Future Opportunities for IoT to Support People with Parkinson's

ABSTRACT

Recent years have seen an explosion of internet of things (IoT) technologies being released to the market. There has also been an emerging interest in the potentials of IoT devices to support people with chronic health conditions. In this paper, we describe the results of engagements to scope the future potentials of IoT for supporting people with Parkinson's. We ran a 2-day multi-disciplinary event with professionals with expertise in Parkinson's and IoT, to explore the opportunities, challenges and benefits. We then ran 4 workshops, engaging 13 people with Parkinson's and caregivers, to scope out the needs, values and desires that the community has for utilizing IoT to monitor their symptoms. This work contributes a set of considerations for future IoT solutions that might support people with Parkinson's in better understanding their condition, through the provision of objective measurements that correspond to their, currently unmeasured, subjective experiences.

Author Keywords

IoT; Parkinson's; Self-monitoring; Quantified self; Design

CSS Concepts

• **Human-centered computing~Human computer interaction (HCI)**; *User centered design*

INTRODUCTION

Parkinson's is a progressive neurological condition, which is thought to affect anywhere up to 10 million people worldwide [4]. The likelihood of receiving a diagnosis of Parkinson's increases with age, thus the Parkinson's community is largely made up of people over 65 [59]. It is caused by a depletion of dopamine in the brain—which regulates movement and emotional response [63]—although the reasons for why this happens are still not clear [50]. Parkinson's is classified as a movement disorder, primarily characterized by three main symptoms [14]: 1) tremor, which is often seen as shaking of the hands; 2) rigidity, causing stiff and inflexible muscles which can affect activities such as getting out of bed in the morning, or dexterity during dressing; and 3) slowness of movement, which can cause a delay in the initiation of movements, such as swallowing food or walking. There are also a multitude

of non-motor symptoms (e.g. pain, fatigue, anxiety and depression), which can further complicate the experience of living with the condition [46].

Previous research has explored the potential for using technology to help people with Parkinson's monitor and manage their symptoms [2, 3, 8, 11, 26-31]; from wearable devices to support freezing episodes [3, 7, 26], speech [30, 31], and drooling [29]; to gaming systems to support motor rehabilitation [2, 28]. These types of technologies offer individuals an opportunity to gain a better understanding of their condition and how to manage it effectively, and ultimately regain a sense of control over their lives [15]. However, to date, literature has largely focused on single platform data collection tools (e.g. mobile/ wearable), which provide information about limited aspects of Parkinson's and thus do not capture the complexity of the condition, in part due to the heterogenicity of symptoms that make the condition so idiosyncratic

In addition, there are acknowledged challenges [29, 32] with these technologies (e.g. a lack of fine motor skills to manipulate small buttons or touch screen interfaces) which can make them less accessible to the wider Parkinson's community. A recent paper by Vega et al. [79] further discusses the need for tools which support people with Parkinson's to self-report their symptoms to be 'frictionless' (in that users should not have to perform actions that might make self-reporting feel like a chore) when considering long-term engagement in practices that require direct user input. With the rise in available connected devices on the market which have the potential to collect health data, often passively without any need for user input, there are multiple opportunities to overcome these issues with accessibility and rethink the way we consider user generated data collection.

In this paper, we describe a series of engagements to scope the future potentials for Internet of Things (IoT) based technologies to support people with Parkinson's. We first ran a 2-day multi-disciplinary event with 23 professionals, with expertise and interest in Parkinson's and/or IoT, to explore the opportunities, challenges and benefits that connected devices might have for people with Parkinson's. Second, we ran 4 workshops, engaging 13 people with Parkinson's and caregivers, to scope out the specific needs, values and desires that the Parkinson's community might have in terms of utilizing IoT technologies to support their health. Our work showed a surprising existing level of engagement and interest in current IoT technologies from the Parkinson's

community, and highlights a culture of self-experimentation that is currently ongoing, which could provide an interesting opportunity for further research. Through this work, we contribute a set of design considerations for future IoT solutions that might support people with Parkinson's in building a better understanding of their condition, through the provision of objective measurements that correspond to their, currently unmeasured, subjective experiences.

BACKGROUND
Clinical Measurement of Parkinson's
Of the tools used within clinical practice to diagnose, and measure the progression and impact of Parkinson's symptoms, the most widely recognized is the Unified Parkinson's Disease Rating Scale (UPDRS) [21]. This tool compiles a series of clinician (clinical assessment and interview) and patient (questionnaire) rated items on a scale of 0-4, providing an overview of severity and impact. Whilst widely revered as the most comprehensive assessment for measuring Parkinson's, the approach itself is subjective, resulting in issues with accuracy and consistency [61].

In addition, clinical assessments tend to be measured over a short duration (e.g. questions ask responders to discuss their symptoms "over the past week") and infrequently, capturing only a brief snapshot of the condition within a consultation period (which typically lasts no more than 30 minutes every 6-12 months) [40]. The challenge with this, is that the severity of Parkinson's symptoms can fluctuate hugely, over weeks, days, and even hours [52]. As such, building a true picture of an individual's condition, and its impact on their life, can be difficult. These issues are further exacerbated through the use of low-resolution scales, which may mask or accentuate small changes in symptom severity [61].

The close monitoring of Parkinson's symptoms is essential to maximize and prolong quality of life [78], with the added complexity that the extended use of Parkinson's medications can cause additional side effects such as 'off periods' (where symptoms can switch dramatically from being well controlled to be uncontrolled, often likened to the 'flicking of a switch') and dyskinesia (involuntary and uncontrollable movements e.g. jerking; writhing) [49].

Technology-Based Approaches
In an attempt to address some of the aforementioned issues, research exploring the use of technology to improve symptom monitoring has emerged. One strand of this work has focused on the detection of Parkinson's symptoms such as freezing [26, 75], and tremor and dyskinesias [18], through wearable devices—typically utilizing inertial sensors such as accelerometers and gyroscopes to determine movement of the trunk and limbs. Similarly, several researchers have used smartwatches to generate time-based estimates of bradykinesia (slowness of movement) during daily activities [54], to support the differential diagnosis of Parkinson's tremor against other types of tremor during daily activities [37], and to improve medication regimes [20].

More recently, literature has emerged exploring the potential for smartphones—powerful multi-sensor platforms, now ubiquitous in our society—to assess and continuously monitor Parkinson's. Several researchers have focused on analyzing mobile interactions as an approach to unobtrusive symptom monitoring [1, 19, 79, 83]. For example, Aghanavesi et al. [1] used touch screen interactions to quantify changes in manual dexterity over time. Vega et al [79] also discuss using a mobile based approach, combining the medical literature, location and activity recognition data to create a set of personal predictions with the potential to track symptom fluctuations around an individual with Parkinson's. This allowed inferences to be made around mood, symptom severity and ability to perform everyday activities when changes in this profile of living are detected. Finally, Zhan et al. [83] developed a mobile based assessment tool, implementing machine learning techniques, to quantify Parkinson's symptom severity, which directly correlated with UPDRS scores, providing a promising solution to the issues of scoring inaccuracy that we have already discussed.

Finally, there are many examples of bespoke or re-purposed off-the-shelf devices being used to detect and monitor Parkinson's. These include the Microsoft Kinect, which has been used for the analysis of impaired speech [5] and gait [16]; the Nintendo Wii for quantification of tremor [71]; and finally, the Google Glass [31] which has been used to provide a continuous monitor of speech volume during conversation.

Despite the significant amount of progress made within the area of technology-based assessment of Parkinson's, the majority of examples focus on either worn, or carried, devices, and often only give an indication of one symptom. In acknowledgement of the multi-faceted nature of the condition, there is real opportunity for approaches that utilize multiple data flows [79, 80] and sensor technologies to paint a full picture of the complexities of living with Parkinson's, to better inform care provision, and personal understanding of the condition.

Monitoring Chronic Health Conditions through the IoT
The term 'Internet of Things' (IoT) has come to describe a network of physical objects that connect and exchange data [81]. Previously non-digital objects can now be augmented with sensors with the ability to collect, and transfer data, enabling us to make sense of their use within daily life. With estimates that the number of Internet connected devices will likely reach 50 billion by 2020 [17], the potentials for utilizing the IoT to help us understand health are unbounded.

In particular, recent years have seen the emergence of literature exploring how IoT devices can support the monitoring of symptoms related to chronic health conditions. Diabetes is one area which has received attention [55, 10, 12, 23]. For example, Rahman et al. [55] discuss the development of a non-invasive IoT breath test, which can monitor complications of diabetes. Chang et al. [10] also discuss a blood glucose monitoring system that interacts with

a phone to send users reminders to change their dietary behavior. The potential for supporting people with respiratory conditions, such as asthma and COPD, have also been studied including; wireless body-worn sensors, measuring factors such as a heart rate, blood pressure, and oxygen saturation levels [13, 57]; and environmental sensors measuring air humidity, and temperature [13] and air quality [44]. Finally, connected pill boxes have the potential to support medication adherence for a range of conditions, by providing relevant reminders that go beyond traditional pre-set alarms [65, 83].

Within the space of monitoring Parkinson's symptoms, there have been several papers which have explored how IoT technologies might be implemented to gain an understanding of the condition [24, 51, 34]. For example, Memedi et al. [34] discussed the highly comprehensive design of an interface, which visualized symptom and medication information on a tablet app, for users with Parkinson's, and a web app for clinicians. Data was collected and integrated through a set of commercial IoT devices: a wrist worn sensor, developed by Global Kinetics [20], which provides measures of tremor, slowness of movement and dyskinesias; a medication dosing device, developed by Sensidose [64], which dispenses correct doses of medication based on schedules defined by clinicians; and a bed sensor, developed by Cenvigo [9], which captures data about sleep patterns. The authors also collected data on self-reported physical activity and meal intake times through a smartphone application. Whilst the authors found that people with Parkinson's were enthusiastic about learning more about their condition, they highlight a further need to consider the discrete individual characteristics of each user. Similar to [79], the authors also discuss the need to ensure that future systems do not place too much of a burden on users, whose physical symptoms and unfamiliarity with certain modern technologies can cause stress and fatigue during early adoption.

Whilst this research provides exciting insight into what a real IoT based system to support Parkinson's care might look like, the authors' focus was on interface design, integrating data streams from several pre-decided, specialist devices. Even in the early stages, participants expressed a desire to monitor more than just the aspects reported, with final findings showing that additional participants had further self-monitoring needs, a finding also echoed by [79]. This again highlights the heterogeneous and complex nature of Parkinson's and calls for research which explores approaches to the design of systems that take these considerations into account.

In an attempt to address this gap in the literature we took a participatory approach to understand the overarching opportunities, challenges and benefits that IoT solutions for Parkinson's might provide. We scoped both wider professional opportunities, as well as the intrinsic motivations and desires for self-monitoring that people with Parkinson's had. Our work yielded insights into a culture of existing self-experimentation and IoT device use in the Parkinson's community, which could be leveraged for future work. Our study was conducted in two stages. The first sought to gain an overarching understanding of the shared interests that different professionals might have when thinking about future opportunities for IoT to support Parkinson's. Through a 2-day multidisciplinary workshop, we conducted a series of targeted activities aiming to drive forward future directions for research and practice in Parkinson's care delivery. Attendees came from a range of disciplines, thus we were attempting to explore key multidisciplinary opportunities and challenges. The second stage of the work involved unpicking some of these key challenges and opportunities with the Parkinson's community, by gaining an understanding of their data needs, and how engagement with IoT technologies might feasibly fit into their already complex lives.

STAGE 1: APPROACH
In order to begin our exploration, we held a 2 day workshop at *Blind* University with 23 professional delegates from a range of disciplines; including clinical practice (n=2), health research (n=3), sociology (n=1), engineering (n=3), design (n=3), and HCI (n=7). We also had representatives from a leading Parkinson's charity (n=2)—a staff member who worked in the involvement and inclusion team, and a person with Parkinson's—and a representative from industry (n=1).

Attendees were invited to the workshop via an open email call for participation, extended to personal and professional contacts and mailing lists that the research team had, as well as then being snowballed to a wider network of contacts. Potential attendees were asked to register their interest via email, providing a brief description of their area of expertise, their experiences of Parkinson's, and their interest in IoT (to allow us to best plan the structure of the event).

Multidisciplinary Professionals Workshop
Workshop activities were held between 10:30 and 17:00 on day 1, and 9:30 and 16:00 on day 2. Both days were structured to include a morning session made up of short talks (to provoke interest around a range of topics), and afternoon sessions made up of collaborative activities (to develop shared areas of interest and explore potential IoT solutions). Talks were provided by a selection of workshop attendees and lasted no longer than 15 minutes each. Topics covered: Parkinson's and its physical and psychological symptoms; current state of the art around monitoring Parkinson's symptoms using mobile and wearable technology; current and future opportunities for digital health in industry; Ethical issues around assistive technologies; and challenges with IoT adoption.

On day 1, the afternoon session started with a scoping activity, which asked attendees to work in small groups of between 4 and 6 (denoted in the findings as 'GroupX'; n=4). Each group contained at least 1 attendee with clinical expertise in Parkinson's), to scope and discuss examples of IoT devices for healthcare and consider the types of devices

Figure 1: Paper-based activity in multi-disciplinary workshop

that they might envision being useful for people with Parkinson's. This activity was facilitated by a booklet depicting images and short descriptions of a selection of IoT products (e.g. heart and respiration monitor, smart home light and temperature control, home energy use sensors, ingestible pill sensors, biometric sensors, connected pill boxes). We asked the groups to brainstorm the types of symptoms, settings and opportunities they could envision IoT being used to support tracking for Parkinson's.

The facilitators then developed 4 themes to further explore, based on the discussion points that were emerging. Attendees were asked to join a table with a theme they found most interesting and quickly brainstorm the types of IoT devices that might be useful to someone with Parkinson's within each theme. They were then asked to extend these initial ideas using Osborne's checklist of manual thinking for idea generation [45], which supports users to modify, magnify, minimize, substitute, rearrange and combine their ideas to provoke creativity and a new way of thinking.

The afternoon sessions on day 2 focused more on applying the broad ideas we had formulated on the first day to specific Parkinson's cases, in an attempt to further explore the feasibility that our ideas might have within the complex everyday lives of people experiencing Parkinson's. We first played participants a set of videos of people with Parkinson's sharing stories of their lived experience (videos depicted various symptoms, severities, home lives and priorities; a person with very severe movement symptoms (created with permission for the workshop), a younger person with a small child [48], and a person who had just returned to work [47]). We asked attendees to focus on a specific case study, considering the needs of the person, and brainstorm ideas for a bespoke IoT solution that might be suitable. Finally, we asked attendees to, in pairs or threes (denoted in the findings as 'PairX'; n=8), discuss some of the challenges and benefits of their ideas for supporting Parkinson's, and how these might be avoided and achieved respectively. Attendees were given a worksheet to conduct this activity on (see figure 1).

Both days of the workshop were photographically documented. In addition, the collaborative afternoon sessions were documented by each group on paper, with whole group discussions being further documented through note-taking by the facilitators. All paper data was analyzed using a top down thematic analysis approach, in that we were specifically focused on understanding the overall opportunities, challenges and benefits of IoT solutions for Parkinson's care, identified throughout the workshop. This allowed us to gain a broad overview of what attendees felt was most important for future researchers to consider.

STAGE 1: FINDINGS
Scoping opportunities for Parkinson's
Our first activities focused on scoping the current state of the art in commercial IoT and beginning to understand how IoT technologies might be of use to people with Parkinson's. The attendees first discussed, more broadly, the range of Parkinson's symptoms that might be able to yield data from an IoT device. They discussed these symptoms across 4 broad categories; 1) Motor, or movement, related symptoms (e.g. tremor, rigidity freezing of gait, issues with balance); 2) cognitive symptoms (issues with memory, attention, or language); 3) psycho-social symptoms (isolation, depression); and 4) other non-motor symptoms (constipation, loss of smell, insomnia).

In their groups, attendees then moved to discuss a range of settings and opportunities to further explore. Perhaps unsurprisingly, due to the nature of Parkinson's as a motor condition, the majority of discussion centered around sensor-based tracking of movement symptoms (Groups 1-4). In particular, how this could then support assessment of symptom severity to facilitate early diagnosis (Groups 1-4), assess medication benefits (Group 1, Group 4), and track the ongoing progression of the disease (Group 1, Group 3). Further discussion focused on improving motor symptoms, through cueing (Group 1), adaptations to medication (Group 1, Groups 3-4), and helping with freezing (Groups 3-4).

Attendees then moved to discuss the potential for multiple technologies both within the person's home, and local community, to help track mental state and social interaction. For example, by correlating emotional state to motor symptoms (Group 2), and tracking contact with other people (Group 1). This sense of connectedness with others was linked to having 'Parkinson's friendly spaces' in the local communities to help, as well as being able to call for help if needed, e.g. through a voice assistant, or automatically through a falls alarm (Group 1).

Finally, there was discussion around the need for future technologies to be adaptive to self-monitoring/management approaches as the condition progresses (or indeed degenerates), i.e. evolving to needs as they change over time (Group 2, Group 4) and encouraging the person to self-care as their needs change, through positive reinforcement or nudges (particularly for those with apathy or low motivation (Group 3)). In addition, the need for personalization of

technology solutions was highlighted, as the most important symptom is often different for individuals (Group 3).

Envisioning future IoT solutions for Parkinson's

The range of potential opportunities for IoT to support people with Parkinson's was seen to be beneficial in a multitude of ways; supporting people to monitor their health and medication regimes (Pair 3), improve quality of life (Pair 4), retain a sense of independence and autonomy (Pair 1, Pairs 7-8), and regain a feeling of increased control over one's health condition (Pairs 2&4). However, attendees also discussed challenges to fully envisioning these opportunities.

The first set of challenges to arise related to the robustness of any future IoT devices, particularly when dealing with a highly heterogeneous group such as people with Parkinson's (e.g. *"inaccuracy in measurements"* (Pair 1); *"reliability of the device"* (Pair 1); variable *"data quality"* (Pairs 5-6)). Suggestions to overcome these issues involved using *"larger numbers of sensors"* (Pair 1) to build a bigger picture of the person (which was also seen as a big benefit by Pair 1 and Pair 5); and using existing commercial technologies (Pairs 5-6) to improve general robustness of the technology and *"fast-track scalability of the research"* (Pair 5). Cost (Pair 2, Pairs 4-6) also arose as a potential barrier to adoption, however the suggestion to *"integrate future solutions with existing devices"* might overcome this issue (Pair 7), in addition to becoming a possible way to overcome the issue of device obtrusiveness (Pairs 1&3), particularly in relation to the visibility of future solutions (i.e. of worn devices) and their potential to stigmatize users (Pairs 6-8).

There was a theme of discussion around power dynamics between a clinician and patient and how, at times, the consultation process can be a de-powering experience for the patient, if they feel they do not have control in leading discussions about their own health (Pairs 2&4). Having the ability to share data with a clinician before a consultation was seen as a useful way to regain a sense of power (Pairs 2&6) and improve interactions between the patient and doctor, to improve personalization of care plans (Pairs 4&6). As such, ensuring patients have control over their own data (Pair 2, Pair 7), maintain a feeling that their data is secure (Pair 5), and feel that they have consented to what data is collected about them (Pairs 5-7) was also seen to be of high importance. Pair 7 expanded this to discuss the need for *"clearly defined pathways around what data will be used for. Consider holding data 'on the edge* [i.e. locally on the device]*' as opposed to in the cloud"* to enhance a feeling of data security.

The final theme of discussion centered around the need to create bespoke solutions that were mindful of the personalized needs of the individual (Pairs 3-4, Pairs 6-8), and how this in itself could be challenging for future researchers dealing with a *"diversity of data"* (Pair 7), which is then *"difficult to generalize to a larger population"* (Pair 6). In addition, the need for technologies to be usable, specifically to the needs of people with Parkinson's, was a

Workshop	Number	Sex	Age	YSD	Working	Symptoms reported
1	P1	M	61-65	6	Full time	Handwriting, speech, dexterity, emotional regulation
1	P2	F	66-70	5	Retired	Tremor, rigidity, fatigue, anxiety, pain
1	P3	M	61-65	3.5	Retired	Rigidity, freezing of gait, speech
1	C4	F	61-65	Carer	Full time	N/A
2	P5	M	80-85	2	Retired	Memory, gait disturbance (i.e. shuffling)
2	P6	M	61-65	10	Retired	Dexterity, mild memory issues, sleep disturbance
2	C7	F	80-85	Carer	Retired	N/A
3	P8	F	66-70	4.5	Part time	Tremor, fatigue, pain, depression
3	P9	M	66-70	2	Retired	Gait disturbance, freezing
3	P10	M	61-65	3	Full time	Tremor, anxiety, handwriting
4	P11	M	61-65	5	Retired	Pain, rigidity
4	P12	M	66-70	12	Part time	Tremor
4	P13	F	66-70	8	Retired	Dyskinesia (i.e. uncontrollable movement)

Table 1: Summary of participants (Number refers to participant number, with C denoting carers; YSD refers to years since diagnosis)

further challenge (Pairs 3-4), with Pair 4 giving the example that *"voice recognition could be a difficulty"* as an input modality (yet at the same time overcomes some of the issues around manual dexterity that people with Parkinson's can experience). Seen to be most vital for overcoming this issue was involving a range of stakeholders in the design process, to understand usability and data needs, rather than taking a techno-centric approach (Pairs 3-5).

STAGE 2: APPROACH

The next stage of our work involved conducting a series of 4 workshops with people with Parkinson's and their caregivers (n=13), to begin to gain an understanding of the types of data they would like to have to help support them in the monitoring and management of their condition, and how different types of IoT technology might fit into their lives. Each workshop lasted 3 hours and was held at various locations across *Blind for Review*.

Participants were recruited into the study through an open call for participation, which was distributed via email through *Parkinson's charity*. A total of 26 people registered their interest and were sent further information. Of those, 18 responded to say they would like to take part in a workshop, however only 13 were able to make the dates and times suggested. Table 1 provides a summary of participant details.

Workshops with people with Parkinson's

Each workshop followed a similar format but remained fluid enough to allow for ebbs and flows in discussion, and variations in the group's needs [28]. We began each workshop with an open discussion around each person's experience of Parkinson's, their interest in the research topic and their general experiences with technology. We then asked participants to complete a brief priority setting activity to help look for overlapping concerns and ultimately add focus to the following activities. Participants were asked to look through a set of 10 priority areas for research (balance and falls, stress and anxiety, uncontrollable movements, personalized treatments, dementia, mild thinking and

memory problems, monitoring symptoms, sleep, dexterity, urinary problems), developed with over 1,000 people with Parkinson's, carers and health and social care professionals [43]). We asked them to place a colored dot on the 3 priorities they felt most concerned about, and then discuss their number 1 concern with the group.

The second activity then involved creating a timeline of the groups' typical day. Participants were asked to, on post-it notes, write the typical things they do day-to-day and place them on a large timeline (with hours of the day on the x-axis, and a rating of how challenging it is for them on the y-axis. See figure 2). Participants were asked to think about whether there was anything they felt would make their day-to-day lives easier, and the types of information they would need to better understand their challenging symptoms or activities. Participants were then probed about what they would like to know more about, what this knowledge would then enable them to do, who they would want to share this information with, and the technology they could envision using.

Each workshop was audio recorded and transcribed verbatim for later analysis, yielding 12 hours of transcribed audio data in total. Four members of the research team analyzed the data independently, conducting an inductive thematic analysis on the transcripts [7]. Data was coded at the sentence to paragraph level using short labels. These were then grouped together, to construct of 23 themes that captured the core topics and concerns from the data. These themes were then synthesized into the 5 broader theme headings that we used to explicate our findings; Understanding the day-to-day challenges of Parkinson's; Maintaining physical activity; the emotional toll of Parkinson's; Tracking the impact of non-clinical interventions; and Current use of IoT technologies.

STAGE 2: FINDINGS
Understanding the day-to-day challenges of Parkinson's
Participants described a wide range of physical symptoms that they experienced (see table 1). Several also discussed co-morbidities that they had to contend with, often seen to lead to confusion over whether *"the symptoms could be something else not Parkinson's"* (P13). In particular, the often unpredictable nature of symptoms was seen to cause difficulties *"you get days where you just shake the whole day…and the next day it's different again"* (P8).

Participants found it difficult to find consistent information about Parkinson's because *"it affects people differently"* (P11). This led to confusion and worry when reading more generic information *"I don't want to read any more about it. It starts making you think 'have I got that?'"* (P12). This was not helped by the fact that participants often saw different clinicians during their regular assessments. For example, P8 described: *"if you see somebody different, they don't really know [you]"*. There was a sense that measurements collected by clinical staff were largely 'subjective': *"they say 'oh yes this is a bit worse, or this is different'"* (P10) and it was difficult for participants themselves to equate clinical
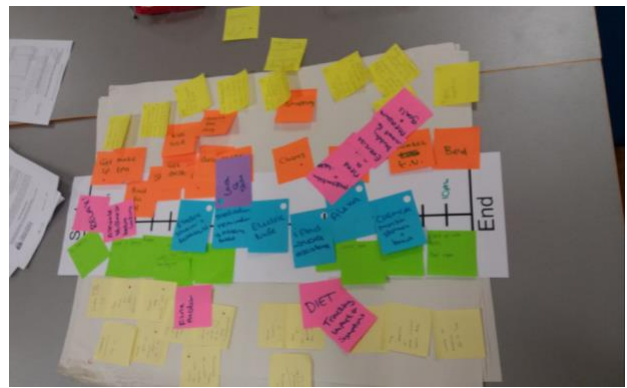

Figure 2: Timelining activity within Parkinson's workshops

assessment to the way they felt *"sometimes [nurse] will say 'I've noticed a deterioration there' …I might not feel it sometimes"* (P8). Participants expressed a desire for: *"a more objective assessment… feel that when you saw the neurologist that your actually getting facts rather than what you feel on the day"* (P9).

Remembering to take medication was highlighted as one of the most common issues that participants wanted support with (P2, 3, 5, 6, 9, 11, 12). P12 described, *"it's trying to fit my tablets in with what I'm doing…I've got such a busy life I tend to forget"*. For P5, concern over sticking rigidly to their medication regime led them to avoid leaving the house for portions of the day: *"At the moment all my medication is taken in the morning, so I don't go anywhere. Once it has got to be taken in the middle of the day I know I am going to get paranoid about that"*. Diet was seen to be a cause of confusion when it came to taking medication. P8 described, *"if you have a lot of protein it's not effective, one works against the other, so you have to have it an hour before your food or sometime later"*. P12 echoed this: *"I've got to have it on an empty stomach its ok in the morning but much more difficult at lunch and tea time"*. Participants expressed a desire to be able to monitor their medication, and its effects on their symptoms, more effectively in order to improve their understanding of the optimal mediation cycle for them: *"you may forget maybe an hour later in the day, may be 2 hours or you might miss a dose, how does that effect your movements?"* (P11). For P9, this was seen to be important as they did not always display worsened symptoms as a result of forgetting: *"If I forget [medication] I don't freeze like with some people. So, having some knowledge to how things are going and how you're doing is really quite important"* (P9).

Being self-aware was seen to be a positive factor for retaining a sense of control *"I think being self-aware knowing what's going on has helped me enormously"* (P2). P6 echoed this sentiment: *"I think it's easier to live your life with knowledge about your condition … to not be told anything about your condition or to not have knowledge doesn't lead to good psychological care"*.

Tracking the Impact of Non-Clinical Interventions

Participants expressed a desire to understand how non-medical, or self-directed, 'interventions' they were currently conducting on themselves (e.g. changes in exercise, changes to diet) were making a difference to symptoms. For example, P11 wanted to understand *"see some correlation between what exercise you done that day and how you feel at different points during the day"*.

As can be seen from the visual example in figure 2, participants led extremely physically active lives day-to-day. They reported conducting a range of activities, including but not limited to, playing football (P1, 12), running (P2), walking regularly (P5, 10, 13), hiking (P6), doing exercise videos at home (P3, 13), attending the gym (P1, 11, 13), and doing yoga and reiki (P2). Participants discussed the need to maintain a 'use it or lose it' (P2, 6, 8) attitude in order to ensure that skills are not lost as Parkinson's progresses. It was clear that participants received great amounts of pleasure and a sense of achievement when completing their activity goals. For some, this was more about hitting targets like *"as long as I've done my 10,000 steps"* (P13), where for others it was seen as an important way to manage their symptoms. For example, P2 described: *"I do reiki and that is brilliant it's like a Parkinson's holiday, its wonderful for the tremor. I've been in some days and I have had a really bad tremor and it just goes"*. However, for some keeping active was at times challenging and unpleasant, although necessary: *"It's very, very hard to keep physically active when legs won't go where you think…[I do] At least 20 minutes a day and it's an unpleasant experience"* (P10).

Participants also discussed a range of interesting dietary changes that they were trying in an attempt to improve their symptoms, based on articles they had read online, or things they had heard from friends. For example, P1 discussed eating red peanuts as *"they are good for motorization"*, while P10 discussed eating melon as a way to help medication absorption: *"I've been on the melon diet…the ability for your stomach to absorb [medication] and for that getting into the bloodstream and therefore ending up in the brain"*. P9 discussed how they had been eating Marmite, a savory spread made from yeast abstract, for a similar reason: *"There was something recently about Marmite being good for neurological conditions… I'm not a great fan of Marmite but I'll have Marmite on toast maybe 3 or 4 times a week"*. Finally P8, discussed taking a turmeric extract powder twice a day for a month, and how her partner felt that he noticed a difference, *"He thinks that I've been walking better with this… he doesn't think my tremor's as bad, I haven't really noticed anything but he watches me at night"*.

Whilst participants were willing to try many new things, their basis for continuing with them was largely subjective; they did not currently have a systematic way to track if said 'intervention' was making an objective difference to their symptoms. P5 and P8 discussed keeping notes about their symptoms, however these were seen to have drawbacks; *"I try to write notes as I'm going along… but I forget, and when it's time to see [clinician] you're wondering well, what did I feel? and when did I feel I t?"* (P8). Improving this process, by adding objectivity to monitoring techniques, was discussed as a real opportunity for technology. Firstly, in informing personal understanding of Parkinson's. P5 explained, *"I know my body and mind are changing but I don't understand why, which causes me to fret sometimes"*, where P10 described: *"We're not the best judge ourselves in some ways because you tend to react to how you feel on the day…[I need] something which is monitoring that I might have had a bad night and woken up 3 or 4 times"*.

Second, there was seen to be benefit in improving conversations with clinicians to better inform care, *"if you were monitoring [rigidity over time] and you could see there a difference then you could tell your neurologist or Parkinson nurse"* (P8). However, despite participants enthusiasm around using technology to support self-monitoring, when asked if participants would be willing to 'log' data—in the sense of opening an application and typing in aspects such as food intake, or symptoms—participants were wary of the effort that this would take. P1 discussed how typing can become challenging if fatigued, *"If it is ticking boxes then yes, but if it is typing then that's a pain because it depends what you have done that day"*. P11 was similarly concerned over the level of 'effort' that detailed self-report might entail: *"there's a lot of effort required to do that, if it can be made simple to input then fine, but counting the carbs and calories is again quite difficult"* (P11). However, P3 suggested a workaround for this might be to use voice as an input modality: *"speech recognition, I would find it a lot easier to do"*.

Current use of IoT technologies

Our participants reported using a range of different technologies; smartphones (P5, 8, 9, 13), tablets (P3, 8, 9), wearables to track physical activity (P13), exercise games or online videos (P9, 13), cloud-based calendars (P5). All used computers for email and internet browsing. Several participants (P1, 8, 10) who were still at work also used the computer for office work, however reported challenges relating to time taken to complete tasks, fatiguing easily, and with manipulating the mouse and keyboard due to tremor: *"The right hand is jiggling about and you're hitting the mouse several times or you're hitting keys constantly and misspelling words… it's amazingly frustrating and hard to get the mouse to get into the right place"* (P8). P1 and P10 both had access to voice recognition software to support them with their computer-based activities in the workplace.

Half of participants (n=6) were already using IoT technologies of some kind in their homes (e.g. Google home hub, smart meters). Voice assistants were most commonly discussed; in particular, Alexa (P1, 3, 4, 11-13), with P9 also using Siri regularly. Speech was one of the symptoms that several of these participants reported as an issue for them (P1, P3): *"my speech is not as good as it used to be. I'm*

speaking quite loud now, very loud for what I'm would normally speak, I do stammer" (P1), but this did not deter them from purchasing and trying out a voice assistant, with seeming success. When asked what he did if Alexa did not understand him, P3 simply said, *"I try again a bit louder until she understands me"*. Voice assistants were seen to particularly have potential as a system for providing reminders, e.g. *"alarms for taking the tablets"* (P3), or *"you could you could get her to remind you to get out of your chair and stretch for 2 mins"* (P2).

It was clear that despite reporting some issues with setting these technologies up; *"the trouble is using your fingers to start it up"* (P9), participants appreciated the benefits smart technologies could bring. P12 described, *"I got the Alexa and I've got all the lights on Alexa to turn on, so at night it comes on... I want to get it rigged up to the heating and different things...it's a challenge for me I'm not really technical minded"*. P11 felt more confident: *"I've got the smart heating, just looking at some of the Google home or the Amazon echo and other devices, smart wireless, smart cookers, well you name it everything is going to be smart...anything that can make your life easier to control and give you information back about how much energy you're using, what you're doing in the house"*

Perceptions of Data Sharing
As we were discussing many examples of commercial IoT technologies, and their potential for supporting the monitoring and management of Parkinson's, it was important to acknowledge that data might be accessible to larger scale technology companies. As we develop application areas for new and emerging commercial technologies in the medical domain this is not a trivial issue, particularly when considering the duty of care we have to protect patient and participant data. Participants were mixed in their views about who they would be happy to share the data collected from IoT technologies with. For some it was clear that the benefit to others with Parkinson's was a driver in their decision to share their data. P8 described: *"I'd share the information with anybody if it helps people newly diagnose to cope..."*; and P4 noted: *"I'm quite happy for anybody who is doing Parkinson's research or can help me with Parkinson's or will have a better understanding of me. Let them all know"*. P2 was more cautious but felt overall that the benefits outweighed the negatives: *"It's important to raise it to consciousness...but it's for the greater good isn't it"*.

Many of the participants discussed how aspects of their online lives were already being tracked and used by companies to personalize advertisements; something that was seen as a current norm: *"You get it all the time with iPad. You look at some shoes and then 3 days later you get adverts for shoes. And you get things like that pinging at you all the time so we are used to that"* (P1). P6 described: *"They already know everything about us"*, where P2 said: "*We live in big brother at the end of the day"*.

However, when further probed, some had concerns about how unlimited access to their data might have an effect on their right to medical privacy: *"would I tell the Doctor the truth about the amount I smoke and drink? No. I wouldn't. I would lie every time, but if my watch is measuring it he would know without even asking....I've said yes go for it, but given chance to think about it then I would have a big list of things that I don't want"* (P4). One participant in particular was concerned about sharing with pharmaceutical companies who might make profit from their data "*It should be free they shouldn't make money out of it... I don't want big pharmaceuticals to be involved"* (P13). The discussion around this topic was mixed however, with several other participants highlighting the need for companies like this to have access to data in order to improve options for treating symptoms of Parkinson's. For example, P11 described: *"the medication has so many side effects, it could look at how to improve the drugs we already have"*, where P4 said: *"they live in a world where unless they can make a profit no one would make tablets"*.

However, participants had remaining concerns that other organizations, particularly those relating to their finances, might use their data maliciously: *"The thing that would be bad about it is if it effected pensions and credit rating that's when it gets toxic"* (P2). This was seen to be the main worry that they had surround data use and sharing: *"As long as it isn't anything to do with banks. If its diet, exercise and everyday life that's fine. But passwords and bank details that's a no"* (P1). Overall however, participants were largely happy to share their data with researchers, so long as they could be sure that it was been managed carefully and respectfully by the research team: *"I think it's the responsibility of the people running the research and then to disseminate that information to a wider field not to just have data blitzed around the internet there has to be a path to where to find the information before it's published"* (P12).

DISCUSSION
Through our work we have explored opportunities for IoT technologies to support people with Parkinson's in understanding more about their condition; both as a way to regain a sense of control over their health, and to improve communication between the individual and clinical professionals, who often vary between visits. In the following, we synthesize our findings to reflect on 4 key opportunities for future research.

Data Supported Decision Making in Care
The IoT has undoubted potential to impact health service delivery [70] and the healthcare industry [57], by facilitating a new healthcare paradigm leading to more personalized, participatory, predictive and preventive health [62]. As the number of connected devices begins to rise [55], so then do the opportunities to implement them within health and care services. One particular area of interest is the potential for new data flows to augment clinical decision making [74, 6]. Our work highlighted several opportunities for supporting

the clinical assessment of Parkinson's which, as we have discussed is currently conducted using subjective assessments which have low levels of resolution and are prone to cross-rater inaccuracies.

The potential for technology to implement automated and continuous assessment, using environmental and body worn sensor systems, alongside machine learning approaches, has insurmountable potential for making this assessment process more objective. Indeed, previous work has already looked at improving this through the detection and classification of Parkinson's symptoms using wearables [27, 75, 18, 54, 37] and mobile based assessment [79, 83]. This not only has impacts for our Western society, but also has the potential to improve this assessment process within lower income countries, where specialist services for conditions like Parkinson's are only beginning to emerge [77].

Our professional participants highlighted how the process of collecting data to discuss within clinical consultations can help an individual regain a sense of power and control during these clinical visits, by helping to open a line of communication through which to discuss care planning needs. In addition, our participants with Parkinson's discussed the need for consistent measurement of their symptoms, particularly when seeing various different members of clinical staff who may, or may not, personally know them and how their Parkinson's is progressing. Mentis et al. [35] describe the benefits of using Fitbit sensors to support the co-interpretation of movement data for people with Parkinson's and their clinicians during clinical assessments. However, the authors highlighted how, despite the individual being involved in the creation and interpretation of the data, challenges around power dynamics remained. Future research should consider how promoting concepts of agency over one's data, and the process of data generation and curation, might be able a useful was to tip the balance of power.

Understanding Complex Symptoms
Throughout our work, with both the professionals and our participants with Parkinson's, there was much discussion around the need to acknowledge the complexity of Parkinson's as a condition—and the highly heterogeneous nature of each person's experiences, symptom profiles and the impact it has on their lives. Participants with Parkinson's expressed a desire to have more than just a 'snapshot' view of their progression during clinical assessment. They wanted a way to identify patterns in their symptoms to better prepare for daily life. We acknowledge that this is not a novel finding in itself, this concept of complexity within Parkinson's is heavily discussed in the literature [28, 79, 32-34, 41, 42]. For example, Nunes and Fitzpatrick [42] comprehensively described the complex processes that go into the everyday management of aspects of Parkinson's. They describe the delicate negotiations and dynamic adaptions that individuals will make during their everyday self-care activities, calling for approaches for technology design that recognize the

effort that it takes. However, our work adds to this body of literature by shining a light on the opportunities for IoT solutions which might support an enhanced understanding of these complex symptoms.

Complex medication regimes, in particular those related to eating habits, caused much confusion for our participants. Future technologies that help users to build an understanding of how variations in in the way medication is taken (e.g. at the wrong time, with the wrong food), and how this then impacts symptoms, would be a valuable step towards enhancing people's understanding of their condition. However, as discussed by [34], a focus on medication and its correlation with movement symptoms, while important, is not enough alone. There are many different factors which feed into having a good quality of life, so we also need to consider how to support observations around the multi-faceted non-motor factors (which are as disabling as motor symptoms) that feed into this.

Our work builds upon understanding into the messy lives of people with Parkinson's, providing opportunities for how we might use technology to augment existing activities that people engage in, without becoming an added burden. Future work should consider how to develop highly personalizable systems that fit easily into the lives of the community, increasing the capacity for the delivery of personalized medicine. For example, one of the benefits of the IoT is the capability to instrument almost anything (e.g. a yoga mat, a dog's leash). Future work considering the development of simple sensor systems that can provide custom data could offer a way for us to better understand the 'mundane' [42] aspects of daily life that people carry out, and the impact that these have on physical function and mental wellbeing.

Opportunities to support Self-experimentation
Our work highlighted several non-clinical interventions that participants currently engaged with in order to self-care. Where reports around the role of exercise, in improving control of movement and mental wellbeing, have been reported before [42], our participants also discussed experimenting with a range of pseudoscientific dietary 'interventions'. For example, one participant discussed eating Marmite daily, despite not enjoying the taste. The study on Marmite was reported widely in the press (e.g. [73]), hailed as a way to prevent neurological conditions such as dementia due to its high levels of vitamin B12. However, the study discussed was preliminary, looking at response rates to visual stimuli in 28 healthy subjects, and the theory has not yet been tested in people with neurological conditions [66]. Another participant discussed taking a turmeric extract powder [76] and reported that her partner had noticed a difference in her symptoms. Whilst curcumin (the active compound found in turmeric) has been showed to prevent neural degeneration and cognitive decline in mice, this theory has also not yet been tested on humans [39].

Participants' willingness to try different things to improve their Parkinson's could be due to the lack of information they

felt they had around their own condition. However, it could also be reflective of the time it takes to bring clinical evidence to the mainstream, and indeed the inaccessibility of clinical evidence (often reported in academic papers and disseminated through conferences) when it gets there (as discussed in [32]). Participants were willing to try a variety of new things to improve their condition, but their basis for continuing with these was largely subjective; they did not currently have a systematic way to track if said 'intervention' was making an objective difference to their symptoms, whether this be a placebo effect (actually shown to have a profound effect on relieving symptoms such as pain, fatigue and depression [38]) or otherwise. Future research might consider leveraging this self-experimentation culture; supporting people to improve the rigor of their practices and providing the objective measurements our participants so desired, to understand if lifestyle changes make a difference.

Self-experimentation in its true form—described as an n=1 experiment, or single case design, in which the individual serves as their own control to test their response to an intervention [58]—is an under-represented area of research within the field of digital health (although there are some broad scoping reviews of its use in social sciences [e.g. 60, 67-69]). Karakar et al. [58] discuss the challenges with existing self-tracking technologies, in that they often don't help the user to answer the specific question that led them to use the technology in the first place. They give the example of a user posing a question around caffeine intake and if it affects sleep. Whilst self-tracking technology may suggest an association, it never really gets to the bottom of whether the caffeine intake is due to the user's tiredness, or if their tiredness is caused by lack of sleep due to caffeine intake. The authors propose a framework which supports people to identify variables, conduct experiments and move towards better informed behavior changes, and discuss an app to support the process. We believe that future work utilizing IoT could be a real benefit to supporting this process, by collecting automated data about multiple different variables, and reducing logging effort of the user [79, 35].

Leveraging Current Technology Use
We were interested to find that many of our participants were already using IoT technologies in their homes. Of course, our workshops were specifically on IoT for Parkinson's, so it is possible we had a biased sample, but this observation somewhat counters a familiar narrative that we often see in research—that older adults, particularly those with accessibility issues, do not want to engage in new and emerging technologies. McNaney et al. [31, 33] similarly found that people with Parkinson's had a willingness to engage in novel technologies to support their needs.

Voice assistants, in particular Alexa, were discussed heavily among our participants. Despite acknowledged issues with speech, our participants were successfully using voice assistants, and with pleasure. One participant even reported modifying his speech patterns to improve the device's ability to understand him. This echoes findings from Pradhan et al. [53] who conducted an analysis of reviews for the Amazon Echo (for which Alexa is the voice assistant) written by people with cognitive, sensory and physical disabilities. Users with speech impairments reported high levels of success when using the system, as well as describing how the device helped them to speak 'slowly, loudly and clearly'. Speech and voice impairments are highly prevalent in people with Parkinson's (approximately 90% will experience issues at some point in their condition [22]). Vocal loudness and increased rate of speech are particular contributing factors to the problem [36]. As such, understanding whether Alexa could help with treating speech and voice issues, or supporting a program of speech therapy, could be a valuable new avenue for research. It may even be possible that simply using Alexa as an 'out of the box' tool could have benefit.

Our participants also discussed the possibility of using voice input as a way to collect self-report data. This in itself is a worthwhile consideration for future work exploring IoT solutions to support self-care. With acknowledged challenges around the burden that self-tracking can have on an individual [79, 34], particularly in the sense that physical symptoms and unfamiliarity with technology can cause stress and fatigue, voice input could offer a light-touch way to collect daily report data [25].

However, it is important to note the potential challenges around data privacy and sharing when using commercial technologies within the healthcare domain. It is not always the case that researchers will be able to fully anonymize participants, or that healthcare workers will be able to control the storage of patient data in full accordance with healthcare data regulations. It is our view however, that this should not exclude the vast potential that these types of technologies might have in supporting patient care. As shown from our study, participants were happy to share their data for research purposes, and to benefit their care and the care of others. Their concerns lay in how their data might be used to affect their financial stability; a finding further echoed in [28]. As such, future work must be particularly careful to ensure that participants are made fully aware of the possible data sharing and ownership guidelines of commercial companies.

CONCLUSIONS
This paper has presented the findings of engagements to scope the future potentials of IoT for supporting people with Parkinson's. This has led to four key considerations for future IoT solutions that might support people with Parkinson's in better understanding their condition; data supported decision-making in care, understanding complex symptoms, opportunities to support self-experimentation and leveraging current technology use. Future research in IoT and Parkinson's should focus on the development of sensor systems that can provide custom data, which are automatically collected, reducing logging effort of the user, but which promote concepts of ownership over one's data generation and curation.

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