Bruce, S., Burke, P., Dockendorf, M. F., Temesi, G., & Wykes, T. (2022). Data Visualization for Chronic Neurological and Mental Health Condition Self-management: Systematic Review of User Perspectives. *JMIR Mental Health*, *9*(4), e25249. https://doi.org/10.2196/25249

Politis, M., Wu, K., Molloy, S., Bain, P. G., Chaudhuri, K. R., & Piccini, P. (2010). Parkinson’s disease symptoms: the patient’s perspective. *Movement Disorders*, *25*(11), 1646–1651.

Popik, P., & Skolnick, P. (1999). Pharmacology of Ibogaine and Ibogaine-Related Alkaloids. In *The Alkaloids: Chemistry and Biology* (Vol. 52199, pp. 197–231).

Potapov, K., & Marshall, P. (2020). LifeMosaic: co-design of a personal informatics tool for youth. *IDC: Proceedings of the Interaction Design and Children Conference*, 519–531.

Powers, R., Etezadi-Amoli, M., Arnold, E. M., Kianian, S., Mance, I., Gibiansky, M., Trietsch, D., Alvarado, A. S., Kretlow, J. D., Herrington, T. M., Brillman, S., Huang, N., Lin, P. T., Pham, H. A., & Ullal, A. V. (2021). Smartwatch inertial sensors continuously monitor real-world motor fluctuations in Parkinson’s disease. *Science Translational Medicine*, *13*(579). https://doi.org/10.1126/scitranslmed.abd7865

Proferes, N., Jones, N., Gilbert, S., Fiesler, C., & Zimmer, M. (2021). Studying Reddit: A Systematic Overview of Disciplines, Approaches, Methods, and Ethics. *Social Media + Society*, *7*(2), 205630512110190. https://doi.org/10.1177/20563051211019004

Puussaar, A., Clear, A. K., & Wright, P. (2017a). Enhancing Personal Informatics Through Social Sensemaking. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI '17*, 6936–6942. https://doi.org/10.1145/3025453.3025804

Puussaar, A., Clear, A., & Wright, P. (2017b). Better together: Reciprocal sharing and social sensemaking of data. *Workshop on "Quantified Data and Social Relationships" -CHI2017*.

Radder, D. L. M., Nonnekes, J., Van Nimwegen, M., Eggers, C., Abbruzzese, G., Alves, G., Browner, N., Chaudhuri, K. R., Ebersbach, G., Ferreira, J. J., Fleisher, J. E., Fletcher, P., Frazzitta, G., Giladi, N., Guttman, M., Iansek, R., Khandhar, S., Klucken, J., Lafontaine, A. L., … Bloem, B. R. (2020). Recommendations for the Organization of Multidisciplinary Clinical Care Teams in Parkinson's Disease. *Journal of Parkinson's Disease*, *10*(3), 1087–1098. https://doi.org/10.3233/JPD-202078

Rapp, A., & Cena, Federica. (2016). Personal informatics for everyday life: How users without prior self-tracking experience engage with personal data. *INTERNATIONAL JOURNAL OF HUMAN-COMPUTER STUDIES*, *94*(1–17). https://doi.org/10.1016/j.ijhcs.2016.05.006

Riggare, S., Scott Duncan, T., Hvitfeldt, H., & Hägglund, M. (2019). "You have to know why you're doing this": A mixed methods study of the benefits and burdens of self-tracking in Parkinson's disease. *BMC Medical Informatics and Decision Making*, *19*(1). https://doi.org/10.1186/s12911-019-0896-7

Riggare, S., Unruh, K. T., Sturr, J., Domingos, J., Stamford, J. A., Svenningsson, P., & Hägglund, M. (2017). Patient-driven N-of-1 in parkinson's disease: Lessons learned from a placebo-controlled study of the effect of nicotine on dyskinesia. *Methods of Information in Medicine*, *56*(MethodsOpen), e123–e128. https://doi.org/10.3414/ME16-02-0040

Rooksby, J., Rost, M., Morrison, A., & Chalmers, M. C. (2014). Personal tracking as lived informatics. *Proceedings of the 32nd Annual ACM Conference on Human Factors in Computing Systems - CHI '14*, 1163–1172. https://doi.org/10.1145/2556288.2557039

Samal, L., Wong, B., Linder, J., & Bates, D. (2011). Leveraging electronic health records to support chronic disease management: the need for temporal data views. *Informatics in Primary Care*, *119*(19), 65–74.

Sampaio, C., Goetz, C. G., & Schrag, A. (2012). *Rating Scales in Parkinson's Disease: Clinical Practice and Research*. OUP USA. https://books.google.co.uk/books?id=E0dva_CQVCwC

Sanders, E. B.-N., & Jan Stappers, P. (2008). Co-creation and the new landscapes of design. *Co-Design*, *4*(1), 5–18. https://doi.org/10.1080/15710880701875068

Santiago, J. A., Bottero, V., & Potashkin, J. A. (2017). Biological and clinical implications of comorbidities in Parkinson's disease. *Frontiers in Aging Neuroscience*, *9*, 1–16. https://doi.org/10.3389/fnagi.2017.00394

Santos García, D., Suárez Castro, E., Expósito, I., de Deus, T., Tuñas, C., Aneiros, A., López Fernández, M., Núñez Arias, D., & Bermúdez Torres, M. (2017). Comorbid conditions associated with Parkinson's disease: A longitudinal and comparative study with Alzheimer disease and control subjects. *Journal of the Neurological Sciences*, *373*, 210–215. https://doi.org/10.1016/J.JNS.2016.12.046

Schroeder, J., Chung, C., Epstein, D. A., Karkar, R., Parsons, A., Murinova, N., Fogarty, J., & Munson, S. A. (2018). Examining Self-Tracking by People with Migraine : Goals , Needs , and

Opportunities in a Chronic Health Condition. *Proceedings of the 2018 Designing Interactive Systems Conference*.

Self-management UK. (2020). *Support for people with long-term conditions*. https://www.selfmanagementuk.org/long-term-conditions-and-self-management

Shapiro, M., Johnston, D., Wald, J., & Mon, D. (2012). *Patient-Generated Health Data*.

Sik Chu, H., & Young Jang, H. (2022). *Exploring Unmet Information Needs of People with Parkinson's Disease and Their Families: Focusing on Information Sharing in an Online Patient Community*. https://doi.org/10.3390/ijerph19052521

Silverman, D. (2005). *Doing qualitative research : a practical handbook* (2nd ed.). London : Sage.

Sjödahl Hammarlund, C., Westergren, A., Åström, I., Edberg, A.-K., & Hagell, P. (2018). The Impact of Living with Parkinson's Disease: Balancing within a Web of Needs and Demands. *Parkinson's Disease*, *2018*, 1–8. https://doi.org/10.1155/2018/4598651

Skjott Linneberg, M., & Korsgaard, S. (2019). Coding qualitative data: a synthesis guiding the novice. In *Qualitative Research Journal* (Vol. 19, Issue 3, pp. 259–270). Emerald Group Holdings Ltd. https://doi.org/10.1108/QRJ-12-2018-0012

Stamate, C., Magoulas, G. D., Kueppers, S., Nomikou, E., Daskalopoulos, I., Luchini, M. U., Moussouri, T., & Roussos, G. (2017). Deep Learning Parkinson's from Smartphone Data. *2017 IEEE International Conference on Pervasive Computing and Communications (PerCom)*, *28*(1–2), 1–2. https://doi.org/10.1016/j.strusafe.2005.03.001

Stamate, C., Magoulas, G. D., Kueppers, S., Nomikou, E., Jha, A., Pons, J. S., Rothwell, J., Luchini, M. U., Iannone, M., & Roussos, G. (2018). The cloudUPDRS app : A Medical Device for the Clinical Assessment of Parkinson's Disease. *Pervasive and Mobile Computing*, *43*, 146–166.

Stebbins, R. (2001). What Is Exploration? In *Exploratory Research in the Social Sciences*. SAGE Publications. https://doi.org/http://dx.doi.org/10.4135/9781412984249

Stocchi, F., & Torti, M. (2017). Constipation in Parkinson's Disease. *International Review of Neurobiology*, *134*, 811–826. https://doi.org/10.1016/BS.IRN.2017.06.003

Storni, C. (2010). Multiple forms of appropriation in self-monitoring technology: Reflections on the role of evaluation in future self-care. *International Journal of Human-Computer Interaction*, *26*(5), 537–561. https://doi.org/10.1080/10447311003720001

Storni, C. (2011). Complexity in an uncertain and cosmopolitan world. Rethinking personal health technology in diabetes with the tag-it-yourself. *PsychNology Journal*, *9*(2), 165–185.

Storni, C. (2014). Design challenges for ubiquitous and personal computing in chronic disease care and patient empowerment: A case study rethinking diabetes self-monitoring. *Personal and Ubiquitous Computing*, *17*(4), 1277–1290. https://doi.org/10.1007/s00779-013-0707-6

Stuart, A. (2017). *More Data to Share!* 100 for Parkinson's A Global Study for Everyone. https://www.100forparkinsons.com/blog/more-data-to-share

Suter, W. (2012). *Introduction to Educational Research: A Critical Thinking Approach*. SAGE Publications, Inc. https://doi.org/10.4135/9781483384443

Swendeman, D., Ramanathan, N., Baetscher, L., Medich, M., Scheffler, A., Comulada, W. S., & Estrin, D. (2015). Smartphone self-monitoring to support self-management among people living with HIV: Perceived benefits and theory of change from a mixed-methods, randomized pilot study. *J Acquir Immune Defic Syndr*, *69*(01), S80–S91. https://doi.org/10.1016/j.physbeh.2017.03.040

Taylor, A. S., Lindley, S., Regan, T., Sweeney, D., Vlachokyriakos, V., Grainger, L., & Lingel, J. (2015). Data-in-place: Thinking through the relations between data and community. *Conference on Human Factors in Computing Systems - Proceedings*, *2015-April*, 2863–2872. https://doi.org/10.1145/2702123.2702558

Todorova, A., Jenner, P., Chaudhuri, K. R., & Chaudhuri, R. (2014). Non-motor Parkinson's: integralto motor Parkinson's, yet often neglected. *Pract Neurol*, *14*, 310–322. https://doi.org/10.1136/practneurol-2013-000741

Townsend, L., & Wallace, C. (2016). *Social media research: A guide to ethics.*

Trappenburg, J., Jonkman, N., Jaarsma, T., van Os-Medendorp, H., Kort, H., de Wit, N., Hoes, A., & Schuurmans, M. (2013). Self-management: One size does not fit all. *Patient Education and Counseling*, *92*(1), 134–137. https://doi.org/10.1016/j.pec.2013.02.009

Tsiouris, K. M., Gatsios, D., Rigas, G., Miljkovic, D., Seljak, B. K., Bohanec, M., Arredondo, M. T., Antonini, A., Konitsiotis, S., Koutsouris, D. D., & Fotiadis, D. I. (2017). PD _ Manager : an mHealth platform for Parkinson's disease patient management. *Healthcare Technology Letters*, *4*(3), 102–108. https://doi.org/10.1049/htl.2017.0007

Vaala, S. E., Lee, J. M., Hood, K. K., & Mulvaney, S. A. (2018). Sharing and helping: predictors of adolescents' willingness to share diabetes personal health information with peers. *Journal of the American Informatics Association*, *25*(2), 135–141. https://doi.org/10.1093/jamia/ocx051

van der Marck, M. A., & Bloem, B. R. (2014). How to organize multispecialty care for patients with Parkinson's disease. *Parkinsonism & Related Disorders*, *20*, S167–S173. https://doi.org/10.1016/S1353-8020(13)70040-3

van Wamelen, D. J., Sringean, J., Trivedi, D., Carroll, C. B., Schrag, A. E., Odin, P., Antonini, A., Bloem, B. R., Bhidayasiri, R., & Chaudhuri, K. R. (2021). Digital health technology for non-motor symptoms in people with Parkinson's disease: Futile or future? *Parkinsonism & Related Disorders*, *89*, 186–194. https://doi.org/10.1016/j.parkreldis.2021.07.032

Visser, L. M., Bleijenbergh, I. L., Benschop, Y. W. M., Van Riel, A. C. R., & Bloem, B. R. (2016). Do online communities change power processes in healthcare? Using case studies to examine the use of online health communities by patients with Parkinson's disease. *BMJ Open*, *6*(11). https://doi.org/10.1136/bmjopen-2016-012110

Vizer, L. M., Eschler, J., Koo, B. M., Ralston, J., Pratt, W., & Munson, S. (2019). "It's Not Just Technology, It's People": Constructing a Conceptual Model of Shared Health Informatics for Tracking in Chronic Illness Management. *Journal of Medical Internet Research*, *21*(4), e10830. https://doi.org/10.2196/10830

Walther, J. B., & Boyd, S. (2002). Attraction to computer-mediated social support. In *Communication technology and society: Audience adoption and uses* (pp. 153–188). Hampton Press.

Wang, J., Yao, Z., Li, B., Wang, S., Wu, Q., & Wang, P. (2020). Research and implementation of Parkinson's dyskinesia monitoring service system. *Proceedings - 2020 13th International*

Symposium on Computational Intelligence and Design, ISCID 2020, 97–100. https://doi.org/10.1109/ISCID51228.2020.00028

Weatherall, J., Paprocki, Y., Meyer, T. M., Kudel, I., & Witt, E. A. (2018). Sleep tracking and exercise in patients with type 2 diabetes mellitus (Step-D): Pilot study to determine correlations between fitbit data and patient-reported outcomes. *JMIR MHealth and UHealth*, *6*(6), 1–10. https://doi.org/10.2196/mhealth.8122

Webb, H., Jirotka, M., Stahl, B. C., Housley, W., Edwards, A., Williams, M., Procter, R., Rana, O., & Burnap, P. (2017). The Ethical Challenges of Publishing Twitter Data for Research Dissemination. *Proceedings of the 2017 ACM on Web Science Conference*, 339–348. https://doi.org/10.1145/3091478.3091489

Willig, C. (2016). Constructivism and 'The Real World': Can they co-exist? *QMiP Bulletin*, *21*.

Wilson, H. J. (2000). The myth of objectivity: Is medicine moving towards a social constructivist medical paradigm? *Family Practice*, *17*(2), 203–209. https://doi.org/10.1093/fampra/17.2.203

Wobbrock, J. O., & Kientz, J. A. (2016). Research contributions in human-computer interaction. *Interactions*, *23*(3), 38–44. https://doi.org/10.1145/2907069

World Health Organisation. (2015). *People-centred and integrated health services: an overview of the evidence*.

Yan, Z., Wang, T., Chen, Y., & Zhang, H. (2016). Knowledge sharing in online health communities : A social exchange theory perspective. *Information & Management*, *53*(5), 643–653. https://doi.org/10.1016/j.im.2016.02.001

York Health Economics Consortium. (2017). *NHS Innovation Accelerator Economic Impact Evaluation Case Study : HealthUnlocked* (Vol. 44).

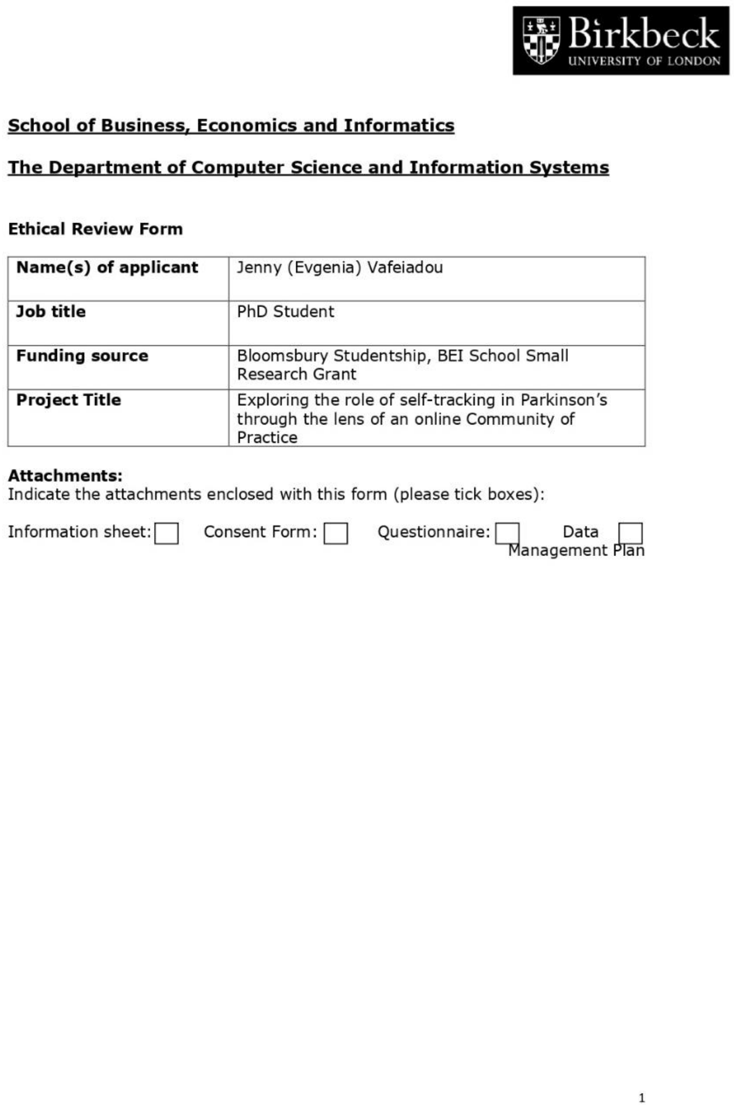
Young, A. L., & Miller, A. D. (2019). "This Girl is on Fire": Sensemaking in an Online Health Community for Vulvodynia. *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, 1–13.

Zhang, J. (2017). Supporting information needs of transitional phases in diabetes management through online health communities. *CSCW 2017 - Companion of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing*, 107–111. https://doi.org/10.1145/3022198.3024942

Zhang, X., & Liu, S. (2022). Understanding relationship commitment and continuous knowledge sharing in online health communities: a social exchange perspective. *Journal of Knowledge Management*, *26*(3), 592–614. https://doi.org/10.1108/JKM-12-2020-0883

Zou, N. (2022). From Data to Action: Toward a Framework for Collective Personal Informatics in Dementia Care. *CHIIR 2022 - Proceedings of the 2022 Conference on Human Information Interaction and Retrieval*, 391–395. https://doi.org/10.1145/3498366.3505844

Appendix 1 – Study I Ethics Application



Birkbeck
UNIVERSITY OF LONDON

School of Business, Economics and Informatics

The Department of Computer Science and Information Systems

Ethical Review Form

Name(s) of applicant	Jenny (Evgenia) Vafeiadou
Job title	PhD Student
Funding source	Bloomsbury Studentship, BEI School Small Research Grant
Project Title	Exploring the role of self-tracking in Parkinson's through the lens of an online Community of Practice

Attachments:
Indicate the attachments enclosed with this form (please tick boxes):

Information sheet: ☐ Consent Form: ☐ Questionnaire: ☐ Data Management Plan ☐

Description and rationale or proposed project

This project aims to capture the learning aspects of experiencing a chronic disease for People with Parkinson's focusing on learning with technologies and further identify how we can improve the design of technologies which support PwP to improve self-management. The rationale is to identify critical cases in the use of self-tracking tools for People with Parkinson's who participate in the online forum HealthUnlocked while highlighting the social dimension of an individual learning practice, that of self-tracking.

The amount of learning which occurs online is rapidly increasing since more and more patients go online to acquire disease specific knowledge, find tools, and participate in online communities. Particularly, the aim of this initial phase of the project is to understand how people with Parkinson's learn about their disease and how the acquire new knowledge and skills. I will especially look into use of self-tracking systems as a learning tool and further identify the strengths and limitations of the existing digital technology. The online forum offers a good starting point as people with Parkinson's interact with peers and express attitudes and beliefs regarding their symptoms and dealing with the disease. Therefore, I am interested in how learning happens in an online social context, how self-tracking as a learning strategy can have a social dimension and how individual self-tracking reports can affect both the individual and the community.

Moreover, through the forum discussions I can identify different cases of people who use such technology efficiently, people who avoid to use such tools or people that could potentially use it in the future. It is important to identify the whole spectrum of the users which will help me capture a clearer picture of how this group responds to the available technology and whether the existing technology satisfies their learning goals. I will also use the Community of Practice theory to capture the social account of self-tracking and how this fits to the wider learning ecology of living with Parkinson's.

The data will be aggregated from the posts published within the last year in the online Parkinson's community embedded in the website Health Unlocked. Initially, I will identify common themes regarding the learning aspects of experiencing Parkinson's. Subsequently, I will apply the concept of the Community of Practice to the context of the online patient community to point out the social quality of learning in relation to patient. Qualitative thematic analysis will be employed after anonymising the posts. Furthermore, I will study which self-tracking practices are used by people with Parkinson's, how members of the community use them and how they communicate their findings in the community.

The overall aim is to understand what matters the most to people with PwP; how important learning is for PwP ; and what the key elements that technologies offer to patients but also the considerations which patients hold and as a result hinder PwP from using them for learning purposes.

Ethical issues:

The data will be aggregated from 5K posts published in the online Parkinson’s community embedded in the website HealthUnlocked. No identiafiable information such as user name, age and country of origin will be used as the posts will be deanonymized by HealthUnlocked before given to us. Also, the number of posts sits within the protection guidelines followed by HealthUnlocked and posts from people who have opted out of research participation will not be included. Qualitative thematic analysis will be employed. The aim is to identify common themes regarding the learning aspects of experiencing Parkinson’s and the use of digital tools without referring to specific individuals.

I confirm that the proposed project conforms with College and professional ethical guidelines, as indicated: *(please delete as appropriate)*

1. Access to participants: **YES** / NO / DON’T KNOW
2. Informed consent: **YES** / NO / DON’T KNOW
3. Anonymity and Confidentiality: **YES /** NO / DON’T KNOW
4. Potential Harm to Participants: YES / **NO** / DON’T KNOW
5. Potential Harm to Researcher(s) YES / **NO** / DON’T KNOW
6. Potential Harm to the College: YES / **NO** / DON’T KNOW
7. Participants’ right to decline to take part: **YES** / NO / DON’T KNOW
8. Uses of the information (including publication): **YES** / NO / DON’T KNOW
9. Conflicts of Interest: YES / **NO** / DON’T KNOW
10. Other relevant ethical concerns, including those arising from internet research (please specify): YES / **NO** / DON’T KNOW

Classification of project *(please delete as appropriate)*:

ROUTINE / SENSITIVE / EXTREMELY SENSITIVE

The applicant: Jenny (Evgenia) Vafeiadou Date: 26/07/2018

I confirm the proposal classification as:

ROUTINE **/ SENSITIVE / EXTREMELY SENSITIVE**

Appendix 2 – Study II Ethics Application

Birkbeck
UNIVERSITY OF LONDON

School of Business, Economics and Informatics

The Department of Computer Science and Information Systems

Ethical Review Form

Name(s) of applicant	Jenny (Evgenia) Vafeiadou George Roussos
Job title	PhD Student Professor of Pervasive Computing
Funding source	Bloomsbury Consortium Studentship
Project Title	Social sensemaking of self-tracked data within an online community

Attachments:
Indicate the attachments enclosed with this form (please tick boxes):

Information sheet: ☐ Consent Form: ☐ Questionnaire: ☐ Data Management Plan ☐

Description and rationale or proposed project

This project forms part of the doctoral programme of research in “Participatory self-quantification for patients through IoT-based medical devices” funded by a Bloomsbury Consortium. During the first part of this doctoral research, a study on the role of self-tracking was conducted in relation to self-management and its complexities specifically for Parkinson’s. Notably, there was a focus on how people individually make sense of their self-tracked data. The data for the above study , containing 5,000 individual posts, were obtained under licensing from the social network for health HealthUnlocked. Data were provided fully anonymized and randomised. Consent was a core element of privacy protection provisions and was obtained as part of signing up for HealthUnlocked. Ethical approval for this study was obtained in December 2017. The findings of the above study suggested that People with Parkinson’s attempt to address the challenges of managing a complex disease through self-tracking and individual sensemaking.

Given the key role of online health communities as part of self-management (Reeves et al., 2014), the current study aims to fill the gap in the literature regarding the social nature of self-tracking in the context of chronic disease self-management. Previous studies of online health communities have focused on information seeking (Nambisan, Permanente, & Hopkins, 2011), emotional and social support (Gui, 2017) and knowledge sharing (Yan, Wang, Chen, & Zhang, 2016). Moreover, existing research offers some insights into collaborative sensemaking processes in online health forums. In one such study, the researchers found that diabetes patients build shared meanings through discussions, perspective negotiation, and conflict resolution (Mamykina, Nakikj, & Elhadad, 2015). Research in domains such as activity tracking has shown both the value and the challenges of sharing self-tracked data in social context towards understanding and making sense of one’s own data (Puussaar, Clear, & Wright, 2017).

Building on existing work on online communities and adapting it to the context of health, the online community will be approached as a sensemaking space (Bourne, 2017). The current project aims to understand how members' collaboration can facilitate or complicate sensemaking of self-tracked data in relation to self-management of a complex disease. Specifically, will research the social context in which self-tracking data can be shared and collectively understood. Particularly, this study will explore how interactions within an online health social network inform or reconfigure the individual self-tracking practices and vice versa.

The analysis will be based on the same data set obtained HealthUnlocked and the Parkinson's Movement. However, the structure of this data set limits the ability to interpret patient forum posts in their context and for this reason the aim is to augment the data with contextual information obtained form the open web. Specifically, a consideraly reduced dataset of less than 100 posts will be selected as critical cases of considerable social interaction in relation to self-tracking. Based on these posts, we will obtain -from a customised google search engine- additional contextual information related to the semantic content of each post for further manual analysis using NVivo 12 software. No personally identifiable information will be added to the data and no attempt will be made to re-identify the patient associated with the original posts. Only text-based context will be employed to provide a richer context within which the post-critical case (part of the original HealthUnlocked dataset) will be analysed.

The purpose of this project is to unpack how an online health community can address the complexities of self-tracking and disease sensemaking in the context of health conditions which do not have well-understood etiology, heterogeneous symptoms, and unexplained differences in treatment responses. This study aims to shed light on how to support PwP in self-tracking, disease sensemaking, and further better facilitate the collective sensemaking processes of self-tracked data in the context of chronic disease.

Ethical issues:

This project will have as a starting point a data corpus of 5,000 posts published in the online Parkinson's community embedded in the website HealthUnlocked. Critical cases-posts from this initial data corpus will be selected to be studied within a broader context which, in this case, suggests the thread. No identifiable information of any type will be used and all analyses will be carried out on fully anonymised data. In particular, the HealthUnlocked social network ensured that the initial data corpus did not include posts from individuals who have opted out of research participation. Therefore, based on posts from the initial data corpus, the studied threads will include only posts from people who have given consent and any posts which cannot be identified as such, will be excluded from the analysis. Qualitative thematic analysis will be employed. All data will be stored fully anonymised at all times and will be stored in password protected format. Finally, all data will be stored on an encrypted file system.

I confirm that the proposed project conforms with College and professional ethical guidelines, as indicated: *(please delete as appropriate)*

1.	Access to participants:	**YES**
2.	Informed consent:	**YES**
3.	Anonymity and Confidentiality:	**YES**
4.	Potential Harm to Participants:	**YES**

5. Potential Harm to Researcher(s) **YES**
6. Potential Harm to the College: **YES**
7. Participants' right to decline to take part: **YES**
8. Uses of the information (including publication): **YES**
9. Conflicts of Interest: **YES**
10. Other relevant ethical concerns, including those arising from internet research (please specify): **YES**

Classification of project *(please delete as appropriate)*:

ROUTINE / SENSITIVE / EXTREMELY SENSITIVE

The applicant: Jenny (Evgenia) Vafeiadou Date: 11/02/2019

I confirm the proposal classification as:

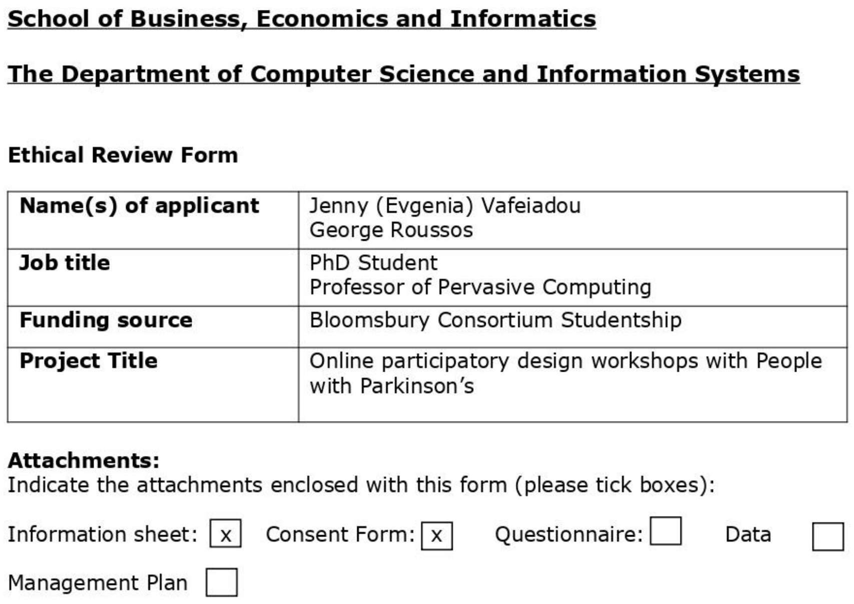
ROUTINE / SENSITIVE / EXTREMELY SENSITIVE

Decision (please delete as appropriate):

Acceptance / ~~Refer to SEC / Refer to CREC / Refer back / Rejection~~

Departmental Research Ethics Officer: Felix Raidl Date: 24/02/2020

Appendix 3 – Study III Ethics Application



School of Business, Economics and Informatics

The Department of Computer Science and Information Systems

Ethical Review Form

Name(s) of applicant	Jenny (Evgenia) Vafeiadou George Roussos
Job title	PhD Student Professor of Pervasive Computing
Funding source	Bloomsbury Consortium Studentship
Project Title	Online participatory design workshops with People with Parkinson's

Attachments:
Indicate the attachments enclosed with this form (please tick boxes):

Information sheet: ☒ Consent Form: ☒ Questionnaire: ☐ Data ☐

Management Plan ☐

Description and rationale or proposed project

This project forms part of the doctoral programme of research in "Participatory self-quantification for patients through IoT-based medical devices" funded by the Bloomsbury Consortium. During the first part of this doctoral research, two studies were conducted to examine the role of self-tracking in self-management and its complexities specifically for Parkinson's as well as the role of online communities to make sense of the self-tracked data. A key outcome of this prior work was the acknowledgement that PwP self-track information across many different domains and self-tracking reports provide a firm way for discussing PwPs' distinctive health experiences within the online community.

The current study aims further builds on this research and examine how we can incorporate design recommendations research for self-tracking features in the user interface of an online community. To do so, 5 members from an online Parkinson's community will be recruited in order to participate in three one-hour online design workshops. Recruitment will be conducted through Parkinson's charities and social media. I will post an open call which will be accompanied by a poster and the participants will be asked to contact the researcher if they are willing to participate. Once they get in touch, they will receive the information sheet which describes in more detail the purpose of the study. All the participants will need to sign a consent form before their participation. It will be explicit that a participant can decide to withdraw their participation at any point either during the workshop or in between sessions.

This study will be conducted in three phases:

Phase 1 – Participants will be asked to complete a creative task that is used to scope the design project in the online session. In line with this, participants will receive a kit with an assortment of cultural probes (the kit will be disinfected thoroughly before sent off). Cultural Probes were first developed by Gaver et al (1999) as a research method to design technologies for the home. It is a technique that is used to inspire ideas in a design process and serves as a means of gathering inspirational data about people's lives, values and thoughts.

Phase 2 – Participants will be asked to generate new ideas on how to design for self-tracking.

Phase 3 – Participants will be asked to give feedback to a prototype developed based on their ideas in phase 2.

This study aims to shed light on how to support PwP in self-tracking, disease sensemaking, and further better design online communities and self-tracking tools. The findings of this research study will be reported in the PhD thesis. Also, they will be published in peer-reviewed publications.

Ethical issues:

People with early stages Parkinson's (without any severe cognitive impairments) will be recruited. The study of how PwP interact with the NHS are outside the scope of this study as the entire focus is on the lived efforts of every day self-management. The participants will receive a thorough explanation of the project and what their participation entails. We do not anticipate any potential harm for PwPs' participation in the study. Carers can also participate if participants find it helpful. We do not anticipate any harm for the researcher or the College from the conduct of this research.

The sessions will be video recorded but no identifiable data will be used for the analysis. Artefacts will be collected and reported as part of the interpretive analysis. The video recordings will be transcribed and qualitative analysis will be employed. All data will be stored fully anonymised at all times and will be stored in password protected format. Video recordings will be deleted as soon as the PhD project concludes. Finally, all data will be stored on an encrypted laptop.

Reference

Gaver, Bill, Tony Dunne, and Elena Pacenti. "Design: cultural probes." interactions 6.1 (1999): 21-29.

I confirm that the proposed project conforms with College and professional ethical guidelines, as indicated: *(please delete as appropriate)*

1. Access to participants: **~~YES~~**
2. Informed consent: **~~YES~~**
3. Anonymity and Confidentiality: **~~YES~~**
4. Potential Harm to Participants: **~~YES~~**
5. Potential Harm to Researcher(s) **~~YES~~**
6. Potential Harm to the College: **~~YES~~**
7. Participants' right to decline to take part: **~~YES~~**
8. Uses of the information (including publication): **~~YES~~**
9. Conflicts of Interest: **~~YES~~**
10. Other relevant ethical concerns, including those arising from internet research (please specify): **YES**

Classification of project *(please delete as appropriate)*:

~~ROUTINE~~ / SENSITIVE / ~~EXTREMELY SENSITIVE~~

The applicant: Jenny (Evgenia) Vafeiadou Date: 18/04/2021

I confirm the proposal classification as:

~~ROUTINE~~ / SENSITIVE / ~~EXTREMELY SENSITIVE~~

Decision (please delete as appropriate):
Application was referred to SEC and accepted on 07/05/2021. The SEC notes that the applicant should take precautions (PPE) when preparing materials to be send to vulnerable participants to avoid potential COVID transmission.

Departmental Research Ethics Officer: Felix Reidl Date: 13/05/2021

Appendix 4 – Study III Poster

Birkbeck
UNIVERSITY OF LONDON

Knowledge Lab
UCL

People with Parkinson's
who participate in Online Health Communities (HealthUnlocked, PatientLikeMe etc)

We Need You

Be part of 3 online workshops to help us design better technologies for supporting people with Parkinson's in their everyday lives

Send an email at
j.vafeiadou@dcs.bbk.ac.uk

Managing Parkinson's in everyday life

Appendix 5 – Study Participant Information Sheet

Department of Computer Science &
Information Systems

Malet St, Bloomsbury, London WC1E 7HX

Researcher : Jenny Vafeiadou, PhD Candidate

Study Title: Online Participatory Design Workshops with People with Parkinson's (PwP)

PARTICIPANT INFORMATION SHEET

1. Why is this research being conducted?

As part of understanding and managing Parkinson's better in everyday life, PwP participate to online health communities and/or self-track. Thus, this study brings these two elements together as we need to understand how we can better design self-tracking features embedded in online health communities to support better PwP in everyday life.

2. Why have I been invited to take part?

You have been invited to take part because you are a Person with Parkinson's, you participate in an online community and/or self-track.

3. Do I have to take part?

No, it is up to you to decide whether to take part. You can ask questions about the research before deciding whether or not to take part. If you do agree to take part, you may withdraw yourself from the study at any time, without giving a reason, by advising me of this decision. At this point, you will be asked what you wish to happen to the data you have provided up to that point. You can withdraw any information you have contributed to the research so anything you shared will not be included in the research outputs.

4. What will happen to me if I take part in the research?

If you are happy to take part, I will ask you to sign a consent form. I will provide you with a kit which will include some materials such as notebooks, stickers, pens that you can use to collect information about yourself and your Parkinson's self-management. Following this, I will schedule three one-hour long design workshops which will happen online using the videoconferencing platform Zoom and will take place on a weekly basis. The workshops will include 4 other People with Parkinson's.

Together we will talk about your thoughts and experiences in a small group. With your consent, I would like to video record the workshops so I can have an accurate record of your ideas. You can ask to pause or stop the workshop at any time.

5. Are there any potential risks in taking part?

There are no obvious and known risks in your participation.

6. Are there any benefits in taking part?

There are a few benefits about taking part. I hope you will enjoy sharing your experiences with me and other People with Parkinson's. Second, you may learn from others' best practices about managing better your disease in everyday life. Third, you will be helping to design better self tracking tools and online health communities for People with Parkinson's.

The research may be published in an academic publication. The research will be seen by my PhD supervisors and examiners.

7. Who has reviewed this study?

This study has been reviewed by, and received ethics clearance through, the Birkbeck, University of London Research Ethics Committee

8. *What happens to the data provided?*

The information you provide during the study is the **research data**. Any research data from which you can be identified (such as Name, Occupation, Age, Video recording) is known as personal data and are protected by UK law.

In this study, your personal data will be protected using a variety of state-of-the-art security measures such as encryption, password-based access control and anonymisation. Only the researcher and her supervisors will have access to the research data.

Any personal data used in presentations and research publications will be anonymised. Personal data will be deleted at the completion of the PhD project.

Data Protection Privacy Notice

The data controller for this project will be Birkbeck, University of London. The Birkbeck Data Protection Office provides oversight of Birkbeck activities involving the processing of personal data, and can be contacted at dpo@bbk.ac.uk.

Any data during this research will not to be transferred outside the UK and the EU. You can request access to your personal data and the correction or removal of such personal data.

If you are concerned about how your personal data is being processed, please contact Birkbeck Data Protection Office in the first instance at dpo@bbk.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data

protection-reform/overview-of-the-gdpr/individuals-rights

Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Jenny Vafeiadou, PhD Candidate

Department of Computer Science and Information Systems

Birkbeck, University of London

Malet St, Bloomsbury

Phone number: 07492429840

University email: j.vafeiadou@dcs.bbk.ac.uk

Appendix 6 – Study III Consent Form

Department of Computer Science &
Information Systems

Malet St, Bloomsbury, London WC1E 7HX

Researcher : Jenny Vafeiadou, PhD Candidate

Study Title: Online Participatory Design Workshops with People with Parkinson's

CONSENT FORM FOR ADULTS

Birkbeck, University of London

Study Approved by the Research Ethics Committee

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by choosing YES in each box below I am consenting to this element of the study. I understand that it will be assumed that NO or no selection in a box means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction	YES/NO
I understand that I will be able to withdraw my information according to the GDPR guidelines.	YES/NO
I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified. I understand that my data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications.	YES/NO
I understand that my information may be subject to review by responsible individuals from the University for monitoring and audit purposes.	YES/NO
I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason.	YES/NO
I understand the direct/indirect benefits of participating.	YES/NO
I understand that the data will not be made available to any commercial organizations.	YES/NO
I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	YES/NO

I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher.	YES/NO
I consent to my participation to be video recorded and understand that the recordings will be stored anonymously, using password-protected software and will be used for specific research purposes.	YES/NO
I voluntarily agree to take part in this study.	YES/NO

___________________________ _________________ ____________________

Name of participant Date Signature

___________________________ _________________ ____________________

Researcher Date Signature