Designing for Participatory Data Governance: Insights from People with Parkinson's

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ABSTRACT

In today's age of data-driven healthcare, the growing utilization of health data to inform critical aspects of patient care and medical research places an ever increasing significance on its governance. This study aims to explore the perspectives of individuals living with Parkinson's Disease regarding their needs and preferences in relation to data governance. We first conducted a survey (n=52) to explore the types of data people with Parkinson's generate through their self-care practices, and then conducted 3 workshops with 9 participants to understand their perspectives on the governance of this type of data. Through this work, we highlight the factors that motivate them to collect self-care data, and present their requirements for its governance, which could inform the design of future infrastructure to support these needs. We also showcase how speculative approaches can be used to engage communities in discussions around data collection and governance.

CCS CONCEPTS

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

KEYWORDS

Parkinson's, Data governance, Self-tracking, Speculative design

1 INTRODUCTION

Parkinson's disease (PD) is a neurodegenerative condition that affects more than 10 million people across the globe [1]. The incidence of Parkinson's disease has doubled over the past 25 years [115],

and it is now thought to be the second most common neurological condition in countries such as the USA [1] and Australia [78]. People with Parkinson's (PwP) experience a range of motor and non-motor symptoms that can greatly impact their well-being and quality of life. Some of the motor symptoms include tremor, muscle rigidity, bradykinesia (slowness of movement), and gait issues; whilst cognitive impairment, pain, and depression are among the non-motor symptoms [79, 115]. These symptoms and their severity differ vastly from person to person [79, 114], and often fluctuate over time as the condition progresses [83, 107]. These fluctuations are caused by prolonged medication usage [83], leading to 'ON' phases when the medication is effective and symptoms are controlled, and 'OFF' phases when symptoms re-emerge as the medication ceases to be effective [34]. This complexity makes self-care and management crucial, helping people maintain their quality of life, facilitate greater control over the condition and reduce healthcare costs [45, 76, 87, 106].

Extensive research has been conducted to explore how technology can support PwP. Wearable devices, equipped with motion sensors such as accelerometers and gyroscopes, have been used to detect and monitor motor symptoms [44, 56, 58, 59, 93]. Similarly, the multifaceted capabilities of smartphones, including touch functionality, sensors, and self-reported input, have been used to monitor both motor and non-motor symptoms [57, 60, 61, 105]. These data collection capabilities have facilitated practices such as self-tracking and self-experimentation, empowering users to monitor, track, and analyze the impact of their condition and self-care practices on their daily lives [70, 74, 90, 105]. This information has proven to be invaluable not only to individuals, but also in clinical care [60, 70], by improving patient-clinician communication, facilitating shared decision-making, and aiding in the development of personalized care plans [60, 70]. In addition, such data is also tremendously valuable for research and innovation [8, 13, 80]. Some of the open datasets for Parkinson's that incorporate both self-report and sensor based data such as mPower [14], the Levodopa Response Study [99] and the Fox Insight dataset [71] have been extensively cited, and have served as fundamental resources for numerous studies over the years.

However, the management of such data poses several governance challenges, and various shortcomings have been identified in traditional research practices aimed at obtaining this information. For example, whilst research relies on informed consent as a means

to empower participants to make informed decisions on participation, several studies [17, 39, 54, 109] have discussed the limitations of this approach. Studies have highlighted that individuals cannot know in advance who will access their data in the future and for which scientific purposes [39, 109]. Additionally, communicating complex data use cases (such as machine learning algorithms) has also been cited as a challenge, owing to limited technical literacy of general populations [17, 54]. Moreover, there is a need to develop governance mechanisms that provide participants the capacity to make informed decisions and not simply "click away their rights" [63, 95].

To address these challenges, our study aimed to investigate approaches for involving end users, specifically PwP, in discussions regarding their data and its governance. We present a two-phase study which engaged PwP to a) understand their data collection and sharing practices around Parkinson's self-care and b) explore their perspectives and drivers regarding the governance of their data. We first conducted an online survey (n=52 respondents) to understand the type of data PwP generate through their self-care and symptom management practices. We then used these identified data types to facilitate discussions around data governance through 3 online workshops with 9 participants, adapting approaches from speculative design to present future use case scenarios. Our findings present the motivating factors that drive PwP to engage in the collection of self-care data. We highlight the principles that hold significance for them when their data is utilized and their perspectives on the governance of this data. Through this work, we showcase how speculative approaches can be used to engage communities in discussions around data collection and governance.

2 BACKGROUND

2.1 Technology driven self-care for Parkinson's

Self-care is defined as the capacity for individuals or communities to enhance their well-being, prevent illness, sustain good health, and manage illness and disability, either independently or with the assistance of a healthcare professional [116]. It is intended to support healthcare systems by leveraging individuals' capacity to manage their well-being, and is considered as an essential component for the management of chronic conditions. Its benefits include reduced risk of mortality [42, 91], improved quality of life [18] and a reduction in healthcare costs [41, 118]. Riegel et. al [88] categorize self-care into three main categories: self-care monitoring, which entails regular symptom surveillance; self-care maintenance, which includes undertaking activities to preserve or improve well-being; and self-care management, involving symptom evaluation to determine the necessity of intervention.

The availability of self-monitoring capabilities in commodity technologies, such as smartphones and wearable sensors has made these aspects of self-care more accessible to the general population, and have contributed to a wealth of research. In particular, these technological advancements have proven indispensable in supporting individuals dealing with complex chronic conditions that require long term self-monitoring and management, such as diabetes [62], Multiple Sclerosis [5, 6] and Polycystic ovary syndrome (PCOS) [20].

For Parkinson's specifically, researchers have explored the use of such technologies to detect and track both motor and non-motor symptoms. Studies have used inertial sensors in smartphones and wearables to monitor motor symptoms such as gait [32, 44, 51, 82, 93], tremor [55–57, 59] and bradykinesia [84]. Embedded microphones and cameras have also been used to detect and manage speech impairments [7, 66, 67], which are another common symptom for PwP. Other research investigations have also explored the use of wrist-worn wearable devices to deliver cueing interventions for the management of drooling [27, 64].

In addition to these, self-reported user data has also been used extensively to support the management of Parkinson's. Self-tracking has been shown to help PwP to develop a better understanding of their condition [74, 89, 90], monitor disease progression [59, 84], identify the impact of self-care practices on their symptoms [68, 74, 105] and improve medication adherence [58, 60]. Despite relying on commodity technologies (which make their data available to large technology companies), individuals retain a considerable degree of control over data-related decisions. They determine what data to collect, how to collect it, the methods of analysis, and with whom to share it. This autonomy empowers them to make decisions aligned with their preferences and needs [70, 90]. However, in the context of providing their data for research purposes, participants rely on researchers to manage and govern their data. While research organisations tend to be trusted entities, bound by legal and ethical regulations [65], configuring research practices to give participants greater control over their data decisions could potentially serve to streamline data re-use and sharing processes. This could save considerable time and resources, while also incorporating mechanisms to empower participants in exercising their data rights.

2.2 Data governance in health research

Data governance involves determining the individuals or entities responsible for decision-making regarding data, and identifying who would be accountable for decisions relating to its purpose, quality, access and life-cycle [50]. It involves policies and procedures that impact the collection, storage, processing and management of data, with the aim of guaranteeing its privacy, security, availability and usability [24, 38]. Beyond traditional health data such as medical records, laboratory test results and medical imaging, technological advancements have paved the way for a new stream of patient generated health data [33]. This has enhanced the breadth of data available, contributing to a greater understanding of individual health profiles [70] and development of personalised health strategies [60]. Whilst such data presents significant advantages for health research, the sheer diversity and volume of data underscore the critical need for robust governance mechanisms, to safeguard individuals and their data rights [73]. Individuals possess rights in accordance with existing legal and regulatory frameworks, such as the EU General Data Protection Regulation (GDPR) [37] and the US Health Insurance Portability and Accountability Act (HIPAA) [104]. These include rights such as data access, control over data use, right of rectification and erasure, and the need for data controllers to communicate this information in a transparent and intelligible way [37]. They also highlight the importance of establishing clear mechanisms through which individuals can exercise these rights.

Extensive research has uncovered the importance individuals place on having control over their data [109] and has documented users' privacy and security concerns when using commodity technologies [10, 52, 65, 112]. Studies have discussed how privacy plays a crucial role in data sharing practices, emphasizing that users are unwilling to share their data if their privacy is not assured [10, 22]. In addition, research has also explored how the lack of transparency regarding data collection, storage, and usage negatively affects user trust in commercial companies [10, 65], impacting their willingness to share their data with such entities. Such studies emphasize the importance of actively engaging with citizens to inform data practices, to foster trust within research and broader data use contexts [65].

2.3 Participatory approaches to data governance

Participatory design is an approach that involves end users, stakeholders, and other relevant participants actively contributing to the design and development process of a product, system, or service [35, 92]. It emphasizes the involvement of the end users throughout the design process, ensuring that the final product aligns closely with user expectations, preferences, and real-world requirements [94]. In a similar manner, participatory data governance places an emphasis on engagement with stakeholders, specifically with the individuals from whom data is gathered, in data decisions [73]. Some approaches to participatory data governance that have been proposed are related to consent processes such as dynamic consent [16, 48] which facilitates interactions over time, allowing participants to modify consent decisions based on changing circumstances, and personalised consent flow[86], where individuals can choose the specific research to provide their data to, the data sources that they want to share and the duration for which they want to share their data. These aim to address the issues with broad consent, wherein users may not be able to anticipate future data use scenarios [39, 109]. However, the implementation and adaptation of such approaches is challenging as it not only requires technical infrastructure, but also changes in policies and processes to compliment this approach [48].

In the context of data management, data trusts [26, 73, 77] and data cooperatives [12, 40, 72] have been two approaches to provide participants greater control over their data. Data trusts encompass a collection of data resources that a trustee (or a group of trustees), oversee on behalf of others (i.e. beneficiaries). These trustees act as data stewards and bear the responsibility of deciding the appropriate usage of a data resource [26, 73, 77]. Data cooperatives are another approach, where individuals voluntarily pool their all data into a single repository and control access themselves. These individuals then make decisions collectively on the use of their data, negotiating the conditions of use [12, 40, 72]. Similarly, Da Silva et. al [23] developed a personal data governance framework to allow citizens to control the availability, access and use of their data through a digital tool. However, they discovered that the users found the tool complex to use, a challenge that could be exacerbated for older populations with low digital literacy. In addition to usability issues, prior studies have also documented the challenges in engaging users in conversations around their data and its governance, specifically due to difficulties in effectively communicating

data usage opportunities and risks [17, 39, 54, 109], hindering users' ability to make fully informed decisions [63, 65, 68, 95].

To address this gap, our study aimed to investigate the approaches for involving end users, specifically PwP, in discussions regarding their data and its governance. We used a series of speculative data use scenarios to aid their comprehension of the potential risks associated with sharing data, using this as a probe to elicit their perspectives and requirements of data governance.

3 METHODS

We conducted the study in two stages, following a mixed methods approach. The first stage was an online survey which provided an understanding of the type of data PwP generated through their self-care practices. This helped us identify the specific data types they would be familiar with and provided a higher-level insight into their data sharing practices. We then used this information to facilitate discussions around data governance in the second phase of the study, which comprised a series of online workshops conducted via Zoom.

3.1 Ethics and Recruitment

Our study received ethical approval from Monash University Ethics Committee. The survey was advertised through both websites and newsletters of Australian Parkinson's non-profit organisations. We also advertised our study on Australian Parkinson's support groups on Facebook, with the approval of the administrators of the relevant groups. An explanatory statement was provided along with the survey link, outlining all study details. Participant consent was indicated through the completion of the survey, which accepted responses for a 9 month period (December '21-September '22). Whilst the survey was anonymous, participants could share their contact information if they wished to participate in future research. Consenting individuals were then contacted for the workshop recruitment. Since we had participants from a wide geographical area, all workshops were conducted online via Zoom.

3.2 Survey

We commenced our study by administering an online survey to gain insights into the types of data generated by PwP through self-care practices. Through the survey, we aimed to understand (1) any lifestyle changes they made to manage their condition, (2) the impact that these had (both positive and negative), (3) the means by which participants monitored the impact (e.g. through self-observation, family/peer observation, self-tracking) and (4) their data sharing practices for the information they collected. We developed and deployed the survey through Qualtrics [85], making sure that all questions were implemented in a manner that fully met Web Content Accessibility Guidelines (WCAG) [117], to ensure that all participants could take part. The survey had a total of 25 questions and the total number each participant had to answer varied dynamically based on their responses (e.g. only those who were tracking aspects of their self-care were asked follow-up questions such as tracking duration, tools used etc). We received a total of 52 complete responses for the survey.

Table 1: Demographics of Workshop Participants: In this context, 'participant ID' comprises both the participant number and the specific workshop in which they took part.

Participant ID	Sex	Age group (years)	Years since PD diagnosis
P1W1	Female	65-74	1-5 years
P2W1	Female	65-74	1-5 years
P3W1	Female	65-74	1-5 years
P1W2	Female	65-74	6-10 years
P2W2	Female	65-74	6-10 years
P3W2	Male	55-64	6-10 years
P1W3	Female	45-54	Less than 1 year
P2W3	Male	55-64	6-10 years
P3W3	Female	55-64	1-5 years

3.3 Discovery workshops

In the next phase of the study, we conducted discovery workshops to explore the data governance preferences of participants. The survey insights played a key role in crafting materials for our workshops and shaping real-world scenarios based on the practices discussed by the participants. Specifically, these workshops aimed to: (1) Explore the motivations that encouraged PwP to experiment with lifestyle changes and observe their impact through data, and (2) Elicit PwP's perspectives on the governance of the generated data. Nine of the original survey respondents participated in these workshops, **Table 1** presents their demographic information. Participants were given the option to participate in one of three online sessions, each lasting two hours. These workshops were kept intentionally small (three participants in each) to encourage maximum engagement. These sessions were audio recorded and transcribed for analysis. Participants were offered a 10 minute comfort break in between activities and were provided a $50 AUD gift voucher as a thank you for their time. We developed Miro boards for discussions, which were used as a visual reference for activities (note that participants were not asked to engage with populating the board). Each session was facilitated by two researchers: one guided the discussion, while the other took notes and mediated participants' responses. Two activities were conducted during each session.

Activity 1: Motivations and influences. The aim of the first activity was to identify how different factors (i.e. sources of information, type of intervention and impacts on PD symptoms) influenced PwP's decisions to experiment with lifestyle changes. We developed a set of 33 cards, which included 5 different information sources, 13 types of interventions and 15 types of impacts. These were developed based on the survey results and through prior literature. For each of the 3 card categories, the goal was to incorporate contrasting information instances that could lead to diverse scenarios being discussed. This involved including sources of varying levels of trust, interventions with varying levels of effort and different types of impacts on PD symptoms. For example, the information sources we used ranged from clinicians to TV/radio, which were the most and least popular sources respectively that survey respondents referred to for PD self-care tips. The notion of trust in such sources has also been discussed in prior research [10, 65, 69]. Similarly, the

Figure 1: The card sets which were provided to the participants. Each card was hidden in the beginning of the activity to facilitate random selection.

interventions ranged from activities that had a low barrier to entry such as specific exercise programs (e.g. Aquatic exercises [19]), and changes to diet [11, 46] to high effort activities (e.g. working part-time, home adjustments/downsizing) which were reported by survey respondents. Lastly, the impact cards listed various types of impact on PD symptoms reported by survey respondents, which included things such as reduced fatigue, regulation of on/off phases, help in regulating body temperature, etc. **Figure** 1 displays the complete set of cards.

Participants were asked to select a hidden card from three different categories. The three cards selected by each participant were overturned and discussed as a scenario by the entire group. For example, one of the sets that was discussed was: *Your support group recommended that not eating until 1pm influenced gastric emptying and reduced freezing episodes.* Each participant was asked to discuss whether they would consider trying this lifestyle change and discuss the factors that would influence their decision.

Our main objective was to investigate how participants could be involved in data collection, by understanding their motivations for experimenting with lifestyle changes. As such, we underscored that the selections were random but had prepared plausible explanations for most combinations, and used these explanations as nudges to make the scenarios seem realistic. For instance, one of the scenarios was: *"You hear on the TV/Radio that walking 10k steps a day helps maintain your problem solving skills, memory and concentration."* The explanation that we provided to the participants was that this
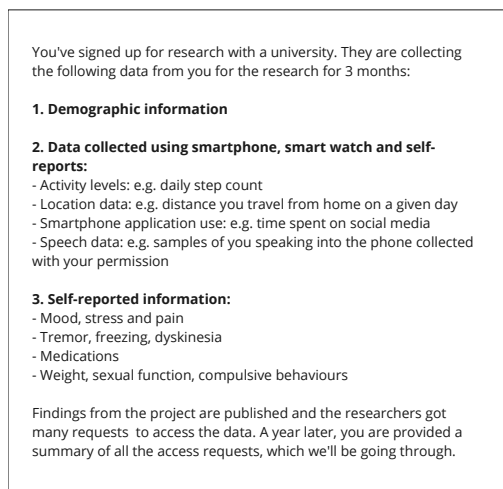
Figure 2: The research scenario that was shown to the participants.

could improve cognitive skills by *"improving blood flow and improving oxygen to the brain."* Based on their responses, we switched either the source, intervention or impact to understand how this change would impact their decision. For example, we changed the source in the above example from 'TV/Radio' to 'Your clinician', to explore how trust/expertise as a factor influenced their decision. Each participant had the opportunity to pick their own set, resulting a total of 3 sets being discussed in each workshop.

3.3.1 Activity 2: Scenario based provocations around data access and re-use. The aim of this activity was to elicit the perspectives of PwP on sharing various forms of data across different entities and understand their needs for the governance of this data. We first developed a set of data types that could be potentially useful for PD research. These included demographic information, actively collected self-reported data, as well as passively sensed data collected through sensors. The aim was to include data types that required both active and inactive engagement from participants. Some of these data types were included based on the survey findings, while others had been collected through smartphones and wearable sensors in previous Parkinson's studies [53, 58, 66, 75, 82]. Using these data types, we presented the participants with a scenario involving their participation in a university research study, a typical research process with which they might be familiar. The exact scenario and the data types are shown in **Figure** 2.

After the introduction of the scenario, our participants were presented with different (hypothetical) data access requests. There were a total of 7 data access requests that were shown to the participants, each from a different type of entity. These seven types of entities were big technology companies (e.g. Amazon, Apple, Google), Parkinson's related technology startups, pharmaceutical companies, other PwP, university students, insurance companies and clinicians. Each data access request listed the requested data types and their intended purpose. For example, *"Several big tech companies (e.g. Amazon, Apple and Google) request access to your*

speech samples so they can improve speech recognition for their products." Our participants were then invited to discuss their feelings around sharing this data with the entity and were asked to provide a rationale for their decisions.

We probed this further by introducing a potential speculative downside or misuse associated with accepting the data access request, providing an illustration of the potential consequences. These were initially hidden from the participants and only shown after they had discussed the valid use case. For example, the misuse associated with big technology companies was *"Your voice assistants (Alexa, Siri, Google Assistant) start to speak to you in your own voice, without you setting this feature up."* They were then asked to reconsider their decision and discuss whether they would share their data with this entity in the future, being aware of this potential downside. Additionally, they were asked to discuss any conditions they would impose on this entity (e.g. provide compensation, seek consent for re-use, share results etc.) if they were to share their data. **Table 2** describes all these access requests and downsides that were shown to the participants.

3.4 Data analysis

After the completion of data collection, the survey responses were exported to a spreadsheet for further analysis. Descriptive statistics were used for the close-ended questions and content analysis [2] was used for the open-ended questions. The workshops were audio recorded and transcripts were generated from the recordings. Inductive thematic analysis [15] was conducted on these transcripts by two members of the research team without a pre-existing coding framework, to explore the interpretation of the themes and sub-themes. The researchers independently coded each of the three workshop transcripts and met to discuss any discrepancies and consolidate findings. A total of 37 sub themes (e.g. low barrier of entry, nothing to lose, non-invasiveness, measurable impact) were grouped together into similar themes. Four final themes were developed from the data analysis, which were 1) Motivating data collection through self-care, 2) Participants as co-researchers, 3) Principles relating to data use and 4) Data governance expectations, which are discussed in section 4.2 Workshop findings.

4 FINDINGS

4.1 Survey results

The survey received a total of 66 responses. Fourteen partially completed responses were excluded, as ethically we only considered participants who completed the survey as fully consenting to the study. This left a total of 52 responses for analysis.

4.1.1 Demographic information. Most of the respondents (n=31, 59.6%) were female, with a large proportion (n=21, 40.4%) between 55 and 64 years; 19 respondents (36.5%) were between 65 and 74 years; 12 respondents (23%) were evenly distributed between the age groups of 45-54 years and 75-84 years.

The majority of our respondents (n=23, 44%) received their PD diagnosis within the past 1-5 years, followed by 14 respondents (27%) who were diagnosed 6-10 years ago. Eight respondents (15%) had been diagnosed 11-15 years ago, and four (8%) were diagnosed within the last year. Very few respondents (n=3, 6%) received their

Table 2: Access requests and potential downsides

ACCESS REQUEST	POTENTIAL DOWNSIDES
Several big tech companies (e.g. Amazon, Apple and Google) request access to your speech samples so they can improve speech recognition for their products.	Your voice assistants (Alexa, Siri, Google Assistant) start to speak to you in your own voice, without you setting this feature up.
PD tech start ups want to access the demographic, activity data and reports of freezing to develop affordable PD products - e.g. walking stick with light that shines with you have a gait freeze.	The company gets taken over by somebody who wants to increase revenue and you notice a significant mark-up in the products, which beyond your budget.
A big pharma company wants to develop a new L-Dopa drug and are interested in using sensor data to measure the effects. They want access to your data to explore which sensor gives the best measure of PD symptoms. They are requesting the entire dataset.	The data was valuable for their trial and helped them launch the new drug. Seeing this value, they are interested in buying and owning the dataset for themselves so that nobody else can access this (e.g. competitors).This would make them the data custodians and they would control access, sharing, selling of the data moving forward.
Some people in your support group have noticed that physical activity has impacted their mood and compulsive behaviours. So they want access to this data to test their hypothesis. What if this was a family member or a friend?	Even through the data was deidentified, people that know you were able to tie the various data points and know that this was your information. They start asking you about your condition and bring up stuff that you haven't specifically told them.
Students want access to the entire dataset for a university project to build AI algorithms to better detect PD symptoms for diagnostic purposes. They will explore relationships in all of the data.	The students share this data around themselves and one of them makes it available on a public forum so that their teammates could access it. It is now available to anybody that enters the forum.
Insurance company requested access the activity levels, location data, demographics and symptoms data to determine what type of covers might be best provided for people with PD.	Your insurance premiums start going up and you start getting targeted advertisements for insurance products.
Clinicians want to access your demographic information and symptom reports to provide better services for people with PD in your area.	They found that very few people have a specific symptom and then use this to remove a specific service that you use in your area to another area where there would be more uptake.

Table 3: Reported Parkinson's symptoms

PD Symptom	Count (%)
Bladder and/or constipation problems	44 (84.6%)
Fatigue	43 (82.7%)
Bradykinesia (Slowness of movement)	38 (73.1%)
Rigidity (Muscle Stiffness)	38 (73.1%)
Tremor	35 (67.3%)
Dystonia (Involuntary muscle tightening)	31 (59.6%)
Gait problems (Walking, freezing, falling)	31 (59.6%)
Eating and swallowing difficulties	27 (51.9%)
Speech and communication difficulties	24 (46.1%)
Low blood pressure	21 (40.4%)
Dyskinesia (Uncontrollable, jerky movements)	20 (38.5%)
Insomnia/sleep difficulties	6 (11.5%)
Pain	5 (9.6%)
Brain Fog	4 (7.7%)
Cognitive difficulties	3 (5.8%)
Difficulty adjusting to temperature changes	3 (5.8%)
Sensory problems (taste/smell)	3 (5.8%)
Sexual dysfunction	2 (3.8%)

diagnosis 16-20 years ago. Table 3 presents the PD symptoms reported by the respondents.

4.1.2 Lifestyle changes. Nearly all of our respondents (n=49, 94.2%) reported that lifestyle changes had an impact on their PD symptoms. The most frequently reported lifestyle changes were increased physical activity and exercise (n=30, 61.2%), dietary changes (n=21, 42.8%) and reduction in working hours/resting more often (n=21, 42.8%). A few respondents also reported making changes in their living environment (e.g. incorporating home aids and assistive technology, home downsizing) (8/49, 16.3%) increasing self-awareness of their physical/mental well-being (n=6, 12.2%) and engaging in cognitive or creative exercises (n=3, 6.1%).

4.1.3 Impact of lifestyle changes. Many respondents (n=22, 42.3%) reported that these changes helped keep their PD symptoms in check, stating *"exercise, diet, flexibility all help practically to reduce symptoms and enhance the effects of medication"* and that they *"slowed the development of symptoms"*. In addition to reducing the direct impact of PD symptoms, participants mentioned how these approaches contributed to their overall well-being (n=15, 28.9%), assisting them in actively managing their PD by fostering motivation and a positive outlook (n=11, 21.1%). Two of the respondents mentioned: *"Overall I feel so much healthier and happier than I was prior to diagnosis. I am much more positive and feel I have my Parkinson's under control"* and *"Generally I feel more accepting of my diagnosis and more in control of how I live"*.

4.1.4 Means of monitoring the impact. The majority of respondents (n=35, 67.2%) indicated that they were tracking one or more aspects of their health and well-being. The most common aspects that were tracked were daily step count (n=22, 62.8%) and PD factors (n=22, 62.8%) such as symptom occurrence, intensity and medication dosage. Some respondents also reported tracking their sleep (n=18, 51.4%) and diet/calorie intake (n=5, 14.3%). The tools that

were being used for tracking included smart watches (n=16, 45.7%), paper diaries/journals (n=15, 42.8%), smartphones (n=7, 20%) and spreadsheets (n=6, 17.1%), with one participant also using an Oura ring.

4.1.5 Data sharing practices. However, the sharing of this data with others was limited, with over a third of people (n=12, 34.2%) mentioning that they did not share the data at all. Amongst those who were sharing, the data was primarily being shared with their clinicians (n=17, 48.6%) and family/peers (n=10, 28.6%). A few respondents were also sharing data with their support groups (n=5, 14.3%).

These findings illustrate the spectrum of lifestyle interventions PwP are using to help manage their symptoms and their attitudes towards data tracking and sharing. The workshop findings serve to highlight the fundamental reasons driving current practices and present participants' requirements when it comes to sharing their data.

4.2 Workshop findings

The workshops we conducted highlighted four prominent themes. These were (1) *Motivating data collection through self-care*, (2) *Participants as co-researchers*, (3) *Principles relating to data use* and (4) *Data governance expectations*. These describe the motivations of PwP to collect data through self-care interventions, the methodological approaches they followed to test the impact of these interventions, and their principles and governance expectations relating to the use of such data.

4.2.1 Motivating data collection through self-care. We found that the perceived effort involved in integrating new approaches into their daily lives was the primary influencing factor across all of the workshops. Individuals were more likely to try different interventions if there was a low barrier to entry and they could easily modify their routines to incorporate them. For example, one of the hypothetical scenarios where support group members recommended delaying meal timings as a strategy to reduce freezing episodes, was perceived as a low effort solution: *"I'd give it a go, it can't hurt. You just get hangry [...] I'd be willing to try it because basically you haven't got much to lose"* [P1W3]. Alternatively, higher effort interventions were less appealing to participants, regardless of the benefit they provided. For example, another hypothetical scenario where walking 10k steps in a day was recommended on the TV/radio to maintain problem solving skills, memory, and concentration, one individual stated: *"I can't manage 10,000 steps, that's beyond me, so I wouldn't walk that many. I'm walking, but it's just that 10,000 steps is too many for me in a day"* [P1W2]. Perceived risk was similarly seen to influence participants' likelihood of engaging in new interventions. Non-invasive solutions were met with an attitude of "nothing to lose" as an individual stated: *"I'd give it a try. It's not like it's, it's you're cutting a limb off [...] definitely if it's non-invasive"* [P1W3]. Similarly, these factors also applied to various forms of exercise programs. Our participants were open to trying such interventions regardless of the extant research behind it *"cause there's no cost. I would have a look at that [...] Can't really lose, can you?"* [P3W2], which resonated with the other members. Another participant stated *"Yes. Not gonna be any hardship to try. I*

go to the exercise physiologist now and I could I do that once a week. And I could ask her to talk me through it and find out what's involved" [P2W1].

This position was different for more demanding lifestyle changes, where the provenance and credibility of the sources promoting them was a more important factor. Our participants were more cautious about the interventions that seemed contentious and emphasized the necessity for these to be verified through their trusted sources. While sources such as internet, television and radio were *"an easy way to consume something"* [P3W1], individuals discussed validating the origin of the information to ensure credibility. For example, in one of the scenarios where CBD (cannabidol) oil was recommended through the internet to overcome sleep difficulties, one participant stated *"Depends where on the internet, what the source was. You know, if it was, if it was something like the Fox Foundation, then you'd probably think, well, that's reliable. If it was just somebody on a blog, I would think about it more carefully"* [P2W2]. Another participant stated *"TV, radio, that's not a good source for me. I prefer Something more credible than where, you know the background of what it was"* [P1W2]. Although seen as a more reliable source, the need to validate information was applicable for support groups too. One participant stated *"The support group might just hint of something, which could be useful, but I need more information beyond that"* [P3W2]. This need for more information often led to people consulting their clinicians, to determine if these suggestions would worth pursuing, *"With the amount of consults I'll have a month with various neurological experts, they're there to bounce any questions off, not a support group"* [P2W3]. This expertise was influential in building trust as *"You'd think that they would've had research backing or got the information from a credible source"* [P1W3].

Although such expertise was available, individuals acknowledged the time and effort required to cultivate those trusted relationships. One of the participants stated *"I don't know whether I talk to my neurologist or not [...] I don't feel I've formed a real relationship with my neurologist at the moment [...] I changed a couple of years ago and I'm still sort of working on it. I haven't seen him smile yet"* [P2W2]. In light of such instances, individuals underscored the necessity of conducting their own thorough research: *"Once I've done my due diligence [...] I'm pretty much pretty open to trying something that I feel comfortable with, once I've researched and weeded out things that aren't looking true"* [P1W1]. This was a common sentiment amongst individuals, with some even scouring for academic literature: *"But there's actually been no peer reviewed research been done. So it's sort of a catch 22. But at the same time, I'm always willing to try new ideas, but I've gotta get to a point where I'm happy to try that idea"* [P3W2]. Another participant added on: *"As much as I can put my hands on, And as much as I can understand what they're saying in those PubMed and all the rest of them [...] I have to make the best decision that I can based on my own intellectual stamina"* [P1W1], highlighting the depth and meticulousness of their due diligence.

In summary participants discussed three main motivating factors that influenced their decision making processes when experimenting with different lifestyle changes; (1) the perceived effort and risk that the intervention might have, (2) the provenance of the source of information that drove their decision to try something new, and

(3) the time and effort that was involved in establishing trusted relationships with clinical professionals, that often led to them conduct their own research rather than relying on professional input.

Key takeaway: providing interventions that address motivating factors and enable participants to conduct thorough due diligence can influence patient led data collection.

4.2.2 Participants as co-researchers. Our participants demonstrated a set of skills and values that aligned more closely with the role of co-researchers, rather than research participants. Individuals were already collecting information and experimenting to discover novel approaches to help ameliorate the symptoms of their condition, as one participant stated *"I'm on high dose vitamin B1, which a lot of neurologists don't even consider. But I've been on it and I've proven ON or OFF there's a difference and I've continued to take it"* [P1W1]. They relied on their own data and observations to test the efficacy of their experiments, demonstrating a persistent mindset for knowledge discovery. Ultimately their goal was to discover effective solutions through trial and error: *"It's just my philosophy on it...try something, if it doesn't work, tick it off the box, try something else. Yeah, that doesn't work, tick it off the box and try something else. And just keep on going and keep on going until we try to find something"* [P2W3]. Given the diverse and individualised nature of PD, people relied on self-expertise to determine what worked best for *their* Parkinson's: *"It seems like Parkinson's different for most people in some way or other. So I am using myself as a Guinea pig as much as I feel comfortable with [...] doing a few Guinea pig activities has been very helpful"* [P1W1]. One participant shared their systematic approach to self-discovery, highlighting how this process empowered them to make better informed decisions:

> *"I tend to pick out something which has caused me the most problem at the moment and I'll spend a month just researching it and talking to, my support group. Or looking it up and seeing what information you can find about it [...] I might try some aspects if I feel appropriate [...] I'll spend a month on a subject like that just before I moved forward, I did that for all my symptoms"* [P3W2].

However, participants not only used their own experience to drive their knowledge discovery, they placed a similar sense of trust in other PwP's experiences: *"Getting opinions from other people with Parkinson's is of high value to me. Because they're experiencing things firsthand"* [P1W3]. The support, advice and guidance from other PwP was seen to be vital towards helping individuals deal with the complexities of PD : *"when you talk about it particularly with people who have lived experience, it's very helpful. Some of the subjects can be quite tricky to deal with sometimes"* [P3W2]. Participants discussed the influential role of such shared narratives in shaping their own individual decisions. One described the role of their support group in helping her decide whether or not to have a high risk invasive procedure (Deep Brain Stimulation (DBS)): *"It was a big decision [...] a couple of people in my support group had also had it and it was very beneficial. So I went along"* [P3W3]. Another participant described the benefit of having a 'strength in numbers' of sorts when it came to health related decision making: *"the majority carries weight [...] I think I could be influenced by a group, whether they're a support group or just a group"* [P2W2].

Key takeaway: participants have the capacity to follow scientific approaches for knowledge discovery through self-research, but would benefit from additional support.

4.2.3 Principles relating to data use. Discussions around data use and sharing emphasized a core value that participants had around the use of their data - that it must have *benefit for the greater good.* Participants emphasised the importance of ensuring that any use of their data (regardless of how sensitive the data was) resulted in benefits for the PD community through research and development: *"[Any] information to do with my Parkinson's can help other people and the medical profession, I'm happy to share it. You know, I think anything that's gonna make this world a better place"* [P2W1]. Participants engaged in extensive discussions across all three of the workshops around the concept of being an "open book" when it came to their Parkinson's, demonstrating an altruistic mindset, e.g.: *"It may not help me, but it might help people in the future so, no problem"* [P3W2]. This showcased a consideration for the well-being of others beyond immediate personal gain and was seen to be the primary condition that anyone using the data had to fulfill: *"Are they gonna benefit the Parkinson community? That's it. That's the first criteria then dependent on, say the demographics of what they want, how they want it, what for"* [P2W3]. Importantly, discussions concerning the potential downsides of access requests and data (mis)use unveiled two core principles for governing this value: 1) ensure that data is either open for all organisations, who might have the potential to benefit the Parkinson's community, or not at all and 2) ensure that there is a reciprocity of outcomes from research.

One of the provocations used during the workshops probed the concept of data custodianship (i.e. a pharmaceutical company taking custodianship and making their data private). This provoked discussion around the importance of open and equal opportunity for information access, as one participant stated *"I'd expect the data would be accessible to all who wanted [it]"* [P3W2]. They strongly voiced their dissatisfaction against privatisation, citing the impact equal access can have on innovation and advancement: *"I think that everyone should be given a chance to use super valuable information. Because you never know where a breakthrough might come from or whether it [will] be something to help people physically or medication"* [P1W3]. Other participants further elaborated that *"another company could come up with something better if they had the same data"* [P2W2] and *"a little guy might come up with an idea, that the big guy hasn't"* [P2W3]. In other words, openness was needed to ensure that all potential options were available, which is perhaps particularly important given the heterogeneity of needs (and thus successful treatments) amongst the Parkinson's population.

The concept of data monetization also arose, leading to discussions about the direct and indirect benefits of data usage. Participants acknowledged the necessity of organizations being able to generate revenue to substantiate their investments, *"They spend a lot of money on research and they're trying to recover. I mean they've gotta be able to make money or else they can't do the research?"* [P3W2], however, they expected a reciprocity of outcomes from the use of their data. They particularly emphasized the need for research outcomes to be accessible and beneficial for the PD community, especially in the context of pharmaceutical and PD technology

companies. Referring to pharmaceutical research, one participant stated: *"When they're developing new drugs, some of the prices of drugs are just outrageous. And I'll just always ask them, how are you gonna make it cheaper so we can afford it?"* [P3W2].

Similar sentiments were echoed regarding PD technology companies, with participants appreciating affordability of products as another individual stated: *"where it says affordable PD products [...] that's good as well because everything can be ridiculously expensive and it's helping people with Parkinson's specifically"* [P1W3]. These findings emphasize that participants contributing their data expected to receive tangible benefits and accessibility to the advancements resulting from the use of their information. On a related note, individuals were skeptical about receiving monetary compensation from such organizations for the use of their data: *"If they offered money, I wouldn't turn it down, but no. You don't expect money for that sort of thing, not these days"* [P2W2]. Instead, they believed that those resources should be allocated for PD research for the betterment of the community: *"If they offered me money, the money should be going towards PD research, not me as an individual because we're doing this for Parkinson's. I'm not doing what I'm doing for the sake of myself"* [P2W3].

Key takeaway: participants were driven by the core value that their data use must have *benefit for the greater good*. This value would be governed by 2 key principles: 1) Data with the potential to significantly advance research and innovation for the benefit of the PD community should be openly available for all organisations and 2) There should be a reciprocity of outcomes, to ensure that any outputs (e.g. assistive technology, medication) arising from data use are accessible for the PD community.

4.2.4 Data governance expectations. Building on from the values and principles of data use, participants shared their perspectives on the governance of their data and discussed their expectations for responsible and ethical data usage. They stressed the importance of transparency and desired assurance about the intended use of the data, which was vital to build their trust. For example, *"I guess a full explanation of what their intentions are to do with the data"* [P1W3] and *"I suppose really just [that] that's all they're going to be using it for"* [P2W2]. Whilst data reuse was acceptable, individuals preferred being informed about each new purpose and having a say in these decisions: *"You'd expect that they would talk to you about, or be in contact with you, if initially all they'd said was they were going to use it for whatever it was in the first place"* [P2W2]. Another participant voiced their discomfort on their data being re-used without their explicit consent: *"It'd be okay if they talk to you first about it. But if they've just done it [...] Yeah, it's difficult"* [P3W2]. Whilst participants recognised the complexities of data sharing, they discussed potential mechanisms for ensuring that data use aligned with their value of 'benefit for the greater good', with one individual citing the example of a contractual agreement:

> *"No, it's not in the terms of reference or the outcomes that are desired [...] I'll be looking at a contract first because if they reneged on it there's no legal avenue. I would be looking at some type of requirement that they have to make it stand instead of just some verbal thing"* [P2W3].

Drawing back to the principle of reciprocity of outcomes, participants discussed mechanisms for putting this principle into operation. The concept of conditional and dynamic consent was raised in discussions about data use by for-profit organisations: *"I dunno how you'd do it, but there can be some sort of condition put on them that what they develop has to be for a reasonable price"* [P3W2]. Another added: *"Well, I think I would be asking them to, if they wanna use my data, then they have to make the product accessible"* [P1W2]. To enforce such conditions, having the ability to withdraw their data was imperative, especially when the purpose did not align with their principles: *"You could always say make it affordable or else I would withdraw draw my data"* [P2W2]. Another participant discussed the consequences of such a misalignment, expressing their reservations of participating in future research: *"the only thing I can say doing differently is not participating in the research [...] we wouldn't do it again, sort of thing"* [P3W2].

In light of the ethical uncertainties surrounding data use, people also highlighted limitations of current consent models in industry and research. Referring to broad consent and trusting organisations with their data, one participant expressed a sense of powerlessness once consent had been given, as unforeseen events like a corporate takeover could occur: *"Well, that's the thing, when you give your consent, you don't know about the future company getting taken over. So there's not much you can do"* [P2W2]. Individuals also voiced caution owing to the unpredictable nature of future information use, stating *"you dunno how they're gonna use information in the future and no one knows that question"* [P3W2]. Another participant, who previously worked in a clinical registry that used an opt-out consent approach, indicated their preference for having control over this decision when dealing with for-profit organisations: *"I probably wanna opt-in if it was a company, given a chance"* [P3W3]. These concerns around consent and control over personal information also sparked a discussion about data identification, and individuals' having access to their own data. Participants emphasized the importance of being de-identified and recognized the risks associated with sensitive forms of data, such as their voice: *"Once data is there, as long as it was depersonalized, I don't have a problem with it. This, it cross the line becomes personal"* [P3W2]. Although anonymity was vital, participants expressed a desire to have control over their data: *"Unless you're being truly de-identified where you're just giving us a number, but if we want to have access to our own information, we need to know that it's us [...] I would like, as a participant to access my own information"* [P3W3].

While participants agreed that deeper engagement in data governance issues would provide them with a greater sense of control, several expressed uncertainty about the practicality of implementing such approaches. They demonstrated varying levels of interest and willingness to engage in data protection responsibilities, with many being uncertain about their ability to uphold this responsibility.: *"I wouldn't have time"* [P2W1] and *"I don't wanna be bothered with it every time"* [P3W1], were some of their statements. Additionally, there were conversations about the scalability challenges of implementing such mechanisms, especially concerning people who have been involved in multiple research projects over the years:

> *"Just trying to remember how many different projects reviews, whatever you've been involved with research.*

There's quite a lot of us who are very proactive. So remembering 10 years down the track exactly what you're involved with [...] Frankly, I can't remember what happened three weeks ago" [P2W3].

These findings highlight participants' expectations about the governance of their data, illustrate the gap between existing practices and their preferences and highlight some of the practical challenges of implementing such data governance mechanisms.

Key takeaway: participants unanimously prioritise trust and transparency regarding the use of their data. They want greater control over their data through the ability to access and withdraw data, different types of consent and access to data outcomes, but more work is required to develop and operationalize mechanisms that can provide this control.

5 DISCUSSION

5.1 Towards patient-driven participatory data generation

Whilst the value of patient-generated data has been extensively discussed, barriers such as loss of motivation to use technology [4] and the time and effort for collecting data [74, 89, 90, 105, 110] impact longer-term engagement with patients, often resulting in technology abandonment. This subsequently impacts data quality, thereby influencing its usefulness and reliability [21, 111, 112]. Whilst providing financial incentives has been shown to be an effective approach to address this issue [100], our findings suggest that our participants were not primarily motivated by financial remuneration.

We found that our participants exhibited persistent willingness to experiment and monitor the impact of self-care practices, driven by a strong desire to gain greater control over their condition. They were strongly motivated to experiment with *low-risk* interventions that they could easily integrate into their daily lives, which were recommended by sources they considered credible, and provided some information that they could verify through their own research. Prior work by McNaney et. al [68] and Vafeiadou et. al [105] reported similar findings, where PwP were experimenting with diet and exercise programs and wanted to have objective ways of documenting the impact. Such individuals are already engaging in forms of data collection and data driven decision making, having a rich source of personalised data. This raises an intriguing question: can such individuals be supported in their data generation and experimentation efforts, and would they be willing to contribute their data for research purposes?

In current research projects, researchers typically determine the research questions and processes, leading to project-based, intermittent engagement with communities, where they contribute their data. By contrast, our participants took a bottom-up approach, performing their own investigations and explorations, which included identifying their own questions. This presents an opportunity to transition from a researcher driven to a patient driven *participatory* data generation approach [35, 92]. Rather than participants simply 'contributing' their data after research questions and protocols have been defined, they could co-formulate their own research questions

and lead investigations alongside researchers, fostering a collaborative enterprise that establishes a genuine partnership between academic researchers and research participants. Under this approach, participant communities could receive support to conduct their own systematic experimentation practices and subsequently have the option to contribute their observations for research purposes. A data donation model [9] could be utilized for such an approach, but key factors such as participant anonymization processes, participant incentives and governance models would need to be carefully addressed to ensure its success. This raises a new research challenge as to how to best implement such an approach, whilst addressing evolving participant engagement and data governance challenges.

A potential approach to supporting patient driven data generation for research could be developed by adapting participatory frameworks applied in movements such as PatientsLikeMe [36, 81, 113]. Here, individuals are supported by other community members to use empirical methods to investigate their own bodies and behaviors, and can subsequently share their data for the benefit of the community. Future research can consider adapting similar participatory frameworks over traditional academic research models. Digital platforms, comprising of motivated participants and researchers could support this effort. Such a platform can be designed such that participants could propose and share interventions that they would be willing to test, allowing other interested community members to vote and express interest in joining their experiment. Interventions with widespread interest could form a participant pool which researchers could support in their experimentation efforts. Researchers could tweak and formulate the research question along with these participants and develop materials to support the collection and analysis of the data, increasing the scientific relevance of the resulting data. Subsequently, the platform could facilitate data donation at the end of the process. The researchers could support the analysis and interpretation of the data, providing participants conclusive outcomes that can benefit their condition. Such a platform could be mutually beneficial to both the research and PD communities [47, 59, 60, 84], and would leverage the bottom-up, co-created experimentation approach through which participants operate.

5.2 Transforming data custodianship practices

Our participants considered *the benefit for the greater good* as their core value, and the principles guiding this value included keeping the *data open for all or not at all*, and ensuring the *reciprocity of outcomes*. These foundational principles are pivotal to individuals, centered on the belief that their active engagement and data contributions serve as catalysts for advancing future research and overall benefit for the PD community. While similar values of benefit for the greater good have been documented in previous studies [10, 65, 68], our participants emphasized the significance of data use aligning with their principles, and expressed their willingness to withdraw support when such alignment was lacking. This raises a fundamental question: How can data custodians engage with participants to ensure this alignment?

Several studies have discussed the implicit trust that patients place in healthcare providers, health organizations, and researchers to "do the right thing," given the knowledge that these entities are

regulated by relevant legal frameworks and are bound by ethical codes of conduct [10, 30, 65]. Despite this trust, our findings have unveiled a strong desire among participants for increased control and oversight in managing and utilizing their data. This need is particularly pronounced due to the extensive research engagement of our participants, many of whom have actively contributed to multiple research projects over the years. This underscores the importance of enhancing participant engagement in data-related decisions, which has also been emphasized by prior research [10, 65]. However, it is crucial to exercise caution and avoid overwhelming individuals with these responsibilities. Our participants raised concerns about their limited time and willingness to actively engage in such decisions, expressing a desire to "just do the right thing". Prior work has also highlighted that individuals prefer having support when making decisions about sharing their health data for research [25]. This prompts the question of how we can design a solution to accommodate this contrast. Whilst individuals may have limited capacity, a collectivist approach could be a viable solution in this case.

Collectivism is characterised as a social structure wherein closely linked individuals identify themselves as members of collectives and are driven by the values associated with these collectives, giving precedence to collective objectives over their personal ones [101]. Our findings illustrate that PwP closely align with this mindset, identifying as members of the Parkinson's community and prioritising greater benefit over personal gain. They place trust in the lived experiences of other PwP and these even influence their own self-care decision making, as they value the collective expertise of the community. This presents an opportunity to leverage such a collective for data decisions. Data cooperatives [12, 40, 72] could be employed to address this need. Instead of having researchers as the sole research data custodians, future research could explore the prospect of adapting this shared model of data custodianship, wherein research participants and related health communities could collectively make decisions about the management and utilization of their research data. The data could be pooled together in a repository, which could be designed so that the collective influences the use of cohort level data, alleviating individual burdens. These decisions would be grounded in shared values, guaranteeing that any data usage aligns with the best interests of the community. Future research could explore factors such as participant composition and logistics of the decision making processes, whilst also understanding end users' willingness to participate and operate in such an initiative. These could inform approaches to sustain public engagement, for example finding the best ways for people to cast votes, developing effective approaches to delegate voting rights [40], and leveraging organizations or governing bodies to provide clarity and support for informed decision-making [25].

5.3 Enhancing a sense of control over data

Our participants were individually quite specific about the types of controls that they wanted to impose, albeit that most of these flowed from the same broad values and concerns. Whilst the factors users wanted control over (e.g control over data re-use decisions, ability to withdraw data) are considered as crucial components of ethical research [31, 108] and data protection regulations [37, 104],

the practical implementation of these end-user controls over data has been historically challenging. While approaches have been explored to address some of these concerns (e.g. blockchain-based smart contracts for data access management [96], different models of consent [16, 48, 86]) the practical implementation and adoption has been limited. In addition, there have been limited approaches to addressing the need for participants to access their data and to facilitate data withdrawal that have been deployed on the ground [48, 97]. The personal data governance framework proposed by Da Silva et. al [23] facilitates data access and withdrawal by placing responsibility on end users. It empowers them to add, delete and modify data while also granting them the ability to control access to external parties. Nevertheless, they observed that the tool posed usability challenges for users due to its complexity, presenting an even greater challenge for older individuals. In addition to such interfaces being accessible by older populations, our findings also emphasized that the level of interest in having such control over data decisions varied significantly among individuals. Users expressed a preference not to feel overly burdened by such decisions. This highlights a potential avenue for future research, namely, the exploration of methods to develop accessible mechanisms for data governance, whilst reducing individual burden.

Future research can explore the design and development of data platforms that could cater to participants' varying levels of interest in such data governance decisions, prioritizing the aspect of personalization. These personalized interfaces could provide the functionality to choose the factors they would like to control (e.g. [86]). For instance, during onboarding, participants could be offered the choice to specify the type of consent they wish to provide to a particular entity, select the categories of data use requests they want to receive notifications about, and determine the frequency at which they would like to be informed about research findings resulting from the use of their data. These preferences would then define participants' interactions and decisions over their data. To explore the viability of such a platform, future research could use a wizard of Oz approach to understand user experiences [28, 49]. In such an approach, participants could be given a high degree of control over simulated research data, allowing them to define their data governance preferences. The *wizard operator* [28] would then use their inputs to simulate the operation of a personalised data governance system, providing users the opportunity to explore consequences of their decisions. Obtaining user feedback through such a method would offer valuable insights into the practical implementation of such interfaces, shedding light on the opportunities, challenges, and overall sustainability of these systems in real-world settings.

5.4 The value of provocations for supporting conversations around data

To finish our discussion, we reflect on our approach to engaging our participants (a largely older group with significant accessibility needs) in discussions around data and its governance. Engaging end users in the finer details about their data has always been challenging. Research has highlighted the challenges of conveying data implications in a manner that most of the population can understand [17, 54], which often corresponds with a public lack of

interest in meaningfully engaging with mechanisms designed to protect data [63, 95]. The result is that few people understand the amount and quality of the data that is being held about them, its inherent value, and more importantly, the potential implications that its use could entail. This was also reflected in our study where participants made statements such as *"I'm an open book"* and *"I don't mind sharing anything as long its going to benefit the community"*, a finding that has also been observed in prior research [65, 68].

By adapting approaches from speculative design [3, 98, 102, 103] we were able to both understand PwP's motivations for collecting data through self-care practices as well as eliciting their perspectives on the management and governance of their data. Speculative design has been widely used in the design of healthcare technologies, to explore alternative futures and open debate about the social and cultural implications of emerging technologies [29, 43, 98]. For example, Hoang et al. [43] created a narrative-driven storybook set in a fictional healthcare world to engage participants in exploring their health conditions and gaining insight into their habits and decisions. In our study, instead of using fully formed speculative designs, we used lower fidelity methods to probe participants into thinking about data governance, through speculative data use scenarios. For the first workshop activity, utilizing the fictional self-care interventions and outcomes generated through randomly selected sets of cards proved to be a valuable tool for understanding people's motivations. The inherent randomness of our approach, resulted in both plausible and unlikely scenarios being generated for discussion. This allowed participants to concentrate solely on the underlying factors influencing their decisions, without being preoccupied by the likelihood or scientific plausibility of the scenarios.

Similarly, in the context of data sharing and use, prior work by McNaney et. al [65] recommended actively exploring both the opportunities and challenges of data use to fully inform participants, enabling them to provide balanced and informed opinions about their data. In our study, we explored the feasibility of this approach to elicit personal data opinions and governance perspectives. Providing explicit (fictional) examples of data use and misuse proved to be an effective method to prompt our participants to thoroughly contemplate the potential scenarios. Moreover, basing these examples on PwP's explicit practices, identified through the survey, enabled them to relate to the data types, and evaluate the risks associated with these based on perceived data sensitivity (e.g. voice data in comparison to activity data). By evaluating such risks, they were able to discuss the controls that they might like to have to help in minimizing the impact of potential misuse. They provided suggestions such as having more power within data re-use decision making, having more control over their data by retaining rights to access and withdraw data, having the ability to select different consent models for different organisations (broad, informed, conditional), and ensuring mutual accessibility of both direct and indirect outcomes arising from the use of their data. Each of these mechanisms, driven from the participants' preferences, provide solid directions for future work wishing to employ more participatory approaches to data governance in the future. Further research could explore the feasibility of applying a speculative data discussion approach to other chronic conditions that require regular self-care

and management, with data captured using digital technology (e.g. Multiple Sclerosis [5, 6], diabetes [62]).

6 LIMITATIONS

There are several limitations to our study. Our online survey received a relatively small number of responses, despite extensive online advertising and the significant amount of time that the survey was kept open. Recruitment in this space is challenging, given the prevalence of survey fatigue. Future research could utilize broader methods of survey distribution and provide compensation to participants for their time, potentially increasing participation rates. Secondly, our findings are based on an Australian cohort, which restricts the extent to which they can be generalized. Whilst previous work conducted in the UK discusses similar outcomes [65, 68], future research should be conducted to understand if similar opinions are shared by the wider PD population. Extending this work to broader geographic and cultural contexts may reveal distinct values and data governance requirements, providing further nuance and understanding beyond the results that we have obtained. Finally, as the participants in our study were derived from the online survey participation phase, it is possible that our sample was biased towards those who already have an interest in, and digital literacy around, technology. Further work could attempt to mitigate this using broader community engagement approaches (e.g. telephone survey or in-person engagement through support group meetings) in order to consolidate findings with a broader population.

7 CONCLUSION AND FUTURE WORK

In this paper, we have offered insights into the types of data that is currently generated by PwP through self-care practices and the motivations driving their activities. We have discussed how they often use scientific approaches to collect data for monitoring the impact of their practices, which could be potentially leveraged to promote patient-driven participatory data generation. Secondly, we present participants' viewpoints on the sharing and reuse of their data, highlighting how their values and principles shaped their expectations of data governance, presenting an opportunity to explore collectivist approaches to data custodianship, and the governance aspects necessary to support such initiatives. Lastly, we reflected on how speculative design approaches might be used to engage communities in complex discussions about data and the practical aspects of its governance.

We encourage future research to explore how involving patients in data decisions influences health outcomes and whether this engagement enhances their overall healthcare experience. Additionally, research can explore whether increased engagement in health data governance impacts the efficacy of long-term treatment plans and how greater control over health data impacts patient trust in healthcare systems.

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