



# Exploring Perceptions of Cross-Sectoral Data Sharing with People with Parkinson's

Roisin McNaney  
roisin.mcnaney@monash.edu  
Monash University  
Melbourne, Australia

Catherine Morgan  
University of Bristol  
Bristol, UK

Pranav Kulkarni  
Monash University  
Melbourne, Australia

Julio Vega  
University of Pittsburgh  
Pittsburg, USA

Farnoosh Heidarivinchek  
University of Bristol  
Bristol, UK

Ryan McConville  
University of Bristol  
Bristol, UK

Alan Whone  
University of Bristol  
Bristol, UK

Mickey Kim  
University of Bristol  
Bristol, UK

Reuben Kirkham  
Monash University  
Melbourne, Australia

Ian Craddock  
University of Bristol  
Bristol, UK

## ABSTRACT

In interdisciplinary spaces such as digital health, datasets that are complex to collect, require specialist facilities, and/or are collected with specific populations have value in a range of different sectors. In this study we collected a simulated free-living dataset, in a smart home, with 12 participants (six people with Parkinson's, six carers). We explored their initial perceptions of the sensors through interviews and then conducted two data exploration workshops, wherein we showed participants the collected data and discussed their views on how this data, and other data relating to their Parkinson's symptoms, might be shared across different sectors. We provide recommendations around how participants might be better engaged in considering data sharing in the early stages of research, and guidance for how research might be configured to allow for more informed data sharing practices in the future.

## CCS CONCEPTS

• **Human-centered computing** → **Human computer interaction (HCI)**.

## KEYWORDS

Parkinson's, Smart home, Data sharing, IoT, Privacy and security

### ACM Reference Format:

Roisin McNaney, Catherine Morgan, Pranav Kulkarni, Julio Vega, Farnoosh Heidarivinchek, Ryan McConville, Alan Whone, Mickey Kim, Reuben Kirkham,

and Ian Craddock. 2022. Exploring Perceptions of Cross-Sectoral Data Sharing with People with Parkinson's. In *CHI Conference on Human Factors in Computing Systems (CHI '22)*, April 29-May 5, 2022, New Orleans, LA, USA. ACM, New York, NY, USA, 14 pages. <https://doi.org/10.1145/3491102.3501984>

## 1 INTRODUCTION

Parkinson's is a progressive neurodegenerative condition affecting approximately 10 million people worldwide [16]. It is mainly characterized by its primary motor symptoms, which include tremor, rigidity (stiffness), and bradykinesia (slowness and delay in the initiation of movement) [53]. A range of non-motor symptoms such as urinary incontinence, pain, fatigue, temperature dysregulation, anxiety, and depression, are also commonly seen amongst people with Parkinson's [59], further adding to its impact.

As there is no definitive test for Parkinson's, its diagnosis and assessment of disease progression are based on a series of clinical criteria [55]. The most widely used clinical rating scale for Parkinson's is the Movement Disorders Society Unified Parkinson's Disease Rating Scale (MDS-UPDRS), a scaled clinical assessment of motor and non-motor symptoms [44]. However, this assessment is limited by patient status at time of rating, and the clinical expertise of the rater [34]. Furthermore, clinical ratings require people with Parkinson's to travel to, or be visited by, a specialist for diagnosis. Also, individuals are required to retain a memory of how their symptoms have impacted them within a certain time-period (e.g., in the past 2 weeks) [27]. In summary, the current gold standard approach for Parkinson's assessment has a range of existing challenges.

Regular assessment of Parkinson's symptoms is vital so that clinicians can accurately and effectively manage treatment approaches. Standard Parkinson's treatments such as levodopa-based medications (a chemical that replaces lost dopamine in the brain) [77] and deep brain stimulation (delivery of electrical pulses to the brain to stimulate activity) [60] require regular monitoring of symptoms. The monitoring allows clinicians to adjust and maximize treatment impacts [27], [61], [80]. In addition, as Parkinson's progresses over

Permission to make digital or hard copies of all or part of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for components of this work owned by others than the author(s) must be honored. Abstracting with credit is permitted. To copy otherwise, or republish, to post on servers or to redistribute to lists, requires prior specific permission and/or a fee. Request permissions from [permissions@acm.org](mailto:permissions@acm.org).

CHI '22, April 29-May 5, 2022, New Orleans, LA, USA

© 2022 Copyright held by the owner/author(s). Publication rights licensed to ACM.

ACM ISBN 978-1-4503-9157-3/22/04...\$15.00

<https://doi.org/10.1145/3491102.3501984>

time, the extended use of medication can lead to a reduction in its overall effectiveness and can cause, what is known as, the on/off phenomenon (i.e., motor fluctuations) [54]. When an individual is 'on', their medication is working effectively and symptoms are controlled, when 'off', the medication is no longer working, and symptoms have re-emerged. This can either happen as a gradual 'wearing off' of medication, during which the individual is aware that the off state is coming, or in the later stages can occur very quickly, likened to the switching on and off a light switch. Improving approaches towards monitoring the impact of medication on symptoms over time will ultimately lead to better treatment and greater quality of life.

There is longstanding research exploring the role of technologies in supporting Parkinson's symptom monitoring and assessment. This includes wearable sensors [21, 38, 39, 82, 84], which contain accelerometers and gyroscopes to observe and quantify motor function. Smartphones [29, 33, 37, 42, 68, 72, 73], which have similar internal sensors, along with touchscreen functionalities can be used to measure fine motor skills and cognitive ability, through additional on-screen assessments. Camera-based sensors [36, 38, 40, 71, 87] have also been used to analyze measurable clinical indicators of Parkinson's, such as gait and postural stability. More recently, several studies have also looked at the use of multi-sensor Internet of Things (IoT) based systems for monitoring Parkinson's in the home [57, 64, 66, 74]. These technologies offer immense potential for tracking symptom fluctuations and disease progression, which offer benefits in relation to clinical care provision and in providing the person with Parkinson's themselves a better understanding of their condition. However, previous work has highlighted people with Parkinson's concerns over the privacy and security of their data when using technologies to monitor or manage their symptoms [35, 62, 64]. This is of particular importance when considering the use of commercial, off-the-shelf, devices in clinical practice, or research, as commercial storage and data sharing practices may not be totally controlled by research or clinical organizations [35, 64].

This paper describes a two-phase study exploring people with Parkinson's perceptions of data and data sharing. We aimed to explore how they viewed data sharing across different sectors (e.g., research, healthcare, industry, government level) to develop insights into how they might be better engaged in future discussions about their data and how it is used in the future. The first phase of our study involved collecting preliminary data, in a smart home environment, from 12 participants (six with Parkinson's and six spousal pairs without Parkinson's), wherein participants were asked to complete a scripted set of activities of daily living (e.g., cooking, cleaning) over a two-hour period. This provided us with a small multi-sensor dataset that we used to frame discussions around different types of data. Participants were interviewed, in their pairs, about their perceptions of the smart home system and its longer-term use in the wild. Our second phase of work engaged eight of the original participants, to understand their perceptions around data sharing. We conducted two data exploration workshops, which looked at the data collected from the smart home and a range of other data types that might be collected in future clinical studies, to understand a) what types of data they would, or indeed would not, be willing to share; b) who they might be willing to share with (e.g. researchers, pharmaceutical companies, industry); and c) the

caveats they might have in relation to this sharing and the levels of involvement and control that they would like to maintain over their data.

The intention of this paper was not to report on the sensor data that was captured, or its ability to measure symptoms of Parkinson's (this is reported elsewhere [49]). Instead, we focus on the participants' experiences of the data capture process and explore their views on how such data might be analyzed and shared across different sectors. We provide recommendations around how participants might be better engaged in considering data sharing in the early stages of research and provide guidance around how research might be configured to allow for more informed data sharing practices in the future.

## 2 BACKGROUND

### 2.1 Challenges and benefits of data sharing across sectors

The market value of big data was estimated to be around \$138.9 billion in 2020 (a figure forecasted to double by 2025) [2], making it one of the world's most valuable commodities [20]. Within the healthcare sector, the use of big data has been shown to make significant cost savings, by lowering healthcare spending [3], accelerating the rate of healthcare innovation and improving patient outcomes. However, research has highlighted that big data use within the healthcare system, which integrates patient-generated data (e.g., coming from wearable technologies or sensor systems) is still dramatically underutilized [83]. Privacy and policy concerns relating to data sharing, and collaboration across sectors and different organizations, are cited as some of the most significant factors impeding the potential for optimizing the benefits of big data use within healthcare settings [3, 83].

That said, practices surrounding cross-sectoral data sharing have steadily gained momentum over the years, as people recognize its economic and social impact. This can be partly attributed to a rise in publicly available 'open data'. The concept of open data within the public sector first arose in 2003 with the first European Union (EU) open data directive [17]. This provided a common legislative framework to encourage EU members to make as much public sector information as available for re-use as possible, with the aim of gaining public trust, achieving transparency, stimulating innovation, and delivering economic growth [24]. Government led open data initiatives were then launched in 2009 by the UK (data.gov.uk) and USA (data.gov), which provided public access to government-generated datasets relating to services funded through taxpayer's money (e.g., national census data, agriculture and ordinance data, health service data). Since then, there has been a global open data movement, with the 2015 International open data charter [15] being adopted by 16 countries worldwide.

The open data movement, has citizen values embedded in its core. Bargh and colleagues [24] highlight how, by making data available, governments can provide transparency into their operations, increase their accountability and compliance, and proactively enhance the public's engagement in contributing to governance processes. Individual citizens themselves can use open data to make better personal decisions about their health and care (e.g., by having access to data around hospital performance), or where they might

want to live (e.g., by having neighborhood statistics and crime rates). Finally, the business and academic sectors can benefit from using more open scientific data, to drive innovation and create new knowledge [6, 95]. Pasquetto et al [75] additionally highlight the broader societal benefits of creating open datasets, including “educational tools to train new scientists, shared common resources to promote capacity building in developing countries, and the ability for crowdsourced and citizen science projects to promote scientific public outreach and engagement” (p.2).

However, the generation of fully open datasets is a complex task, and it is, by definition, data that “anyone can freely access, use, modify, and share for any purpose (subject, at most, to requirements that preserve provenance and openness)” [15]. This lack of restriction around data sharing and use does not lend itself well to the, often highly sensitive, healthcare context, where the security, use and governance of private healthcare data is particularly important. In addition, increased regulatory mandates in recent years (e.g., the EU’s General Data Protection Regulation (GDPR)) has been shown to create a sense of reluctance for data processors to share data amongst one another [76, 97]. As such, considering data that is semi-open (with restrictions on its availability or access [13]) is more realistic. Semi-open data sharing practices are gaining much more traction within healthcare and academia, particularly for within-sector sharing (e.g., academia-academia) and between academia and healthcare organizations. For example, in the space of Parkinson’s alone, there are multiple (extensive) semi-open datasets available for research by organizations that are proven to be reputable by the data holders [8, 12]. These contain various data types such as MD-UPDRS scores, participant demographics, qualitative symptom diaries, and raw sensor data. However, while health data sharing practices across academia and healthcare are well defined and health communities apply a level of trust to these practices [93], this is not necessarily the case within the industry sector. Research has shown a level of unwillingness from citizens to share their health data with commercial organizations due to a perception that company motivations are driven by profit, as opposed improving health and wellbeing [50, 89, 93].

## 2.2 Citizen engagement in data sharing for health

Over the past decade, there have been rising attempts to engage citizens in the process of collecting and sharing their health data. Data donation platforms [5] allow individuals to upload their health data in the form of wearable data, medical records, lifestyle information and personal stories to “allow researchers and medical professionals from around the world access to data to use in their research and contribute to the development of preventive, personalized and predictive medicine”. Similarly, Patients Like Me [11] is a crowdsourcing platform that connects users with long-term medical conditions to share real-world health experiences, donate data for the greater good of their health community, and advance research. There are clear benefits to sharing one’s health data from a personal perspective (e.g., better decision making around treatments based on the experiences of others; personalization of treatments based on individual data). Other benefits include the altruistic motivations to do so by providing collective data that might benefit other members

of their health community and advancing science to improve future care.

However, as [23] highlights, fully open data is open to anyone (including for-profit organizations), which has caused significant public concern in the past. For example, in 2013 the UK government launched a (failed) initiative called Care.data [96] which provoked extreme public resistance and media controversy, mainly because the intention was to enhance the sharing of large-scale National Health Service (NHS) data with researchers and industry. The public view was that the NHS had become a data broker [96], making a profit by selling personal patient data. It led to around 1.5 million people opting out of data sharing outside of their GP practice [1, 58], which caused widespread challenges.

There is a sense of trust from the public in how their health data will be stored and managed, both in clinical and research contexts. As such, not centrally involving citizens in conversations around data sharing practices which step outside this worldview of data management (i.e., in the case of cross-sectoral data sharing) can dramatically impact the sense of trust that they might have. With increasing opportunities to leverage, for example, commercial technologies (such as voice assisted devices [35, 79], smart watches [48], and even social media platforms such as WhatsApp [56])—which have not been originally designed for health monitoring, but can support health needs—these notions of trust become even more complex. Previous work within HCI has identified a range of fears, concerns and general lack of understanding relating to how commercial companies might use health data [63, 64].

## 2.3 Speculative design as an approach for exploring future data scenarios

In response to some of the aforementioned challenges, there is a body of work within the speculative design space that has used design fictions to explore the possible ethical, legal, policy and legislative implications that might arise around the introduction of new technologies within the health and care space [22, 25, 26, 31, 88, 92]. For example, [88] describe HealthBand, a near future design fiction which describes a modular wearable consisting of a series of sensors. They present a fictional scenario that sees makers gaining crowd funding to develop the HealthBand for monitoring diabetes, supporting memory in dementia, and a tremor stabilizer for Parkinson’s. The authors provided draft government legislation for DIY wearable devices for health a domestic fabrication permit that makers might require to develop such devices and finally a patient guide for gaining home-made health wearable certification, which provides guidance for conducting patient-led research. Whilst the authors did not discuss any participant engagements with this design fiction, they presented it as a provocation tool, to stimulate discussion around the broader implications and regulatory requirements necessary to truly implement concepts such as DIY technology for health. Tsekleves and colleagues [92] worked with 21 older adults to co-design design fictions which explored assisted dying and smart homes within assisted living facilities. They found that the process of co-designing these near future scenarios around a fictional technology design helped to stimulate discussions around the plausibility and acceptance of future technologies and services. They also described how it helped participants consider ethical

issues within the health technology space and supported the capture of future design requirements. Whilst these examples focus more on product adoption as opposed to data sharing, it is evident that design fiction approaches might be utilized in a similar way to support citizens in considering, particularly the legal and ethical, implications of data sharing.

Given the acknowledged complexities surrounding cross-sectoral data sharing, particularly when it is relating to people's health, our study aimed to explore approaches towards engaging health communities in defining how their data might be ethically and responsibly sourced and used. We conducted our exploration through the lens of smart home sensing in the context of Parkinson's symptom monitoring for several reasons. Firstly, our smart home set-up could be considered a specialist facility; the house itself is a testbed and the platform, when implemented in people's homes, requires specialist knowledge, skills and equipment to set it up. Secondly, Parkinson's is a complex condition with a range of movement and non-movement related symptoms, so collecting a large dataset of this kind is a significant undertaking. As such, exploring opportunities for creating pathways towards sharing this kind of dataset outside of a single research organization would have consequential value.

### 3 OUR STUDY

The smart home that we discuss below is equipped with a range of sensors that can passively collect data. Table 1 provides a summary of the available sensors and their data collection capabilities. The smart home sensors were embedded within a fully furnished University-owned home but can be set up and deployed in users' own homes for longer-term use. Currently, the sensor platform has been trialed with healthy volunteers in 50 homes for over a year. The researchers who originally developed it are now in the process of looking at clinical applications, with studies to date being conducted in hip and knee replacement surgery, dementia, and Parkinson's [47, 70, 78]. The original design of the smart home was conducted in extensive consultation with members of the public.

Our study was conducted in two phases. The first aimed to provide participants with a simulated experience of free-living, within a smart home full of sensors that would potentially measure their Parkinson's symptoms in a larger scale clinical experiment. This allowed us to investigate early perceptions of smart home sensing, both with people with Parkinson's and their partners (who would also potentially be living with the sensors longer term). The second phase aimed to explore the data that had been captured within the smart home environment, to understand participants' broader views around how data relating to their Parkinson's should be collected, used, and shared in, and between, different organizations (e.g., research, healthcare, industry). This data exploration and inquiry process also allowed us to have open conversations with participants around the facilitators and barriers of data sharing. This included how they would want data sharing, particularly across different sectors, to occur in the future (if at all).

#### 3.1 Participants

Twelve participants took part in the study. They were made up of six heterosexual spousal pairs (one with Parkinson's and one without)

who were roughly age-matched (within five years). Within the Parkinson's group, we had three males, three females with an age range of 58 to 73. The range of years since diagnosis was between one and a half and nine (mean= 5.3 years) and all participants were between Hoehn and Yahr stages one (unilateral symptoms only) and two (bilateral symptoms with no impairment of balance) [43]. All participants were Caucasian. Participants were recruited via a Parkinson's charity organization, following an email call for participation. Ethical approvals were obtained from our University Research Ethics Committee prior to the onset of work. Written consent was provided by each participant.

#### 3.2 Phase 1: Experiencing the smart home

Through this phase we were aiming to a) give participants a snapshot view of the types of activities the smart home might be able to capture in a typical day; b) the types of activities that might be useful to capture in the Parkinson's context; and c) explore how comfortable participants might be having these types of sensors in their home, on a longer-term basis (in order to capture longitudinal changes to Parkinson's symptoms over time).

Each pair of participants was asked to attend a 2-hour session at the smart home at a time and date that suited them. Participants were first fitted with the wearable. Each individual participant (both the person with Parkinson's and their partner) was then asked to complete a set of scripted activities (see below) that might represent a typical 'day in fast forward' and would capture a range of movements relevant to assessing and monitoring Parkinson's. During this time the other participant was asked to remain in the dining room (magazines and newspapers were provided to avoid boredom). A research team member prompted the participants with each activity and documented the time that each activity began, to help guide later data extraction. There were 4 activities that each participant was asked to perform:

- **Meal preparation:** The participant was asked to walk to the kitchen and prepare an omelet and hot drink (a complex task requiring dual task performance). Both the hob and kettle were used, providing data from the humidity and electrical sensors. They then served this meal to their partner, who ate it in the dining room.
- **Cleaning:** The participant was asked to enter the living room, sweep the floor and wipe down the tabletops (simple activities requiring gross motor movements). They were asked to rest on the sofa (providing a sofa sit-to-stand transfer, which tends to be lower than a standard chair).
- **Sleep-related activity:** Participants were asked to climb the stairs and enter the bedroom. They were asked to sit on the bed and take off their shoes (requiring fine motor movements) before lying down and rolling over twice, to simulate turning over in bed (a challenge for many people with Parkinson's due to rigidity and movement initiation). Following this, they were asked to put their shoes back on and walk down the stairs to the bathroom, where they washed their hands (aiming to simulate getting out of bed to use the bathroom at night).
- **Washing up and resting:** Participants were asked to descend the rest of the stairs and enter the kitchen, where they were

**Table 1: Sensor information and sensing capabilities**

Sensor Type	Sensing Capabilities
Wearable 3-axis accelerometer	Activity recognition Indoor location Mobility recognition
Wall-mounted environmental sensors	Human presence Temperature Pressure Humidity Light
Silhouette video cameras	Silhouette motion recordings of human activity
Current sensors	Appliance usage: TV, microwave, kettle, washing machine, toaster, refrigerator
Mechanical flow sensors	Water flow through sinks, toilets, baths

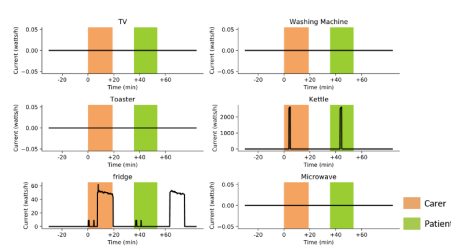
asked to wash the dishes from the cooking activity (providing data from the water sensors). Following this, they were asked to enter the living room and rest in a chair (providing a sit-to-stand transfer on a chair with arms). Finally, they were asked to join their partner in the dining room, where the script ended.

Once both participants had completed their scripted activities they were interviewed in their pairs, to gather their initial perceptions of the smart home sensor system, the type of data that was being captured, and explore how they would feel about having the system (or a subset of the sensors) in their own homes for longer periods of time.

### 3.3 Phase 2: Data exploration workshops

In this phase of the research, we wanted to explore the captured data alongside the participants. We specifically provided them with a tangible conceptualization of the types of data the house was collecting about them, to explore how this data might then be interpreted and shared with different people and organizations, and to envision future use cases that might arise around the sharing of this data.

We ran two workshops with a total of eight participants (two pairs in each workshop); the other two pairs were unable to attend

**Figure 1: Current sensor data shown to the participants, indicating appliance usage.**

due to planned holidays over the workshop dates. Each workshop lasted two hours and was held on the University campus. Participants were first shown a series of graphical data visualization examples, representing the wearable, environmental and current sensor data collected during the study Figure 1. Participants were then shown a series of silhouette videos showing the data captured by the smart home cameras (see Figure 2 for stills from these videos). A researcher verbally provided a layman's explanation of each sensor (e.g., "this sensor measures the amount of electricity flowing through different appliances such as the kettle, or tv, so we can tell when they are switched on and being used") and what the data captured represented (e.g., "we can see here from the peak in the graph that the kettle was used"; "we can see in the silhouette that the person is bending down to take something from the fridge"). Participants were given the opportunity to ask questions about the data and how it might be used. They were then asked to discuss if this data differed from their initial perceptions of the smart home data capture.

Participants were then asked to consider all possible data that might be collected as part of a clinical study which used the smart home to monitor Parkinson's symptoms (e.g., clinical rating scales, participant symptom diaries, information such as the number of times they leave the house, use the bathroom, cook a meal, how long they sleep). There were a total of 38 different data points to consider, which included potential activities that could be captured

**Figure 2: Stills from the silhouette videos shown to the participants.**

by the smart home. The list of data points was developed in consultation with the research team, two Parkinson's clinicians, and an industry representative, who provided information, relevant to their respective sectors, that they might want to collect as part of a clinical trial into daily activity and symptom monitoring in people with Parkinson's. Each individual data point was presented to participants on a separate slip of paper (distributed on the shared table during the workshop) so these could be seen as an entire potential clinical trial dataset. Participants were asked to consider if any of these data points felt 'high risk' to them, regarding their privacy and security, and whether there were any data types that they would not feel comfortable sharing.

Finally, participants were asked to discuss who they might share their data with. Participants were provided with 15 examples of 'people' who might be interested in this data (again presented on slips of paper to aid memory and facilitate discussion). These included technology companies (big tech companies such as Amazon and Google, as well as smaller tech companies such as start-ups), pharmaceutical companies, health professionals (e.g., Parkinson's specialists, GPs), government agencies (e.g., local city council), University researchers, and family and friends. Participants were asked to discuss the type of data they would, or would not, be willing to share with these people and organizations and any concerns that they had around data sharing.

### 3.4 Data analysis

Each paired interview (n=6) and workshop (n=2) was audio recorded and transcribed verbatim for later analysis. An inductive thematic analysis on a line-by-line basis was conducted by two members of the research team, to explore our interpretation of the themes and sub-themes, without a pre-existing coding framework [30]. Any thematic discrepancies were discussed before the final set of themes were decided upon. Participant quotes are identified in the findings according to the following: i) Parkinson's (P) or Carer (C); ii) male (M) or Female (F); iii) pair number (1-6). For example, PF4, or CM4.

## 4 FINDINGS

### 4.1 Phase 1: Interview findings

Participants were interviewed in their spousal pairs following the completion of a set of scripted activities in the smart home. Each interview lasted between 19:40 and 28:09 minutes and aimed to explore participants' initial perceptions of the smart home, and their willingness to have the sensor platform in their own homes for a longer time period. Participants had very similar perspectives and were largely positive. As such, data saturation was reached in the analysis very quickly (by the third transcript). Given the similarity in participants' views, we present the phase 1 findings narratively and briefly.

Participants were asked about their very early perceptions of the smart home sensors (before they had even arrived at the house) and whether they had any preconceived ideas of what the monitoring environment and sensors were going to be like. Several of the participants had no idea what to expect when coming into the smart home environment. For example, PF4 was surprised that we were using a wearable device *"I thought of cameras, but I hadn't thought of body-loaded devices"* whereas PF5 was simply unsure

how to develop a mental model of the smart home set up before seeing it *"I knew that there would be sensors around the house but I wasn't quite sure how it would function in a sort of test set up"*.

As expected, participants were primarily concerned about the camera-based sensor. For example, CF3 stated: *"I was rather nervous because I hate the idea that I'm being filmed or recorded in some way... I thought there might be things right in front of my face sort of thing"*, however, most of their original concerns around being filmed were alleviated when they had the chance to see the set-up in the smart home, and the silhouette capture was explained in further detail upon arrival. Participants were generally happy with the thought of having the camera set-up at home longer term *"I think I'd be quite happy to have them [cameras] at home"* (PM5). PF6 explained how it was the thought of recording audio that was more of an issue for her: *"You're not recording sound, are you?... [in that case] I wouldn't have a problem with that at all."* For all participants, they were all willing to engage in this research and to have the sensors in their home for more continuous monitoring, if they perceived that it would benefit themselves, or others, in the future, e.g., *"if it would help, I'd be happy to"* (PF6).

All participants considered the sensors to be unobtrusive. For example, PM3, when discussing the wearable said: *"Never gave them a thought, actually, once we had them on,"* where CM6 explained more generally about the home sensors *"It didn't bother me at all, I forgot about them"*. They did not have any overriding concerns about data that might be captured about them by the smart home, however, CM6 did mention it would be necessary to take into consideration other people living at home: *"the only other thing is our son lives with us at the minute so it might be a bit intrusive for him."*

The majority of participants' concerns with using the sensors longer term centered around the wearable, and possible challenges with either remembering to put it on: *"in a funny way, because they're easy to forget, they're easy to forget. So the issue would become just remembering to put them back on again"* (PM3) or whether or not the devices would be resilient enough to fit in with some of their everyday activities, such as working out, swimming and showering.

### 4.2 Phase 2: Workshop findings

The thematic analysis of the data exploration workshops identified four major themes of discussion across participants: Personal Opportunities for Data Usage; Trust and Transparency; Data Misuse; and For-Profit data.

**4.2.1 Personal Opportunities for Data Usage.** The collection of sensor data was not only seen to be beneficial to researchers, but also to the participants themselves, by providing a way to support communication with a clinician during appointments. The opportunities for presenting a more exact picture of symptom progression, and particularly symptom fluctuations, were discussed as clear benefits: *"it gives a consultant a snapshot of how you are during the day, which can be very difficult to explain I think"* (PF4). PM1 explained how he had signed up for the study in the first place due to inadequacies of current clinical monitoring approaches: *"the reason I signed up for this is because the UPDRS is like what?! There must be a better way of doing it than this, there must be. And the technology seems to offer that possibility"*. However, in this context, participants also

discussed the volume of data, and the necessity to present this using good visualizations of the results in order to have direct benefits to them over time: *"your consultant wouldn't be interested in all that data anyway, unless it could be refined down in such a way that it gives a dozen bullet points, and it can compare to the dozen bullet point three months ago, a year ago whatever it was"* (CM4).

While it was clear that participants were very cognizant about symptom changes, and the symptoms that had most of an effect on their everyday living, there were also some challenges discussed in relation to monitoring these. Several participants discussed how awareness often did not arise until symptom severity was much worse. PF6 even discussed how she took less of her Parkinson's medication, despite being advised to take it more frequently: *"I have this idea that if I take less medication it will be better for me, if I'm not feeling that I'm going into an off [off state], I would try and sort of stretch it out a bit"*. Participants also discussed opportunities for the sensing technologies to improve their understanding of the impact of self-directed, non-clinical interventions that they were carrying out in an attempt to improve their Parkinson's (e.g., taking regular exercise): *"you could actually show that if somebody is say exercising for 10 minutes every day that actually their decline is slower [...] that could actually be really valuable couldn't it?"* (PF4). This was seen to be more important to quality of life and symptom improvement than other clinical measures that might be collected: *"if someone likes to go out for a walk every day, and they do three miles, and then they do two miles and then one mile... that's more indicative to me than whether they flush the toilet at night or not"* (CM6).

The benefits regarding sensor-based monitoring of their symptoms over time were clear to participants. For this reason, their views regarding having the sensor platforms in their own homes for longer were largely unchanged between the two phases of research. Echoing the stage 1 findings, video was the main discussion point during the activity exploring the captured data. However, the silhouette data (which we showed participants in motion) was seen to be obfuscated enough to retain their anonymity: *"I don't think it's very easy to recognize in silhouette"* (CF1); and *"I think in the form that you've shown it, for me, it's fine. It's not like watching a video where you're recognizable"* (PF4).

**4.2.2 Trust and Transparency.** When discussing data sharing, participants began with a familiar narrative that they would be happy to share all of their data for 'the greater good' of the Parkinson's community: *"as far as I'm concerned anybody can know anything about me, I really don't care, if it's going to move the Parkinson's cure forward"* (PF6); *"you could be comfortable with any of it, if it was shown to be useful in some way"* (CM6) and *"you have to trust that the people that are looking at and using this data are doing it for a specific and worthwhile reason, and so on that basis I wouldn't have a problem"* (PF2).

Trust and transparency were seen to be vitally important in the data sharing process. This was generally seen to be well defined within the research sector (i.e., research conducted by universities, healthcare organizations or charities): *"as long as you feel like you're working with a reputable organization he's going to look after the data, you're happy to share it"* (PF2), with these types of organizations having standard procedures that were clear to participants, and thus made them feel confident that their data would be protected:

*"While it's for the university or a health authority, I kind of feel a certain confidence that they are bound by codes of conduct of some sort"* (CM6). These organizations were seen as trusted gatekeepers to the data, whose responsibility it was to ensure that *"the rules are obeyed by everyone concerned"* (PM1).

As we progressed through our discussions however and began to more deeply explore how data might be interpreted, shared, and used by different people and organizations in other sectors, it became clear that this trust was seen to be trickier to obtain at the industry level. Participants noted a perceived lack of transparency over how their data might be used: *"sometimes it's not very clear what they do, sometimes they deem commercial confidence and the people that develop [commercial devices] will not reveal what they do"* (PM1). This discussion led to participants considering their views on consent and data sharing. While participants were happy to share their data if they are fully informed about who might access it: *"it's not so much the data your collecting, for me it's more about who is going to have it"* (PF2), they wanted to retain a sense of control over this process, on a case by case basis: *"I think it would have to be very specific about what you're sharing and who with [...] it would have to be on an each basis, looking at exactly was being shared I think"* (PF4). PF4 went on to say *"who has access to the information, in what form and how it's interpreted? That would be my concern"*. Participants discussed the need for specificity when asking for consent to share data. They felt that in order to be fully informed they needed to know the exact context of how the data would be used. This was relevant even in the research context when considering extended storage and re-use of data for research purposes. Blanket level consent was not seen to be enough: *"unless someone's gone through this and said, well this is going to be useful in a specific way, it's hard to know whether [to feel happy about it or not]"* (CM6). This was seen to be particularly important in older participants: *"The complication arises about, again, for the frail and elderly, about what informed consent actually looks like in some cases, do they know that you're watching them in that way and are they comfortable with it?"* (CM2).

**4.2.3 Data Misuse.** Participants had several polarizing opinions relating to discussions around the use of their data by different people and organizations. On one hand they wondered why anyone would want their data in the first place. Participants were unconvinced that data about their everyday living would be of interest to anyone outside of the research team: *"There's potentially an embarrassment factor, do you want people to know how many times you go to the loo in a day, no not really, but why would anyone care?"* (PM1); and *"whether or not I could make a good omelet, for instance, was not going to be interesting"* (CM4). Even when considering issues of data security, some participants could not see why data around their Parkinson's symptoms might be used with malicious intent: *"I'm struggling to think in what ways a malicious actor would want to try and use this data [...] giving away banking details you know why people want it, but what is it about this data that anyone feels they might take advantage of me as a result of knowing that about me?"* (PM1).

However, as discussions progressed, participants began to consider the broader implications that open access to different data types might have, if it were to be shared. Participants discussed how



standard utilities services, which encourage the use of electricity and water sensors, could impact aspects of their personal safety and security and be open to malicious behavior. PF2 described: *“suddenly there’s no water going through the system [...] They can tell from that that you’re not in the house”*. While this was seen as an underlying concern, rather than a barrier towards ‘moving with the times’ (PF2 had a water meter in her own home), participants reconsidered their views on what they originally considered as relatively unassuming sensors, yielding anonymous data: *“people knowing what your habits are and what happens in your own house have security implications”* (PM1).

Aside from individual data types, Participants also discussed the possibility that cohort level data on people with Parkinson’s could potentially be misused, and ultimately have negative implications for members of the Parkinson’s community. CM6 discussed how insurance companies could potentially use cohort level data to drive up the price of insurance, even if data is fully anonymized: *“there are still risks with cohort data... it [insurance prices] might extend to much more than that if they have cohort data that said Parkinson’s has this impact after so many years”*. CM4 had similar concerns in relation to driving restrictions and car insurance, with the thought that decisions based on cohort level data could have top-down negative effects on individuals: *“it’s not necessarily individual data, it could be cohort data that could impact insurance company policies on people with Parkinson’s, it could impact the DVLA’s approach to how long they give you a license for”*. PM1 also discussed the fact that pension calculations were made in relation to medical conditions, undoubtedly made through cohort level data: *“potentially they will use it to calculate the value of an annuity, they say”*. However, participants also discussed the fact that this type of data was of such a nature that it should be self-disclosed anyway *“it’s important that they do have the information. I mean local authorities, local councils, DVLA is very important that people have your information”* (CM2). PF2 also discussed how sharing of data about their condition within local city council services might be beneficial to ensuring that services specific to Parkinson’s retain funding and are kept going: *“if the local council don’t know that there’s this number of people that need the long-term gym, then they’ll shut it”*.

**4.2.4 For-profit data.** Within the context of data use and misuse, participants extensively discussed targeted advertising from commercial companies. Participants were very aware of the fact that major technology companies collected and used their data: *“There’s a huge number of them already have a huge percentage of my data anyway... judging by the number of ads that come up on my computer, the whole world out there knows what I’m interested in”* (CF1). There was a nonchalance relating to the fact that their data was “out there already” (PF2) and, even if participants did not want their data to be shared with these big companies, there was a sense of blind acceptance: *“I’ve signed up now to two Facebook groups which are Parkinson’s related, so Facebook now know that I’m interested in Parkinson’s, so that horse has already bolted”* (PM1).

Participants discussed how they might be identified as someone with Parkinson’s through their internet habits: *“that can relate very easily to your condition can’t it? You know, if you are buying certain things it can tell them quite a lot about you”* (PF4); and *“suddenly you’re targeted in a way that you don’t realize you are being targeted.*

*Someone with Parkinson’s is identified”* (CM4). Whilst this type of condition related targeted advertising was seen to be beneficial in some company contexts: *“you’ve got a small tech company, give other people [mobility ads] and things like that could obviously be beneficial”* (CM6), participants also discussed the potential harms, particularly if there is not a sense of trust over where advertisements have come from, or whether or not they were from a reputable source. For example, CM2 stated: *“It’s not qualified by a consultant or a practitioner, so you don’t know whether it’s good information coming to you”*. He furthered this by discussing how this was particularly important in relation to medication *“You get a lot of these pseudo-companies, pseudo-pharmaceutical companies from abroad... offering you all these miracle cures or whatever it happens to be. And that’s disruptive isn’t it? It muddies the waters. You’re never quite sure what’s true and what isn’t true”*.

Even in the case of reputable drugs companies, there was a sense of mistrust from participants due to their perception of *“the way they behave really”* (PF4); that these companies were more concerned about profit margins than individuals’ health and wellbeing. PF6 said: *“I think pharmaceutical companies are bad boys rather than good boys I have to say. Because it would be nice to think that they put us first, but they put profits first obviously”*. However, this view was not shared by all. Participants also saw the value that data sharing might have within drug companies, to further innovations into research that would ultimately benefit them: *“the more information they’ve got, the big pharmaceutical companies, the more research and the more data to do their research they’ve got”* (PF2). CM4 explained how and these companies are often the ones who fund clinical pharmaceutical research, and this was seen to counterbalance their need to turn a profit: *“the big pharmaceutical companies have got to make money, and they’re the only ones that have the money to develop new drugs, so clearly we don’t want to discourage that. You need to know what they are giving away to some extent”*. Questions remained however in relation to how cross-sectoral data sharing might occur (e.g., from university research to pharmaceutical research conducted by a company) and the format that shared data outputs might take *“one of the questions would be do you analyze this data and produce a number of studies papers, provide those to the big pharmaceuticals, or do you give them the data? Or sell them the data I should say?”* (CM4).

This concept of ‘selling data’ was also discussed at length. Interestingly, this was seen more as an issue with smaller, perceived as *“more vulnerable”* (CM4) companies, where there was an uncertainty about the legacy of participants’ data, should the company cease to trade: *“they’re very worthy, and upstanding pillars of society, yet they go bankrupt or they get taken over by someone else and that information doesn’t disappear does it, with them? It gets sold off”* (CM6). Despite the fact that bigger technology companies used data extensively internally, and as already discussed, sold data for advertising purposes, participants felt this was a low-risk use case. Their discomfort arose more around the uncertainty of what might happen to their data with smaller, less stable entities, where there is less transparency over data practices: *“[it’s] their intent at the beginning [...] not to do anything, but things change don’t they? In a couple of years’ time there might be somebody at the head of the company that feels [it could be used differently]”* (PF6); and *“data is worth money isn’t it? So if you’re a small company and you’ve got data to sell, I*



*mean you'll sell it, unless you're contractually obliged not to"* (CM6). The control over data, and thus the ethical use of said data, within a smaller company was equated to specific individuals, as opposed to company values, which was, in itself, seen as changeable factor: *"it could actually be very difficult to get someone concerned, because they might have moved mightn't they?"* (PF4); and *"this Mr. Blogg in the technical company, I mean nobody starts off with the intention of things going awry do they? But things happen and things change ... a couple of years they've moved on and something else has changed and the people [pass the data on]"* (PF6).

## 5 DISCUSSION

### 5.1 Engaging participants in data sharing discussions

The concept of exploring data with health communities is not new. Indeed, work has been researching optimal approaches to improving patients' understanding of health data for years. However, the majority of research in this area is focused on the individual level [46, 67, 86]. In addition, the data sharing contexts that have been previously explored tend to center around patient-clinician sharing, to support better symptom communication and shared decision making around care [46, 67].

Our approach, on the other hand, aimed to begin exploring some of the broader data collection, interpretation and sharing contexts that might be applied to highly valuable datasets (i.e., multi-sensor data captured from a specialist facility with a potentially hard to reach health community). We conducted our data explorations in several ways to elicit participants' views. We first showed participants sample visualizations of their own data. We then orientated participants to the types of additional information that could be captured on them, in a larger scale study, including the types of activities (clinically relevant to Parkinson's) that might be labelled for machine learning algorithms. Finally, we discussed the types of people and organizations that data sharing might potentially occur with, whether this was relevant to the participants themselves (e.g., GP, family members), their community (e.g., local council authorities), or for the benefit of the broader research community (academia, health and industry). Our intention was to develop participants' understanding of what the smart home sensors could do if paired with specific data types in the future, and how this data might be used by different organizations if shared.

Informed consent is the cornerstone of ethical research, and the design of our study allowed us to engage participants in considering how informed consent might be developed in the future. We found that participants' acceptance of the sensors and having them for longer periods of time in their homes, were largely unchanged between the two phases of work (i.e., they were happy to collect the data as long as the benefits to themselves, or to others, were clearly outlined), which is a finding echoed throughout other research exploring sensor acceptance [41, 64]. However, as we progressed in our discussions and considered the different types of data that might go along with this sensor data, and how this then might be interpreted and used by different entities, participants were able to consider some of the more nuanced privacy and security issues that sharing their data might bring. Interestingly, participants were relatively balanced in their views, seeing the positives and negatives

of certain scenarios (such as sharing their data with pharmaceutical companies and receiving targeted advertisements), which shows the value of engaging participants more broadly in discussions around these types of use case scenarios.

We propose that, whilst not a simple task, the only way to ensure participants are fully informed in data sharing scenarios is to actively explore challenges (e.g. insurance companies gaining access to cohort data and using this to drive up premiums for a specific health community), alongside opportunities (e.g. insurance companies using cohort data to better target coverage for services that might be more needed by a community), by bringing them to the forefront as provocations for discussion. Citizen juries are an approach that can facilitate the elicitation of positive and negative opinions and have been widely used to elicit public views regarding cross-sectoral health data sharing in the past [4, 93]. This approach balances arguments for and against specific data use cases, helping participants to understand the reasons behind their views, by providing a range of perspectives and highlighting both opportunities and challenges in an open and transparent way. Speculative design approaches have also been shown to be highly successful in exploring provocative issues with health communities [22, 25, 26, 31, 92], by allowing participants a sense of distance when exploring fictional, near future scenarios, as opposed to interrogating their own immediate experiences. In addition, recent work [32] has developed an online resource (the Ethical Roadmap [7]) containing provocations to supporting discussion around ethical frameworks in health research. Approaches such as these could be used in the future to engage the Parkinson's community (and indeed other health communities) in discussions around larger, more complex data sharing issues, such as ethical practices in data sharing, maintaining data provenance once it has been shared, and data legacy (i.e., what happens if an individual passes on, or is no longer able to actively consent to data use due to cognitive impairment).

### 5.2 Building trust into data sharing practices

Throughout our discussions with participants, it transpired that they had clear ideas around who 'trusted' data gatekeepers were in their minds. Universities, charities, and health services were seen to be trustworthy, primarily due to the perception that their interests were in helping the Parkinson's community. In addition, trust within these sectors was built on participants' views of organizational 'reputation' and the 'codes of conduct' that they were governed by. As such, participants felt that their data would be adequately protected by these organizations, as they had a level of familiarity over the Data Protection Legislation (e.g. GDPR [9]) that was underpinning the management and use of their data, when collected for research or health service delivery reasons. This finding is not new, there has been a wealth of research exploring trust around data in health research [30, 52, 69, 94] and beyond [51, 91], with transparency of practice, and retaining a feeling of safety, security and privacy being the main elements that make up trust in data sharing. In the case of cross-sectoral data sharing however, these notions of trust seemed to blur for our participants. They were not persuaded that these protections were in place in the real world and were able to give examples from their day-to-day lives where data protection obligations were, in their mind, breached. For example,

in the case of cohort level data being used to drive decisions around insurance, or data being used for advertising purposes.

Whilst targeted advertising may not seem like a harmful action, and indeed our participants were somewhat indifferent and accepting that this was happening, it is worth noting that this was a model of data, flowing across sectors, that they brought to their understanding of data sharing and use, particularly in industry. In this sense, their lack of knowledge around the provenance of their data in these instances (i.e., where the data had originated from), and how their data was being reused (or indeed ‘sold’) by different companies for advertising was contributing to their views on data sharing. In addition to this, participants raised interesting concerns around how much the advertisements themselves could be trusted (i.e., whether it had come from a reputable source), which was seen to be particularly important when considering medical advice. Previous work by McNaney et al. [64] explicitly discussed how participants with Parkinson’s used pseudoscientific dietary products to alleviate or slow the progression of their Parkinson’s symptoms, without understanding the underlying scientific research. As such, this fear from participants is particularly valid, especially when considering the possible contra-indications that could occur when coupling these products with Parkinson’s medication. Additional work [65] has highlighted how important medical reputation is to the Parkinson’s community, with medical professionals who are not Parkinson’s specialists being deemed to have insufficient knowledge to advise on Parkinson’s matters.

In the broader healthcare space this concept of harm through targeted advertising is a particularly challenging and yet under-explored area of research, with most narrative around this topic coming from blogs and opinion pieces [10, 18, 19]. For example, the use of solely demographic data for targeted advertising on social media could be, in specific cases, detrimental to users’ mental health if the possible negative scenarios are not fully considered (e.g., weight loss products advertising for those with eating disorder, pregnancy test advertising for those who have experienced miscarriage) [10, 18].

Finally, participants’ discussions around trust and data sharing within the context of smaller commercial companies yielded some insights that were surprising to the research team. Whilst data sharing practices in larger tech companies were not necessarily transparent to participants, they felt they had a basic understanding of the data use cases these companies might have. Small companies on the other hand were seen to be less stable, with trust attributed more to an individual than the company values themselves (i.e., a CEO who might eventually sell the company, and the data along with it). Even though some of these smaller companies could provide products that could be viewed as more beneficial to specific health communities, they were seen to be less trusted for these reasons.

In summary, our study has highlighted a necessity for transparency from participants in relation to data sharing practices, particularly within industry, where data use might generate a profit. We propose that future work collecting data with cross-sectoral value should consider this an opportunity for future collaborative work, which may help to build participants’ levels of trust in the industry sector, by leveraging trust in other sectors. For example,

work by Sillence et al. [85] has explored trust in online health information and has shown that sources provided with a ‘seal of approval’ from trusted health organizations such as the NHS are viewed to be more trustworthy by association. Companies aiming to fill this gap are already beginning to emerge. For example, ORCHA [14] is an example of an app review company that works directly with NHS organizations to build trusted app libraries for the prescription of digital health apps in different areas of health and care. Future work in this space should explore the design of transparent data collection, use and sharing policies that specifically consider the following: a) the communication of company or organizational values, b) providing a level of transparency over how data will be used, even if this is for-profit reasons, c) explicitly discussing the potential future sale or sharing of data, and d) clarifying expectations around the legacy of users’ data if the company changes hands.

### 5.3 Retaining a sense of control and data ownership

Our participants discussed how situational consent (particularly consent regarding who they share their data with) would help them make better informed decisions. Rake et al. [81] explored the co-design of personalized consent flows around data sharing for health research and highlighted how engaging participants in situationally specific consent processes—such as requesting that users collect data for specific studies or allowing participants to add expiration dates to their data—can enhance a sense of control. Similar approaches which make use of situationally specific data requests from health community samples can be seen in the crowdsourcing literature [28, 90, 98], as well as on citizen science platforms such as PatientsLikeMe [11]. This model of requesting data is largely framed in standard research practices (i.e., finding a cohort of participants and gaining their consent to take part in a specific research project). Research recruitment processes are designed to allow for informed decision making, whilst highlighting the benefits for participants, or their wider health community, and leveraging altruistic desires to share data for the ‘greater good’.

However, whilst this might be a useful approach for collecting data in the context of an individual study, complexities arise when considering how we might enhance a sense of control and data ownership in sharing more fluid sources of longitudinal data (with data reuse in mind). Insights during this type of data collection are often generated throughout the lifespan of the project, with incremental findings driving new areas of research. Data might therefore gain new value as research progresses. In addition, data collection and analysis can require a large investment of resources (making data reuse particularly desirable). For example, data collected with specialist equipment, that might not be accessible to all researchers (e.g., those in lower-income settings [75]), or data which is extensively labelled, particularly if this labelling has been conducted by people with specific expertise such as specialist clinicians. Goodman et al [45] call for researchers to consider data re-use from the very outset of their projects, which would include engaging participants themselves in discussions around data sharing and future use case scenarios.

However, as evidenced through our study, it can be difficult for participants to imagine all the possible scenarios that their data might be used in if it were to be openly (or even semi-openly) available. As such, having a means to keep participants informed about how their data is being used, and offering them a choice regarding specific data use scenarios, could be an approach towards enhancing their control and ownership over their data in the future. To make this operable in practice, approaches could consider engaging participants in the provision of advanced directives surrounding their comfort levels in certain data use scenarios. Data use scenarios would of course differ depending on the research context, and one cannot expect to cover every possible scenario. However, we would expect that discussing the possibility for data sharing and use across a range of different sectors (e.g. industry (with a proposed list of possible interested parties), health and care (professionals involved in current care, professionals involved in future care, health and care services for improving service delivery), research (clinical, social sciences, technology etc.), education (training university students or health and care professionals) and so on) would be a good starting point for building informed consent. As data reuse opportunities evolve (with the progression of research and knowledge), participants should be able to update their preferences if certain use cases arise that sit outside of those they have consented to. Such an exercise need not be elaborate from the participant engagement perspective (an email or app notification with opt-out ability may be enough here for requests that sit outside of the original consent form). However, work would be required in the early stages of research design to define these possible data scenarios and to ensure that datasets are configured appropriately to allow for opt-out ability if required. We propose that considering these factors early on, and planning research effectively to address participants' needs surrounding data control and sense of ownership, could make this a worthwhile endeavor based on the potential value gained from data sharing. Future work could consider the development of an online platform to support researchers through this process of considering possible data reuse scenarios, and could streamline this consent process for both researchers and research participants.

## 6 LIMITATIONS

There were several limitations to our study which should be considered. Firstly, this work was completed with a relatively small sample of participants in the United Kingdom ( $n=12$ ). The small sample size itself is a limitation, as it makes it challenging to generalise our findings to the broader Parkinson's population, however it is worth noting the recruitment challenges into a study of this kind. Participants had to travel to the smart home in Bristol (some of our participants lived in different cities so they travelled over an hour to take part in the study) and they needed to be mobile enough to safely navigate their way around a new environment. Due to this requirement, we also only captured data from participants who had relatively mild Parkinson's (Hoehn and Yahr stage 1 and 2), thus it may be difficult to generalise their priorities to those with a greater severity of disease. Future work should, of course, attempt to engage a more diverse sample of participants across various disease states, but should understand the safety and recruitment

challenges that come with this. One suggestion might be to supplement similar data workshop based approaches with less intensive forms of engagement, such as surveys or questionnaires, which could be used to explore broader community perspectives that are built on workshop findings. The second limitation is related to the UK sample. The UK has had very widely publicised changes to their data protection legislation in recent years, with the introduction of national level GDPR requirements on all forms of personal data. As such, there is a possibility that our participants may have been familiar with data protection and sharing language and general public conversations about data. Future studies could capture participant ratings on their own 'familiarity' or 'confidence' with data concepts in order to better report on general understanding. In addition, similar studies conducted in other countries may find different concerns relating to data sharing. This comparison would be a useful avenue of future research to add to our understanding of how health communities view cross-sectoral data sharing data more globally.

## 7 CONCLUSION

Our paper has highlighted the benefits and opportunities for open data, but also the challenges of implementing open datasets within the health space, in particular the need for engaging health communities in discussions around how their data is shared across different sectors in order to ensure that trust is maintained. Through the process of collecting and exploring the outputs of a simulated free-living dataset, in a multi-sensor smart home environment (with people with Parkinson's and their carer's), we have provided qualitative insights into their understanding of data, their perceptions of its use, and their concerns relating to cross-sectoral data sharing practices. Through our discussion we have begun to draw out some specific insights for the design of participatory research which embeds discussions of data sharing from the outset. We have provided suggestions for the design of future research that might enhance participants' sense of ownership and control over their data. Whilst we acknowledge the small number of participants in our study, and the need for future work to engage specific health communities in these types of discussions on a much broader scale, this paper is a useful starting point for considering how health communities might be better engaged in considering more open data sharing practices in the future.

## ACKNOWLEDGMENTS

This work was performed under the SPHERE Next Steps Project funded by the UK Engineering and Physical Sciences Research Council (EPSRC), Grant EP/R005273/1. This work is supported by the Elizabeth Blackwell Institute for Health Research, University of Bristol and the Wellcome Trust Institutional Strategic Support Fund, grant code: 204813/Z/16/Z, by The Cure Parkinson's Trust, grant code AW021 and by IXICO, grant code R101507-101. Dr Jonathan de Pass and Mrs Georgina de Pass made a charitable donation to the University of Bristol (of which Jonathan is a graduate) through the Development and Alumni Relations Office to support research into Parkinson's Disease. The funding pays for the salary of Catherine Morgan, PhD student and Clinical Research Fellow, and she reports to the donors on her progress. We gratefully acknowledge the

study participants for their time and efforts in participating in this research. We also acknowledge the local Parkinson's and Other Movement Disorders Health Integration Team (Patient and Public Involvement Group) for their assistance at each step of study design. This work was facilitated by the dedication of our colleagues who were involved in study implementation including but not limited to Emma Tonkin, Julia Carey, David Bailey, Daniella Hale, Antonis Vafeas, Gregory Tourte, George Oikonomou, Sam Whitehouse.

## REFERENCES

- [1] [n. d.]. [ARCHIVED CONTENT] *Care Information Choices, May 2016 - NHS Digital*. <https://webarchive.nationalarchives.gov.uk/ukgwa/20180328133352/http://digital.nhs.uk/catalogue/PUB20718>
- [2] [n. d.]. *Big Data Market by Solutions & Services - 2025 | MarketsandMarkets*. <https://www.marketsandmarkets.com/Market-Reports/big-data-market-1068.html>
- [3] [n. d.]. *The big-data revolution in US health care: Accelerating value and innovation | McKinsey*. <https://www.mckinsey.com/industries/healthcare-systems-and-services/our-insights/the-big-data-revolution-in-us-health-care>
- [4] [n. d.]. *Citizens' Jury 2017 - Connected Health Cities*. <https://www.connectedhealthcities.org/chc-hub/public-engagement/citizens-juries-chc/citizens-juries/>
- [5] [n. d.]. *DATEVA - Health Data to Health Insights*. <https://dateva.biz/>
- [6] [n. d.]. *Early insight 2: Definitions of open data | Open Data Research Network*. <http://www.opendataresearch.org/content/2013/566/early-insight-2-definitions-open-data>
- [7] [n. d.]. *Ethical Roadmap*. <https://ethicalroadmap.org/en/>
- [8] [n. d.]. *Fox Insight | Parkinson's Disease*. <https://www.michaeljfox.org/fox-insight-data>
- [9] [n. d.]. *General Data Protection Regulation (GDPR) - Official Legal Text*. <https://gdpr-info.eu/>
- [10] [n. d.]. *How to stop pregnancy ads following you after a loss | Tommy's*. <https://www.tommys.org/about-us/charity-news/how-stop-pregnancy-ads-following-you-after-loss>
- [11] [n. d.]. *Live better, together! | PatientsLikeMe*. <https://www.patientslikeme.com/>
- [12] [n. d.]. *mPower Public Researcher Portal - syn4993293 - Wiki*. <https://www.synapse.org/#!/Synapse:syn4993293/wiki/247859>
- [13] [n. d.]. *NARCIS > About NARCIS*. <https://www.narcis.nl/about/Language/en>
- [14] [n. d.]. *ORCHA*. <https://appfinder.orchs.co.uk/>
- [15] [n. d.]. *Principles - International Open Data Charter*. <https://opendatacharter.net/principles/>
- [16] [n. d.]. *Statistics | Parkinson's Foundation*. <https://www.parkinson.org/Understanding-Parkinsons/Statistics>
- [17] [n. d.]. *Synopsis report of the public consultation on the revision of the Directive on the reuse of public sector information | Shaping Europe's digital future*. <https://digital-strategy.ec.europa.eu/en/synopsis-report-public-consultation-revision-directive-reuse-public-sector-information>
- [18] [n. d.]. *Targeted ads can make you feel terrible - Vox*. <https://www.vox.com/the-goods/2020/4/9/21204425/targeted-ads-fertility-eating-disorder-coronavirus>
- [19] [n. d.]. *Targeted Medicine: Advertising to the Medically Vulnerable | Bioethics.net*. <http://www.bioethics.net/2018/05/targeted-medicine-advertising-to-the-medically-vulnerable/>
- [20] [n. d.]. *The world's most valuable resource is no longer oil, but data | The Economist*. <https://www.economist.com/leaders/2017/05/06/the-worlds-most-valuable-resource-is-no-longer-oil-but-data>
- [21] 2017. Wearable sensors objectively measure gait parameters in Parkinson's disease. *PLOS ONE* 12 (10 2017), e0183989. Issue 10. <https://doi.org/10.1371/JOURNAL.PONE.0183989>
- [22] Naseem Ahmadpour, Sonja Pedell, Angeline Mayasari, and Jeanie Beh. 2019. Co-creating and Assessing Future Wellbeing Technology Using Design Fiction. *She Ji* 5 (9 2019), 209–230. Issue 3. <https://doi.org/10.1016/J.SHEJI.2019.08.003>
- [23] Seb Bacon and Ben Goldacre. 2020. Barriers to Working With National Health Service England's Open Data. *J Med Internet Res* 2020;22(1):e15603 <https://www.jmir.org/2020/1/e15603> 22 (1 2020), e15603. Issue 1. <https://doi.org/10.2196/15603>
- [24] Mortaza S. Bargh, Sunil Choenni, and Ronald Meijer. 2016. Meeting open data halfway: On semi-open data paradigm. *ACM International Conference Proceeding Series* 01-03-March-2016 (3 2016), 199–206. <https://doi.org/10.1145/2910019.2910037>
- [25] Genevieve Bell, Mark Blythe, and Phoebe Sengers. 2005. Making by making strange: Defamiliarization and the design of domestic technologies. *ACM Transactions on Computer-Human Interaction* 12 (2005), 149–173. Issue 2. <https://doi.org/10.1145/1067860.1067862>
- [26] Mark Blythe. 2014. Research Through Design Fiction: Narrative in Real and Imaginary Abstracts. (2014). <https://doi.org/10.1145/2556288.2557098>
- [27] Babak Boroojerdi, Roozbeh Ghaffari, Nikhil Mahadevan, Michael Markowitz, Katie Melton, Briana Morey, Christian Otoul, Shyamal Patel, Jake Phillips, Ellora Sen-Gupta, et al. 2019. Clinical feasibility of a wearable, conformable sensor patch to monitor motor symptoms in Parkinson's disease. *Parkinsonism & related disorders* 61 (2019), 70–76.
- [28] Riley Bove, Elizabeth Secor, Brian C. Healy, Alexander Musallam, Timothy Vaughan, Bonnie I. Glanz, Emily Greeke, Howard L. Weiner, Tanuja Chitnis, Paul Wicks, and Philip L. De Jager. 2013. Evaluation of an Online Platform for Multiple Sclerosis Research: Patient Description, Validation of Severity Scale, and Exploration of BMI Effects on Disease Course. *PLOS ONE* 8 (3 2013), e59707. Issue 3. <https://doi.org/10.1371/JOURNAL.PONE.0059707>
- [29] Capecchi, Pepa, Verdini, and Ceravolo. 2016. A smartphone-based architecture to detect and quantify freezing of gait in Parkinson's disease. *Gait & posture* 50 (10 2016), 28–33. <https://doi.org/10.1016/J.GAITPOST.2016.08.018>
- [30] Emma Cherif, Nora Bezaz, and Manel Mzoughi. 2021. Do personal health concerns and trust in healthcare providers mitigate privacy concerns? Effects on patients' intention to share personal health data on electronic health records. *Social Science & Medicine* 283 (8 2021), 114146. <https://doi.org/10.1016/J.SOCSCIMED.2021.114146>
- [31] Paul Coulton, Joseph Lindley, and Rachel Cooper. 2018. The Little Book of Design Fiction. (2018). <https://www.petrashub.org/the-little-book-of-design-fiction-for-the-internet-of-things/>
- [32] Claire Craig, Jayne Wallace, Kyle Montague, Nantia Koulidou, Helen Fisher, Luis Carvalho, Linnea Groot, Julie Trueman, Shaun Lawson, Kellie Morrissey, Trevor Duncan, and Joshua South. 2021. Development of an ethical roadmap. <https://doi.org/10.1080/24735132.2021.1908653> 5 (5 2021), 140–160. Issue 1. <https://doi.org/10.1080/24735132.2021.1908653>
- [33] Ana Lígia Silva de Lima, Tim Hahn, Nienke M de Vries, Eli Cohen, Lauren Bataille, Max A Little, Heribert Baldus, Bastiaan R Bloem, and Marjan J Faber. 2016. Large-scale wearable sensor deployment in Parkinson's patients: the Parkinson@home study protocol. *JMIR research protocols* 5, 3 (2016), e5990.
- [34] Silvia Del Din, Alan Godfrey, Claudia Mazzà, Sue Lord, and Lynn Rochester. 2016. Free-living monitoring of Parkinson's disease: Lessons from the field. *Movement Disorders* 31, 9 (2016), 1293–1313.
- [35] Orla Duffy, Jonathan Synnott, Roisin McNaney, Paola Brito Zambrano, and W George Kernohan. 2021. Attitudes Toward the Use of Voice-Assisted Technologies Among People With Parkinson Disease: Findings From a Web-Based Survey. *JMIR Rehabil Assist Technol* 2021;3(1):e23006 <https://rehab.jmir.org/2021/1/e23006> 8 (3 2021), e23006. Issue 1. <https://doi.org/10.2196/23006>
- [36] Amr Elkholy, Mohamed E. Hussein, Walid Gomaa, Dima Damen, and Emmanuel Saba. 2020. Efficient and Robust Skeleton-Based Quality Assessment and Abnormality Detection in Human Action Performance. *IEEE Journal of Biomedical and Health Informatics* 24 (1 2020), 280–291. Issue 1. <https://doi.org/10.1109/JBHI.2019.2904321>
- [37] Robert J. Ellis, Yee Sien Ng, Shenggao Zhu, Dawn M. Tan, Boyd Anderson, Gottfried Schlaug, and Ye Wang. 2015. A Validated Smartphone-Based Assessment of Gait and Gait Variability in Parkinson's Disease. *PLOS ONE* 10 (10 2015), e0141694. Issue 10. <https://doi.org/10.1371/JOURNAL.PONE.0141694>
- [38] Claudia Ferraris, Roberto Nerino, Antonio Chimienti, Giuseppe Pettiti, Nicola Cau, Veronica Cimolin, Corrado Azzaro, Lorenzo Priano, and Alessandro Mauro. 2019. Feasibility of Home-Based Automated Assessment of Postural Instability and Lower Limb Impairments in Parkinson's Disease. *Sensors* 2019, Vol. 19, Page 1129 19 (3 2019), 1129. Issue 5. <https://doi.org/10.3390/S19051129>
- [39] James M. Fisher, Nils Y. Hammerla, Thomas Ploetz, Peter Andras, Lynn Rochester, and Richard W. Walker. 2016. Unsupervised home monitoring of Parkinson's disease motor symptoms using body-worn accelerometers. *Parkinsonism & Related Disorders* 33 (12 2016), 44–50. <https://doi.org/10.1016/J.PARKRELDIS.2016.09.009>
- [40] Brook Galna, Gillian Barry, Dan Jackson, Dadirayi Mhiripiri, Patrick Olivier, and Lynn Rochester. 2014. Accuracy of the Microsoft Kinect sensor for measuring movement in people with Parkinson's disease. *Gait & Posture* 39 (4 2014), 1062–1068. Issue 4. <https://doi.org/10.1016/J.GAITPOST.2014.01.008>
- [41] Abir Ghorayeb, Rob Comber, and Rachael Goberman-Hill. 2021. Older Adults' Perspectives of Smart Home Technology: Are We Developing the Technology That Older People Want? *International Journal of Human-Computer Studies* 147 (3 2021), 102571. <https://doi.org/10.1016/J.IJHCS.2020.102571>
- [42] Pieter Ginis, Alice Nieuwboer, Moran Dorfman, Alberto Ferrari, Eran Gazit, Colleen G. Canning, Laura Rocchi, Lorenzo Chiari, Jeffrey M. Hausdorff, and Anat Mirelman. 2016. Feasibility and effects of home-based smartphone-delivered automated feedback training for gait in people with Parkinson's disease: A pilot randomized controlled trial. *Parkinsonism & Related Disorders* 22 (1 2016), 28–34. <https://doi.org/10.1016/J.PARKRELDIS.2015.11.004>
- [43] Christopher G. Goetz, Werner Poewe, Olivier Rascol, Cristina Sampaio, Glenn T. Stebbins, Carl Counsell, Nir Giladi, Robert G. Holloway, Charity G. Moore, Gregor K. Wenning, Melvin D. Yahr, and Lisa Seidl. 2004. Movement Disorder Society Task Force report on the Hoehn and Yahr staging scale: Status and recommendations The Movement Disorder Society Task Force on rating scales for Parkinson's disease. *Movement Disorders* 19 (9 2004), 1020–1028. Issue 9.

- <https://doi.org/10.1002/MDS.20213>
- [44] Christopher G. Goetz, Barbara C. Tilley, Stephanie R. Shaftman, Glenn T. Stebbins, Stanley Fahn, Pablo Martinez-Martin, Werner Poewe, Cristina Sampaio, Matthew B. Stern, Richard Dodel, Bruno Dubois, Robert Holloway, Joseph Jankovic, Jaime Kulisevsky, Anthony E. Lang, Andrew Lees, Sue Leurgans, Peter A. LeWitt, David Nyenhuis, C. Warren Olanow, Olivier Rascol, Anette Schrag, Jeanne A. Teresi, Jacobus J. van Hilten, and Nancy LaPelle. 2008. Movement Disorder Society-sponsored revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS): Scale presentation and clinimetric testing results. *Movement Disorders* 23 (11 2008), 2129–2170. Issue 15. <https://doi.org/10.1002/MDS.22340>
  - [45] Alyssa Goodman, Alberto Pepe, Alexander W. Blocker, Christine L. Borgman, Kyle Cranmer, Merce Crosas, Rosanne Di Stefano, Yolanda Gil, Paul Groth, Margaret Hedstrom, David W. Hogg, Vinay Kashyap, Ashish Mahabal, Aneta Siemigowska, and Aleksandra Slavkovic. 2014. Ten Simple Rules for the Care and Feeding of Scientific Data. *PLOS Computational Biology* 10 (2014), e1003542. Issue 4. <https://doi.org/10.1371/JOURNAL.PCBI.1003542>
  - [46] Adrian Gradinar, Jeremy Davenport, Heather Hill, and Paul Coulton. 2017. Improving the Visualisation of Renal Blood Test Results to Enhance Patient – Clinician Communication. <https://doi.org/10.1080/14606925.2017.1352751> 20 (7 2017), S2363–S2374. Issue sup1. <https://doi.org/10.1080/14606925.2017.1352751>
  - [47] Sabrina Grant, A W Blom, Michael R Whitehouse, Ian Craddock, Andrew Judge, Emma L Tonkin, and Rachael Goberman-Hill. 2018. Using home sensing technology to assess outcome and recovery after hip and knee replacement in the UK: the HEmiSPHERE study protocol. *BMJ Open* 8 (7 2018), e021862. Issue 7. <https://doi.org/10.1136/BMJOPEN-2018-021862>
  - [48] Marian Haescher, Denys J.C. Matthies, Karthik Srinivasan, and Gerald Bieber. 2018. Mobile assisted living: Smartwatch-based fall risk assessment for elderly people. *ACM International Conference Proceeding Series* (9 2018). <https://doi.org/10.1145/3266157.3266210>
  - [49] Farnoosh Heidarivincheh, Ryan McConville, Catherine Morgan, Roisin McNaney, Alessandro Masullo, Majid Mirmehdi, Alan L Whone, and Ian Craddock. 2021. Multimodal Classification of Parkinson's Disease in Home Environments with Resiliency to Missing Modalities. *Sensors* 21, 12 (2021), 4133. <https://doi.org/10.3390/s21124133>
  - [50] Elizabeth M Hill, Emma L Turner, Richard M Martin, and Jenny L Donovan. 2013. "Let's get the best quality research we can": public awareness and acceptance of consent to use existing data in health research: a systematic review and qualitative study. *BMC Medical Research Methodology* 13 (2013), 72. Issue 1. <https://doi.org/10.1186/1471-2288-13-72>
  - [51] Michael J. Hollaway, Graham Dean, Gordon S. Blair, Mike Brown, Peter A. Henrys, and John Watkins. 2020. Tackling the Challenges of 21st-Century Open Science and Beyond: A Data Science Lab Approach. *Patterns* 1 (10 2020), 100103. Issue 7. <https://doi.org/10.1016/J.PATTERN.2020.100103>
  - [52] Ruth Horn and Angeliki Kerasidou. 2020. Sharing whilst caring: solidarity and public trust in a data-driven healthcare system. *BMC Medical Ethics* 2020 21:1 21 (11 2020), 1–7. Issue 1. <https://doi.org/10.1186/S12910-020-00553-8>
  - [53] A J Hughes, S E Daniel, L Kilford, and A J Lees. 1992. Accuracy of clinical diagnosis of idiopathic Parkinson's disease: a clinico-pathological study of 100 cases. *Journal of Neurology, Neurosurgery & Psychiatry* 55 (3 1992), 181–184. Issue 3. <https://doi.org/10.1136/JNPN.55.3.181>
  - [54] Joseph Jankovic. 2005. Motor fluctuations and dyskinesias in Parkinson's disease: Clinical manifestations. *Movement Disorders* 20 (5 2005), S11–S16. Issue S11. <https://doi.org/10.1002/MDS.20458>
  - [55] J Jankovic. 2008. Parkinson's disease: clinical features and diagnosis. *Journal of Neurology, Neurosurgery & Psychiatry* 79 (4 2008), 368–376. Issue 4. <https://doi.org/10.1136/JNPN.2007.131045>
  - [56] Jasmeet Kaur, Asra Sakeen Wani, and Pushpendra Singh. 2019. Engagement of pregnant women and mothers over WhatsApp: Challenges and opportunities involved. *Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW* (11 2019), 236–240. <https://doi.org/10.1145/3311957.3359481>
  - [57] Dae-Young Kim, SH Hwang, Min-Gyu Kim, Joon-Hyun Song, Sin-Woong Lee, and Il Kon Kim. 2018. Development of Parkinson Patient Generated Data Collection Platform Using FHIR and IoT Devices.. In *MEDINFO 2017: Precision Healthcare Through Informatics: Proceedings of the 16th World Congress on Medical and Health Informatics*, Vol. 245. IOS Press, 141.
  - [58] Brandin Hanson Knowles and Roisin McNaney. 2017. The Dark Side of Data Sharing: Considering the Ethicality of Data Brokering within the Context of Health. (2017).
  - [59] Chaudhuri KR, Healy DG, and Schapira AH. 2006. Non-motor symptoms of Parkinson's disease: diagnosis and management. *The Lancet. Neurology* 5 (3 2006), 235–245. Issue 3. [https://doi.org/10.1016/S1474-4422\(06\)70373-8](https://doi.org/10.1016/S1474-4422(06)70373-8)
  - [60] Andrea A Kühn and Jens Völkman. 2017. Innovations in deep brain stimulation methodology. *Movement Disorders* 32, 1 (2017), 11–19.
  - [61] Bryan BA Lieber, Blake BA Taylor, Geoff Appelboom, Guy McKhann, and E Sander Connolly. 2014. Motion Sensors to Assess and Monitor Medical and Surgical Management of Parkinson's Disease. (2014). <https://doi.org/10.4172/2329-9096.1000221>
  - [62] Roisin McNaney, Madeline Balaam, Amey Holden, Guy Schofield, Dan Jackson, Mary Webster, Brook Galna, Gillian Barry, Lynn Rochester, and Patrick Olivier. 2015. Designing for and with people with Parkinson's: A focus on exergaming. *Conference on Human Factors in Computing Systems - Proceedings* 2015-April (4 2015), 501–510. <https://doi.org/10.1145/2702123.2702310>
  - [63] Roisin McNaney, Madeline Balaam, Amey Holden, Guy Schofield, Daniel Jackson, Mary Webster, Brook Galna, Gillian Barry, Lynn Rochester, and Patrick Olivier. 2015. Designing for and with People with Parkinson's: A Focus on Exergaming. In *Proceedings of the 33rd annual ACM conference on Human Factors in Computing Systems*. 501–510.
  - [64] Roisin McNaney, Emmanuel Tseklevs, and Jonathan Synnott. 2020. Future Opportunities for IoT to Support People with Parkinson's. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. 1–15.
  - [65] Roisin McNaney, John Vines, Andy Dow, Harry Robinson, Heather Robinson, Kate McDonald, Leslie Brown, Peter Santer, Don Murray, Janice Murray, David Green, and Peter Wright. 2018. Enabling Participation of People with Parkinson's and Their Caregivers in Co-Inquiry around Collectivist Health Technologies. *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems* (2018). <https://doi.org/10.1145/3173574>
  - [66] Mevludin Memedi, Gaki Tshering, Martin Fogelberg, Ilir Jusufi, Ella Kolkowska, and Gunnar Klein. 2018. An Interface for IoT: Feeding Back Health-Related Data to Parkinson's Disease Patients. *Journal of Sensor and Actuator Networks* 2018, Vol. 7, Page 14 7 (3 2018), 14. Issue 1. <https://doi.org/10.3390/JSAN7010014>
  - [67] Helena M. Mentis, Anita Komlodi, Katrina Schrader, Michael Phipps, Ann Gruber-Baldini, Karen Yarbrough, and Lisa Shulman. 2017. Crafting a view of self-tracking data in the clinical visit. *Conference on Human Factors in Computing Systems - Proceedings* 2017-May (5 2017), 5800–5812. <https://doi.org/10.1145/3025453.3025589>
  - [68] Bhuvan Molparia, Brian N. Schrader, Eli Cohen, Jennifer L. Wagner, Sandeep R. Gupta, Sherrie Gould, Nelson Hwynn, Emily G. Spencer, and Ali Torkamani. 2018. Combined accelerometer and genetic analysis to differentiate essential tremor from Parkinson's disease. *PeerJ* 6 (7 2018), e5308. Issue 7. <https://doi.org/10.7717/PEERJ.5308>
  - [69] Lisa A. Moon. 2017. Factors influencing health data sharing preferences of consumers: A critical review. *Health Policy and Technology* 6 (6 2017), 169–187. Issue 2. <https://doi.org/10.1016/J.HLPT.2017.01.001>
  - [70] Catherine Morgan, Ian Craddock, Emma L Tonkin, Kirsi M Kinnunen, Roisin McNaney, Sam Whitehouse, Majid Mirmehdi, Farnoosh Heidarivincheh, Ryan Mcconville, Julia Carey, Alison Horne, Michal Rolinski, Lynn Rochester, Walter Maetzler, Helen Matthews, Oliver Watson, Rachel Eardley, and Alan L Whone. 2020. Protocol for PD SENSORS: Parkinson's Disease Symptom Evaluation in a Naturalistic Setting producing Outcome measures using SPHERE technology. An observational feasibility study of multi-modal multi-sensor technology to measure symptoms and activities of daily living in Parkinson's disease. *BMJ Open* 10 (2020), 41303. <https://doi.org/10.1136/bmjopen-2020-041303>
  - [71] Karen Otte, Bastian Kayser, Sebastian Mansow-Model, Julius Verrel, Friedemann Paul, Alexander U. Brandt, and Tanja Schmitz-Hübisch. 2016. Accuracy and Reliability of the Kinect Version 2 for Clinical Measurement of Motor Function. *PLOS ONE* 11 (11 2016), e0166532. Issue 11. <https://doi.org/10.1371/JOURNAL.PONE.0166532>
  - [72] Sarah J. Ozinga, Andre G. Machado, Mandy Miller Koop, Anson B. Rosenfeldt, and Jay L. Alberts. 2015. Objective assessment of postural stability in Parkinson's disease using mobile technology. *Movement Disorders* 30 (8 2015), 1214–1221. Issue 9. <https://doi.org/10.1002/MDS.26214>
  - [73] Di Pan, Rohit Dhall, Abraham Lieberman, and Diana B Petitti. 2015. A Mobile Cloud-Based Parkinson's Disease Assessment System for Home-Based Monitoring. *JMIR Mhealth Uhealth* 2015;3(1):e29 <https://mhealth.jmir.org/2015/1/e29> 3 (3 2015), e3956. Issue 1. <https://doi.org/10.2196/MHEALTH.3956>
  - [74] Cristian F. Pasluosta, Heiko Gassner, Juergen Winkler, Jochen Klucken, and Bjoern M. Eskofier. 2015. An emerging era in the management of Parkinson's disease: Wearable technologies and the internet of things. *IEEE Journal of Biomedical and Health Informatics* 19 (11 2015), 1873–1881. Issue 6. <https://doi.org/10.1109/JBHI.2015.2461555>
  - [75] Irene V. Pasquetto, Ashley E. Sands, and Christine L. Borgman. 2015. Exploring openness in data and science: What is "open," to whom, when, and why? *Proceedings of the Association for Information Science and Technology* 52 (1 2015), 1–2. Issue 1. <https://doi.org/10.1002/PRA2.2015.1450520100141>
  - [76] David Pelouquin, Michael DiMaio, Barbara Bierer, and Mark Barnes. 2020. Disruptive and avoidable: GDPR challenges to secondary research uses of data. *European Journal of Human Genetics* 2020 28:6 28 (3 2020), 697–705. Issue 6. <https://doi.org/10.1038/s41431-020-0596-x>
  - [77] Werner Poewe, Angelo Antonini, Jan CM Zijlmans, Pierre R Burkhard, and François Vingerhoets. 2010. Levodopa in the treatment of Parkinson's disease: an old drug still going strong. *Clinical Interventions in Aging* 5 (2010), 229. <https://doi.org/10.2147/CIA.S6456>
  - [78] Rafael Poyiadzi, Weisong Yang, Yoav Ben-Shlomo, Ian Craddock, Liz Coulthard, Raul Santos-Rodriguez, James Selwood, and Niall Twomey. 2020. Detecting Signatures of Early-stage Dementia with Behavioural Models Derived from Sensor Data. *arXiv preprint arXiv:2007.03615* (2020).

- [79] Alisha Pradhan, Kanika Mehta, and Leah Findlater. 2018. "Accessibility Came by Accident": Use of Voice-Controlled Intelligent Personal Assistants by People with Disabilities. (2018). <https://doi.org/10.1145/3173574.3174033>
- [80] Christopher L. Pulliam, Dustin A. Heldman, Tseganesh H. Orcutt, Thomas O. Mera, Joseph P. Giuffrida, and Jerrold L. Vitek. 2015. Motion sensor strategies for automated optimization of deep brain stimulation in Parkinson's disease. *Parkinsonism & Related Disorders* 21 (4 2015), 378–382. Issue 4. <https://doi.org/10.1016/J.PARKRELDIS.2015.01.018>
- [81] Ester A. Rake, Marleen M.H.J. Van Gelder, David C. Grim, Barend Heeren, Lucien J.L.P.G. Engelen, and Tom H. Van De Belt. 2017. Personalized Consent Flow in Contemporary Data Sharing for Medical Research: A Viewpoint. *BioMed Research International* 2017 (2017). <https://doi.org/10.1155/2017/7147212>
- [82] Daniel Rodríguez-Martín, Albert Samà, Carlos Pérez-López, Andreu Català, Joan M Moreno Arostegui, Joan Cabestany, Àngels Bayés, Sheila Alcaine, Berta Mestre, Anna Prats, et al. 2017. Home detection of freezing of gait using support vector machines through a single waist-worn triaxial accelerometer. *PLoS one* 12, 2 (2017), e0171764.
- [83] Joachim Roski, George W. Bo-Linn, and Timothy A. Andrews. 2017. Creating Value In Health Care Through Big Data: Opportunities And Policy Implications. <https://doi.org/10.1377/hlthaff.2014.0147> 33 (8 2017), 1115–1122. Issue 7. <https://doi.org/10.1377/HLTHAFF.2014.0147>
- [84] Erika Rovini, Carlo Maremmi, and Filippo Cavallo. 2019. Automated systems based on wearable sensors for the management of Parkinson's disease at home: A systematic review. *Telemedicine and e-Health* 25, 3 (2019), 167–183.
- [85] Elizabeth Sillence, John Matthew Blythe, Pam Briggs, and Mark Moss. 2019. A Revised Model of Trust in Internet-Based Health Information and Advice: Cross-Sectional Questionnaire Study. *J Med Internet Res* 2019;21(11):e11125 <https://www.jmir.org/2019/11/e11125> 21 (11 2019), e11125. Issue 11. <https://doi.org/10.2196/11125>
- [86] Brian K. Smith, Jeana Frost, Meltem Albayrak, and Rajneesh Sudhakar. 2006. Integrating glucometers and digital photography as experience capture tools to enhance patient understanding and communication of diabetes self-management practices. *Personal and Ubiquitous Computing* 2006 11:4 11 (8 2006), 273–286. Issue 4. <https://doi.org/10.1007/S00779-006-0087-2>
- [87] Sofija Spasojević, Tihomir V Ilić, Slađan Milanović, Veljko Potkonjak, Aleksandar Rodić, and José Santos-Victor. 2017. Combined vision and wearable sensors-based system for movement analysis in rehabilitation. *Methods of information in medicine* 56, 02 (2017), 95–111.
- [88] Michael Stead and Paul Coulton. 2017. Old, Sick And No Health Insurance. Will You Need A Permit To Use Your Home-made Health Wearable?. In *Proceedings of the 2017 ACM Conference Companion Publication on Designing Interactive Systems*. 101–105.
- [89] Fiona Stevenson, Nigel Lloyd, Louise Harrington, and Paul Wallace. 2013. Use of electronic patient records for research: views of patients and staff in general practice. *Family Practice* 30 (4 2013), 227–232. Issue 2. <https://doi.org/10.1093/FAMPRA/CMS069>
- [90] Melanie Swan. 2012. Health 2050: The Realization of Personalized Medicine through Crowdsourcing, the Quantified Self, and the Participatory Biocitizen. *Journal of Personalized Medicine* 2012, Vol. 2, Pages 93-118 2 (9 2012), 93–118. Issue 3. <https://doi.org/10.3390/JPM2030093>
- [91] Lauren Thornton, Bran Knowles, and Gordon Blair. 2021. Fifty shades of grey: In praise of a nuanced approach towards trustworthy design. *FAccT 2021 - Proceedings of the 2021 ACM Conference on Fairness, Accountability, and Transparency* (3 2021), 64–76. <https://doi.org/10.1145/3442188.3445871>
- [92] Emmanuel Tsekles, Andy Darby, Anna Whicher, and Piotr Swiatek. 2017. Co-designing design fictions: A new approach for debating and priming future healthcare technologies and services. *Archives of Design Research* 30 (5 2017), 5–21. Issue 2. <https://doi.org/10.15187/ADR.2017.05.30.2.5>
- [93] Mary P. Tully, Lamiece Hassan, Malcolm Oswald, and John Ainsworth. 2019. Commercial use of health data—A public “trial” by citizens’ jury. *Learning Health Systems* 3 (10 2019). Issue 4. <https://doi.org/10.1002/LRH2.10200>
- [94] Tjeerd-Pieter van Staa, Ben Goldacre, Iain Buchan, and Liam Smeeth. 2016. Big health data: the need to earn public trust. *BMJ* 354 (7 2016). <https://doi.org/10.1136/BMJ.I3636>
- [95] Stefaan Verhulst, Beth Simone Noveck, Robyn Caplan, Kristy Brown, and Claudia Paz. 2014. The Open Data Era in Health and Social Care. *SSRN Electronic Journal* (6 2014). <https://doi.org/10.2139/SSRN.2563788>
- [96] Paraskevas Vezyridis and Stephen Timmons. 2017. Understanding the care.data conundrum: New information flows for economic growth:. <http://dx.doi.org/10.1177/2053951716688490> 4 (1 2017). Issue 1. <https://doi.org/10.1177/2053951716688490>
- [97] Antonia Vlahou, Dara Hallinan, Rolf Apweiler, Angel Argiles, Joachim Beige, Ariela Benigni, Rainer Bischoff, Peter C. Black, Franziska Boehm, Jocelyn Céraline, George P. Chrousos, Christian Delles, Pieter Evenepoel, Ivo Fridolin, Griet Glorieux, Alain J. van Gool, Isabel Heidegger, John P.A. Ioannidis, Joachim Jankowski, Vera Jankowski, Carmen Jeronimo, Ashish M. Kamat, Rosalinde Masereeuw, Gert Mayer, Harald Mischak, Alberto Ortiz, Giuseppe Remuzzi, Peter Rossing, Joost P. Schanstra, Bernd J. Schmitz-Dräger, Goce Spasovski, Jan A. Staessen, Dimitrios Stamatialis, Peter Stenvinkel, Christoph Wanner, Stephen B. Williams, Faiez Zannad, Carmine Zoccali, and Raymond Vanholder. 2021. Data Sharing Under the General Data Protection Regulation. *Hypertension* 77 (2021), 1029–1035. <https://doi.org/10.1161/HYPERTENSIONAHA.120.16340>
- [98] Paul Wicks, Dorothy L. Keininger, Michael P. Massagli, Christine de la Loge, Catherine Brownstein, Jouko Isojärvi, and James Heywood. 2012. Perceived benefits of sharing health data between people with epilepsy on an online platform. *Epilepsy & Behavior* 23 (1 2012), 16–23. Issue 1. <https://doi.org/10.1016/J.YEBEH.2011.09.026>