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# Self-tracking in Parkinson's

## The lived efforts of self-management

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### ABSTRACT

People living with Parkinson's disease engage in self-tracking as part of their health self-management. Whilst health technologies designed for this group have primarily focused on improving the clinical assessments of the disease, less attention has been given to how people with Parkinson's (PwP) use technology to track and manage their disease in their everyday experience. We report on a qualitative study in which we systematically analysed posts from an online health community (OHC) comprising people with Parkinson's. Our findings show that PwP track a diversity of information and use a wide range of digital and non-digital tools, informed by temporal and structured practices. Using an existing framework of sensemaking for chronic disease self-management, we also identify new ways in which people with Parkinson's engage in sensemaking, alongside a set of new challenges that are particular to the character of this chronic disease. We relate our findings to technologies for self-tracking offering design implications.

### CCS CONCEPTS

• **Human-centered computing** → **Collaborative and social computing**; *Empirical studies in collaborative and social computing*

### KEYWORDS[22]

Parkinson's disease, self-tracking, sensemaking, self-management

## 1 Introduction

One third of the people worldwide live with a chronic disease [18]. To address the challenges resulting from the increasing numbers of people with chronic diseases, public health systems are revisiting the traditional doctor-driven model of healthcare and embracing a patient-centric approach [65]. A central tenet of this approach is for patients to be informed, and thus empowered to practise 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” [57].

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 for example following a demanding treatment plan, changing long-standing routines and habits, or managing physical symptoms [62]. Personal



informatics (PI), a “class of systems that help people collect personal information to improve self-knowledge” [30], 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 PI 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. [39, 62], or by designing and evaluating new PI tools e.g. [8, 23]. In the context of this research, researchers have investigated a wide range of PI applications and sensing domains including symptom tracking [34], tracking physiological measurements such as sleep [64] and lifestyle activities [43].

In this paper, we focus on Parkinson’s disease, the second most commonly occurring neurodegenerative disease [51] and one of the most common illnesses in later life. More than 10 million people worldwide live with Parkinson’s disease and 60,000 are newly diagnosed each year in the United States alone [50]. Parkinson’s is multidimensional in its presentation including physical, cognitive, and emotional symptoms [51] and hence, requires numerous self-management decisions to be made daily as well as significant alterations to one’s lifestyle as the disease progresses [51]. Moreover, PwP often also experience other comorbidities, which further affect their everyday experiences [55]. Previous studies have investigated the design and use of information technology tools that support self-tracking of motor symptoms and medication adherence [3, 19, 22]. Yet, little attention has been given to the *lived efforts* of self-management, that is the “practical, prospective and felt experiences of personal tracking for health and wellbeing” [54], with a view to examine the complexities that result from living with a chronic disease such as Parkinson’s. 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, setting this investigation in the context of everyday experience of PwP can inform new design opportunities for self-tracking technologies that better support individuals in day-to-day self-management.

To achieve this goal, we conducted an exploratory qualitative study of a social network dedicated to health called ‘HealthUnlocked’. In line with our aim to capture the nuances of people’s lived efforts to manage the disease, we make a clear distinction between self-tracking and PI. We adopt a broader definition for the concept of self-tracking that focuses on *practice* rather than on the use of PI technology. Additionally, our definition of self-tracking encapsulates both quantitative (e.g. motor measures) and qualitative (e.g. mood) data. Therefore, reflecting a “lived” perspective on self-tracking [54], we 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” [30]. This information “could be in the form of numbers generated by wearable sensors, nominal or categorical, ordinal scales, photos, notes, etc.” [1].

The contributions of our empirical study are threefold. First, our study provides a descriptive account of how PwP carry out self-tracking and sensemaking for their self-management. Second, we contextualize a previously developed framework of sensemaking for chronic disease self-management [37] to Parkinson’s demonstrating that the characteristics of this chronic disease pose particular challenges during the process of sensemaking. Lastly, building on our empirical understanding of self-tracking practices and sensemaking, we 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 PwP’s lived efforts to manage their health; (ii) the continued need of tracking 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.



## 2 Related Work

### Self-tracking in chronic disease self-management

Research has shown that a one-size-fits-all approach to self-management is not efficient for maintaining patient wellbeing as people's needs differ substantially even when they have the same condition [17]. Taking into consideration the need for personalised care [45], a growing number of studies explore how self-tracking through the use of PI can address the need for personalization by supporting people to collect personally meaningful data that inform decisions about their health. To this end, previous research has taken different perspectives to understand the use of self-tracking and its benefits in the self-management of a chronic disease. Self-tracking has been viewed from a clinical lens with a focus on how PI tools can support clinical consultation goals, such as helping people take medications as prescribed in order to reduce treatment non-adherence [28], or examining how data from existing fitness technologies such as Fitbit reshape the clinical practice [42].

Other research has explored the use of PI tools in relation to different dimensions of people's disease self-management [35]. This work has demonstrated that people with chronic disease can benefit from employing self-tracking to better understand the elements of their disease through increased awareness [40], work on a specific goal that improves their health [56], facilitate self-monitoring as a self-directed intervention strategy for self-management [62] or use it as a self-diagnostic strategy for finding associations and cause-effect patterns [36, 54]. Furthermore, a different line of work has recognized that self-tracking can be employed in diverse ways to serve a variety of goals informing chronic disease self-management [35]. This diversity stems from the broader complexities that derive from the everyday experience of self-management. Whilst self-management can include predictable tasks linked to the clinical aspect of the disease, such as treatment, it is also informed by the person's particular informational, emotional and even technological needs [38].

Building on this last lens, researchers have begun to investigate the alignment between the clinical requirements of self-tracking for the purposes of self-management and the everyday experience of people with a chronic disease [47, 60]. Karkar et al. [23] built a self-tracking tool to facilitate the identification of food triggers for people with irritable bowel movement. In evaluating this tool, the researchers found that users sometimes could not sustain the scientific rigor of their practices as they did not always fit with the nature of the everyday experience. For example, some participants were not interested in a binary outcome from tracking their diet and they were more interested in how much of a particular food they could have without a significant effect on their quality of life. Storni [59] examined how diabetic patients employ self-monitoring technologies (e.g. blood pressure monitors and glucose meters) and found that people often appropriated them in unique and sometimes idiosyncratic ways, contrary to the rigid criteria indicated by the manufacturers of these technologies. He concluded that when designing this kind of technology, we should acknowledge that everyday experience includes many factors at play that differ from person to person, and thus there is not a single way of practising self-management. This line of research shows that the use of self-tracking technology based on principles of clinical practice can be reshaped by the lived effort of self-management in the context of everyday experience.

### Parkinson's and health technologies

Parkinson's disease is a very complex chronic disease and one of the most common neurodegenerative illnesses in aging. The multidimensional character of Parkinson's disease demands daily self-care decisions and significant alterations to one's lifestyle, with major effects on people's routine [51]. Parkinson's disease symptoms vary between people affecting them differently at a motor, cognitive and emotional level [51]. This in turn requires the individuals' active self-management including the management of motor symptoms such as tremor, freezing, unbalance, as well as cognitive and emotional symptoms such as mood alteration, dementia or sleep disturbances. As the disease progresses, PwP can face an increasing set of physiological, emotional, and medical issues that introduce new needs for information and healthcare support. Another characteristic of Parkinson's disease is its intraindividual variability which reflects the relatively short-term



and reversible changes in an individual's performance across occasions of the same task [16]. This disease characteristic introduces challenges to providing standardised information regarding day-to-day self-management, which becomes a highly personalised issue. Given the progressive and often non-predictable nature of the disease, being adherent to a predetermined care plan is generally not feasible over the course of a person's life with Parkinson's. PwP must exercise a high-quality, frequent self-reflection, as well as have an adaptive attitude in order for their self-management plans to work effectively. This contrasts with self-management of other chronic conditions which are considered to be relatively stable such as diabetes mellitus, hypertension or asthma [29]. The status of the symptom manifestation in these diseases doesn't tend to change dramatically over the course of a person's life if an appropriate treatment plan is in place [49]. Consequently, these diseases do not require persistent changes to how they are managed, as is the case in Parkinson's.

Aligning with the clinical lens reported in the previous section, research examining the role of health technology in Parkinson's has tended to prioritise improvements in clinical assessments [58] and particularly that of motor symptoms [3, 19, 25]. Taking into consideration the current limitations of performing a one-off assessment, which provides a limited view on the progression of the disease and PwPs' overall condition, this approach addresses the need for supplying long-term information to the doctor [58, 68]. A further objective of this clinical focus has been to facilitate the individual's adherence to self-management plans as devised by clinicians [63]. For example, Stamate et al. [58] developed a medical device that performs smart-phone clinical assessment of motor symptoms and can be used by Parkinson's patients and their carers at home. This self-tracking technology provides high-quality data collection, while also minimizes the time of data collection in order to facilitate user adherence. Another example is the uMotif app, which was designed to support medication adherence and clinical consultation in Parkinson's disease [28] 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.

Whilst this work has contributed new tools for the self-management of Parkinson's from a clinical point of view, some researchers have begun to highlight the need to understand the lived efforts of PwP in relation to their self-tracking and everyday self-management. As reported in Section 2.1, this lens on self-management has been taken in the context of other chronic diseases, such as work by Storni [59] in diabetes self-management. Taking a holistic view on self-management in Parkinson's, Nunes and Fitzpatrick [48] found that self-management is informed by competing needs, such as disease-related tasks and practical, as well as routine activities, including family and work responsibilities. Based on their findings, the researchers argue that self-management does not align with the structured medical processes which typically guide the design of Parkinson's health technology. Alongside the complex tensions PwP face in managing their disease in the context of their everyday experience, other work has shown how the disease characteristics can introduce particular challenges for PI technology. Mishra et al. [44] examined the role of Parkinson's symptom trackers in how PwP coped with their progressive chronic disease. They described the ambiguity of Parkinson's symptoms and the challenges this creates for PwP to identify and track their symptoms. They propose the need to design PI technologies, which account for this ambiguity in light of the progressive nature of the disease.

## **A sensemaking approach to chronic disease**

In the introduction, we defined self-tracking as a practice that is carried out through PI tools, or other self-tracking means, for the purpose of fostering individuals' self-knowledge and self-reflection [30]. In this paper, we conceptualise this process in line with sensemaking, which is a cognitive process that informs health-related actions reflecting people's efforts to make sense of their health [27]. Sensemaking is also an active inquiry that recognises the individual's agency [6]. Applied to the context self-tracking for chronic disease self-management, the sensemaking lens has been taken to move beyond what people track, and why, to how they understand their disease through the aid of self-tracking and how this affects the way they can engage in self-management (e.g. [67]).



Faisal et al. [13] explain that sensemaking is “a compound process that takes into account various interconnected components ranging from medical readings to the surrounding environment and associated lifestyle”. This view emphasises the application of sensemaking to the lived efforts of self-management in the context of everyday experience, as well as the many interconnected factors that people with chronic disease must make sense of. The same authors propose that 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 [13] – aligning with our definition of self-tracking as a practice.

Past research has theorised how individuals collect and reflect on their personal data through different frameworks and models such as the Stage-based Personal Informatics model [30] or the Self-Experimentation framework [24]. In our work we adopt the definition and framework of sensemaking developed by Mamykina et al. [37] 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” [37]. This sensemaking definition accounts for the complexities that come with managing a chronic disease while emphasizing the cognitive process underpinning disease management. By highlighting ‘the chaos of lived experience’ it aligns with the findings by Nunes and Fitzpatrick [48], who showed that PwP may juggle a complex combination of everyday self-management tasks in an effort to minimize the disruption of their lifestyle and maintain an acceptable quality of life. Thus, employing the sensemaking framework for our analysis is in a conceptual alignment with the perspective taken in this research and our focus on the lived character of self-tracking.

## **Sensemaking Framework**

Built on the case of diabetes, Mamykina et al. [37] argue that the sensemaking framework (see Fig. 1) is generalisable to other chronic diseases that require self-monitoring as part of the self-management. According to the framework, self-management activities are carried out either 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 is the result of experience and it comes naturally to individuals without requiring explicit effort and attention. An individual engages in perception through the monitoring and classification of new information about one’s health. For example, measuring the sugar blood level every day provides new information with every measurement. Explaining the measurement of the sugar blood level, in this example, 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 characterizes 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 use a combination of their general knowledge, past experiences and knowledge of others to construct possible explanations and new models which are consonant with the new information. In the action phase, the individual selects the most plausible explanation, which will allow 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 model of self-management is updated accordingly and the new action becomes routine. Therefore, the habitual mode is re-established and the model of self-management mode is in place until new observations and experiences challenge the individuals’ existing mental models requiring re-examination of inferences or redefinition of variables.



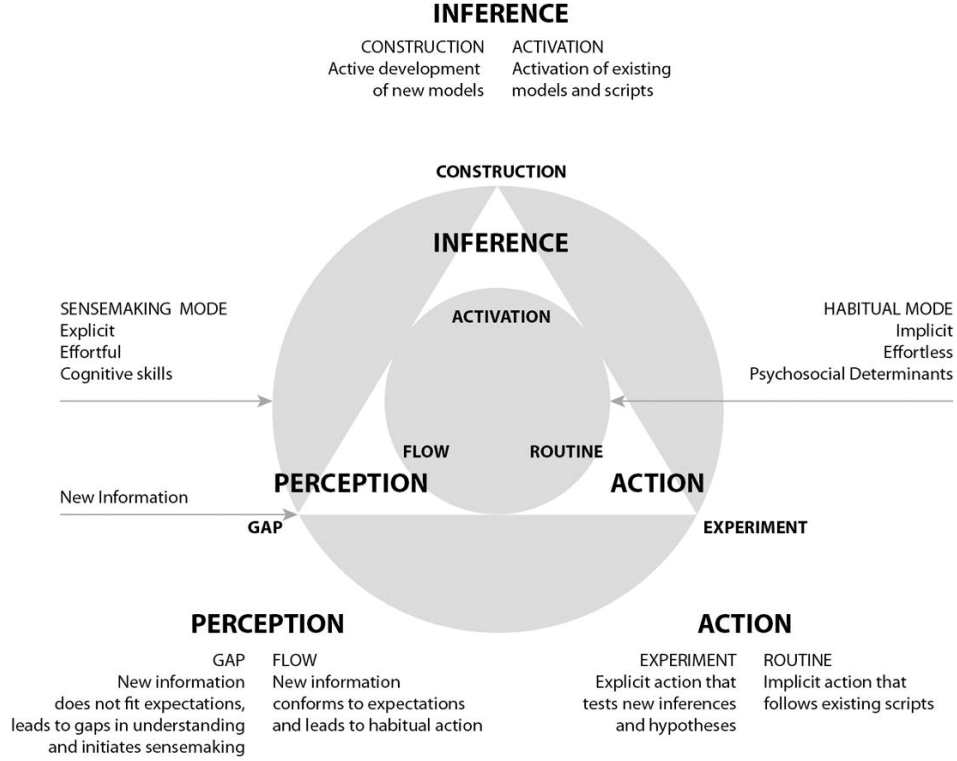


Figure 1: Sensemaking framework for chronic disease self-management [37]

### 3 Motivation and Research Questions

In summary, a growing body of research shows that self-tracking for disease self-management is lived and needs to be understood in the everyday context [23, 47]. In adopting the lens of self-tracking as “lived” [54] we define self-tracking as a practice. In the context of Parkinson’s, where self-tracking has been often studied from a clinical perspective, this lens can support a new understanding of how self-tracking happens in the context of self-management as there is not currently a standard practice in Parkinson’s self-tracking because of its complex disease character. Furthermore, to understand the value of self-tracking for self-management, it is necessary to additionally consider the cognitive process of disease sensemaking. Past work [25] indicates that self-tracking in itself is important, but not sufficient, in motivating individuals into action. Given the multidimensional character of the disease, the interpersonal differences as well as the intravariability in disease manifestation, it is ever important to understand self-tracking as part of people’s effort to understand the different ways the disease manifests. We use the Sensemaking framework [37] to understand how self-tracking currently fits within people’s self-management and address these gaps. This approach can help us 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 Parkinson’s self-management.

Building on previous research which has investigated self-tracking and sensemaking in the context of other chronic diseases and, our research contributes a new conceptualization of how Parkinson’s disease is negotiated and self-managed while opening up new opportunities to support the everyday needs of PwP. Our study seeks to address this through three research questions:

- What information do PwP self-track and why? (RQ1)
- What tools do PwP use for self-tracking and how they make their tool choice? (RQ2)

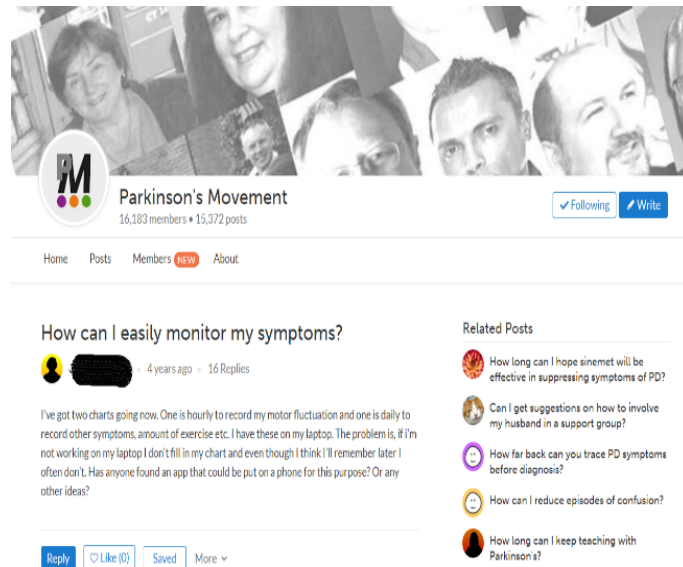


- How do PwP engage in sensemaking of self-tracked information and what self-tracking practices underpin sensemaking? (RQ3)

## 4 Methodology

### Research context and procedure

Parkinson's is a complex neurodegenerative disease. 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. In order 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 [15], we 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.



**Figure 2: Snapshot from Parkinson's Movement Posts**

The context of this study is the Parkinson's Movement, which is an OHC active within HealthUnlocked (HU). Established in 2011, and similar to other social networking sites, HU offers functionality for creating a personal profile, updating one's personal status and viewing news feeds (see Fig. 2). At present, HU includes over 700 health communities, each centred on a different condition, or health issue, with 4 million total active users [66]. While the Parkinson's Movement community was established in the UK through a partnership with the charity 'The Cure Parkinson's Trust' [69], 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 our research, we 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 thereof as they relate to Parkinson's self-management. Given that OHC, such as Parkinson's Movement, attract people who take ownership of their health we 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’, we anticipated that its members would be to some extent engaged self-advocates.

HU requires membership and thus posts are not publicly available [21]. Following the ethical research regulations of HU, we formally requested access to the posts. HU provided us 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, which usually belongs to a longer thread of 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 regarding 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 University ethics committee.

## Selection of events

We uploaded the 5,000-post data corpus obtained from HU to the qualitative data analysis software Nvivo (Version 12). Since our aim was to identify discussions held by online members about their self-tracking in relation to performing Parkinson’s self-management, we identified a set of keywords that would allow us to select appropriate events. To construct the keyword list and run the initial queries, the first author of the paper 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 conceptualizations of self-tracking [4, 13, 28]. We 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 are tracking [61] (see Table 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 were outside the scope of the study and were thus excluded. In total, this process resulted in 405 posts.

**Table 1: Types of information tracked by PwP reported in [61]**

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? The outside today Sweets treats Time Spent outside	Less Common



## Data Analysis

Following the selection of events, we started with a familiarization stage recommended in qualitative analysis where we read the posts extensively [7]. Three types of analysis were conducted collaboratively between the paper authors until the coding scheme was finalized (see Table 2). Any disagreements were resolved through discussion among the researchers. Subsequently, the first author analysed the remaining dataset.

First, we 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 us to create a comprehensive list of self-tracking information types and tools reported by PwP across the entire dataset. Second, we 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, we used the sensemaking framework [37] as a conceptual framework to identify instances of PwP's sensemaking (RQ3). For this last stage, a combined technique of deductive and inductive coding [14] was employed. Using the sensemaking framework, we created initial codes aligning with the framework's two modes and three phases. We then looked in the data for evidence of these pre-determined codes using them as a pre-existing coding frame (deductive analysis). If we diagnosed that the sensemaking process expressed in a post did not align with the codebook, we 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 reviewed and updated to fit the data [10].

**Table 2: Analytic Approach**

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

## 5 Findings

### Information tracked & Parkinson's everyday experience

Our findings revealed that PwP tracked a variety of information, which coalesced into four 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) captures 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 wellbeing, 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. The Table that follows summarises each domain and the associated information PwP tracked.

**Table 3: Parkinson's tracking domains and information**

Domain	Information tracked
Treatment	<ul style="list-style-type: none"> <li>• Medication schedule and/or adherence</li> <li>• Medication side effects</li> <li>• Medication efficiency</li> <li>• Alternative/Natural medicine efficiency</li> <li>• Overall Levodopa intake <sup>1</sup></li> </ul>
Parkinson's symptoms	<ul style="list-style-type: none"> <li>• Pain experienced</li> <li>• Fatigue experienced</li> <li>• Motor symptoms (Tremor, Rigidity, Dyskinesia, Slowness, Falls)</li> <li>• Drooling experienced</li> <li>• Psychology &amp; Emotions (Mood, Depression, Panic attacks)</li> </ul>
Generic health indicators	<ul style="list-style-type: none"> <li>• Bowel movement/Constipation</li> <li>• Blood pressure</li> <li>• Weight</li> <li>• Sugar levels</li> <li>• Temperature</li> <li>• Oxygen levels</li> <li>• Urine levels</li> </ul>
Lifestyle	<ul style="list-style-type: none"> <li>• Timings of meals in relation to medicine timings</li> <li>• Content of meals, diet, calories intake, protein intake</li> <li>• Physical activity and exercise</li> <li>• Sleep levels</li> <li>• Perceived quality of life</li> <li>• Amount of time spent on activities e.g. chores, hobbies</li> <li>• Timings of the day during which PwP are productive</li> </ul>

Across these four domains, the information tracked was captured and represented either quantitatively and/or qualitatively. Quantitative information included tremor severity (Parkinson's motor symptoms), medication timings (Treatment), and falls (Parkinson's motor symptoms). Qualitative information typically relied on the individual's subjective assessment such as perceived 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 recognized 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*

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<sup>1</sup> Levodopa is a synthetic substance that is converted in the brain to dopamine. It is used chiefly in the treatment of Parkinson's disease.



*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 as a means to make sense of their experience of living with Parkinson's. To express their lived efforts of 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 Parkinson's disease 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 the 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."*

## Self-tracking tools and the criteria for tool selection

Our 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 they were already using and were embedded in their daily routine. Table 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. The variety of digital tools employed evidences the diversity of quantitative and qualitative information tracked, as reported in the previous section. 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)..."*

**Table 4: Tools of self-tracking**

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



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 were 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, yet lack of access to their 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.”*

**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 as the following example shows: *“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 your next day or week give yourself 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 in order to evaluate the improvement, or deterioration, of their symptoms. One PwP, for example, reported tracking treatment across a period of 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.”*



## Sensemaking in Parkinson's

### 5.1.1 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 [37]. Our 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 after which their existing mental models were 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: *"Morning 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 were 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, as a result triggering the person's sensemaking mode due to a gap in disease understanding.

*"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 a hour or 2."*

While engaging in the inference phase of sensemaking, similar to the sensemaking process reported for diabetes [37], 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*, 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."*

Our analysis showed that once an action had a positive impact, PwP adopted the new activity and the new inferences developed were 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 and used multiple information types in order make sense of the situation. As a PwP explained, tracking different information informed their understanding of not suitable 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.”*

### **5.1.2 The distinctive character of sensemaking in the context of Parkinson's disease**

While our findings concurred with the sensemaking framework for chronic disease, there were also features of Parkinson's 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 [46] and thus, are often affected by more than one chronic condition that needs to be managed. Our findings showed 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 were 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 Parkinson's, or of a comorbid disease. For example, in the following quote, a PwP explained how they tracked his blood pressure in relation to his Parkinson's medication regime. Their aim was to understand if his doctors' diagnosis of hypertension was correct, or if the elevated blood pressure was the result of their Parkinson's 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 we 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 Parkinson's and its changing symptoms [46] were reported across many of the posts analysed. New gaps in understanding triggered the sensemaking mode as 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 his/her 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 were 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.

*“We have went along with the same plan for the last 5yrs and it seemed to be working fine, however my condition had deteriorated and we had not considered a change in the way we 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 were continuously questioned and revised. Rather than rely 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 [37] posits that self-tracking is an action-oriented activity aiming to ultimately reach a successful self-management routine. This example quote suggests that PwP constantly seek to optimise their self-management and this motivation acts as the trigger to the sensemaking mode.

### 5.1.3 Awareness-oriented sensemaking

Contrasting to the sensemaking framework, we found that Parkinson's self-tracking was sometimes awareness-oriented and did not involve the action phase. To this end, PwP used self-tracking to understand how their disease manifested; for instance, how their treatment worked, or if a particular disturbance they experienced was associated with Parkinson's. 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 your 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 he kept a chart about his 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 Parkinson's 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 implementing continuous planning and tracking their time spent on activities they know that they can make things happen:

*“All of it has challenged my morale, confidence, self esteem and at times it has felt impossible. But thats 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.”*

## 6 Discussion

Our 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, we wanted to explore how PwP build on these practices to engage in sensemaking in order to manage their disease. In this section, we discuss these themes to present Parkinson’s particularities of sensemaking in relation to their day-to-day self-management. We interpret our findings from a design lens and we aim to identify design opportunities for digital self-tracking designed to support the everyday experience and lived character of self-management.

### Self-tracking tools for sensemaking

In agreement with Faisal et al. [13] who argue that people with a chronic disease value diverse information, our findings show that PwP track information types across four interrelated domains. Reflecting the multidimensional character of Parkinson’s [20, 52], the symptoms tracked ranged from motor symptoms to emotions, or pain experienced. Furthermore, our findings support Mamykina et al. [37] 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 our study 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. Our 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” [48], which could be facilitated through the tracking of the different domains and types of information that concern PwP.

Toward this goal, our research poses a number of implications for the design of technology that can support self-management through self-tracking. First, we 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 Mutiple Sclerosis [5]. Thus, technology that may support the pre-configuration of information types and custom scales could provide a motivation and scaffold for the tracking process of qualitative aspects of the disease.

Second, we 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. [39] 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 – can support the future design of self-tracking technology more broadly, while specifically suggesting the value of building upon already adopted, portable technology.

## **The Particularities of Parkinson's sensemaking**

When applying the sensemaking framework [37] 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 and 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 time frame. 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, our 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 motor symptoms, as well as 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. [23] and Ayobi et al. [4] who have already identified the importance of explicitly supporting self-experimentation in the design of self-tracking for other chronic diseases.

On the whole, our findings show similarities in sensemaking between diabetes and Parkinson's. However, there are also core differences which derive from Parkinson's disease characteristics. Young and Miller [67] have previously argued for the need to refine the sensemaking framework to account for chronic diseases with unknown or complex causal mechanisms. Our study offers empirical support for this claim. As presented in Section 2.2, there is not a single symptom profile of Parkinson's, as there are significant differences in disease manifestation among PwP. The sensemaking process of PwP was in part shaped by their disease characteristics.

Our study shows that *comorbidity* creates ambiguity, causing PwP difficulty to ascertain whether a gap in understanding is related directly to Parkinson's, or if it is caused by a different condition. Ancker et al. [2] explained the hidden "illness work" people with multiple conditions incur when tracking [2]. Our 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. [44] have previously highlighted the importance of supporting PwP to disambiguate what constitutes a symptom through the design of self-tracking. Our 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 [9]. Drawing on our findings we suggest 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 our study, *disease progression* created a gap in understanding, triggered by the often unpredictable and progressive nature of Parkinson's 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 Parkinson's disease were closely connected with comorbidity and the unpredictable, as well as progressive, nature of symptoms. This characteristic of Parkinson's sensemaking contrasts with diabetes where the opportune moments for sensemaking predominantly relate to tracking blood glucose whose low/high reading is the most common trigger of sensemaking [37].

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 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 in order to improve their quality of life and potentially even delay the disease progression [5].

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 our dataset were 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, our 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 [2], similar to 'diagnostic' tracking reported in past work [54]. 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, which can be fostered through self-tracking [56]. Similarly, the awareness-oriented approach to self-tracking and sensemaking observed in our 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 our findings demonstrate, self-awareness could foster an understanding of the disease and its different dimensions. 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 order to reach successful self-management. Some supporting evidence from Ayobi et al. [5] in the context of Multiple Sclerosis 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 supported the individual to explore how their current behaviour can be adapted to the new circumstances through self-discovery. To this end, our 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. We, thus, suggest that self-tracking technologies designed to facilitate this narrative aspect may be able to facilitate self-discovery during the sensemaking process.

## 7 Limitations

This study presents some limitations that could be addressed in follow-up studies. First, we collected our data from an OHC so the sample consisted mainly of PwP that had certain digital skills and wanted to share their experiences with others online. This population might not be representative of all PwP. For example, it is expected that our dataset will not reflect experiences from PwP in later stages of Parkinson’s due to the cognitive and physical impairments that PwP often experience as the disease progresses making it more difficult for PwP to participate in OHCs. Moreover, 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 our sample. Furthermore, Parkinson’s Movement community was established in the UK, though it also operates internationally suggesting as a result a globally distributed community. There is, however, the assumption 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 into the needs of this diverse population as well as how it supports people in more advanced stages of the disease. 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, analyzing online posts may miss certain issues that PwP face in their daily lives 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, we found that carers often act on the 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.

## 8 Conclusion

Previous research on self-tracking technologies designed for Parkinson’s has tended to take a clinically-oriented approach aiming to improve the quality of clinical consultation, or outcomes. This approach predominantly investigates “pushed” self-tracking [33] 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 practise self-tracking. This study investigated self-tracking and sensemaking in the context of Parkinson’s everyday experience. We found that PwP track a diversity 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, our study identified some particularities of Parkinson’s sensemaking that derive from comorbidity, disease progression and self-management best practices. Finally, we discussed how self-tracking technologies can be designed to facilitate sensemaking to additionally support PwP in two underrepresented dimensions of sensemaking: disease self-awareness and iterative self-experimentation.

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