Bridging Ontologies of Neurological Conditions: Towards Patient-centered Data Practices in Digital Phenotyping Research and Design

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Amidst the increasing datafication of healthcare, deep digital phenotyping is being explored in clinical research to gather comprehensive data that can improve understanding of neurological conditions. However, participants currently do not have access to this data due to researchers' apprehension around whether such data is interpretable or useful. This study focuses on patient perspectives on the potential of deep digital phenotyping data to benefit people with neurodegenerative diseases, such as ataxias, Parkinson's disease, and multiple system atrophy. We present an interview study (n=12) to understand how people with these conditions currently track their symptoms and how they envision interacting with their deep digital phenotyping data. We describe how participants envision the utility of this deep digital phenotyping data in relation to multiple stages of disease and stakeholders, especially its potential to bridge different and sometimes conflicting understandings of their condition. Looking towards a future in which patients have increased agency over their data and can use it to inform their care, we contribute implications for shaping patient-driven clinical research practices and deep digital phenotyping tools that serve a multiplicity of patient needs.

CCS Concepts: • **Human-centered computing** → **Empirical studies in accessibility**; *Information visualization.*

Additional Key Words and Phrases: Digital phenotyping, neurology, mobility impairment, Ataxia, Parkinson's disease, ethics

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1 INTRODUCTION

The fields of Computer-Supported Cooperative Work (CSCW) and Human-Computer Interaction (HCI) have increasingly investigated chronic illness, with a small but growing body of work on

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neurological conditions in particular (e.g., [55, 57, 69, 73–75, 82, 104]). Neurological conditions affect more than one in three people and are "the leading cause of ill health and disability worldwide", as reported by the World Health Organization [5]. Within neurological conditions, neurodegenerative diseases such as ataxias, Parkinson's disease, and multiple system atrophy are particularly difficult to manage. These conditions progress slowly and unexpectedly, are life-limiting, manifest differently for every individual, and are still being understood by physicians. These complexities require patients to navigate the unknowns of their condition without others who fully understand their individual disease experience [64]. Amidst the unprecedented datafication of health and healthcare, research on neurological conditions and chronic illness in general has subsequently looked at how technologies such as self-tracking devices [7, 23, 77, 104, 110, 111], gamified rehabilitation technology [17, 46, 56, 66, 80], remote monitoring technologies [53, 85], and assistive robots [23, 79, 105] can support patients' management of their illness and clinicians' ability to provide care.

More recently, an emerging data-driven approach to better understanding and managing neurological conditions has been deep digital phenotyping. Deep digital phenotyping uses a wide range of sensors to capture an individual's phenotype, or set of observable characteristics, to detect differences in motor behavior in ways that are imperceptible to the human eye [108]. Unlike technologies like wearables or remote monitoring, deep digital phenotyping entails a more extensive use of sensors that gather more comprehensive information and which are hypothesized to deepen insights into neurological conditions. This form of data collection is unique in that it has potential utility for both patients and their physicians, while also offering the ability to create large, standardized datasets across multiple patients to help researchers understand neurological conditions [40]. However, because this data is still experimental, access and use of it is currently largely restricted to researchers, despite patients contributing time and energy to produce data about themselves—these dynamics are similar to other datasets related to accessibility and aging [3, 49]. Given calls from researchers in HCI and beyond for a paradigm shift around data to recognize data sovereignty [41], and to respect participants' right-to-know [21], we seek to understand how patients view the utility of deep digital phenotyping data.

In this paper, we report on an interview study with 12 neurology patients with progressive neurological movement disorders, particularly ataxias, Parkinson's disease, and multiple system atrophy. Participants had taken part in Neurobooth, a deep digital phenotyping study that quantifies motor and cognitive function through a series of eye movement, speech, motor, and cognitive tasks. Currently, participants do not have access to their data collected in this or other similar studies while researchers create algorithms to extract information from the sensor data, determine the data's clinical validity and develop reports to convey insights derived from it (e.g., [60]). Our interviews with participants probed their current data practices around their conditions. We then asked them to speculate on whether and how they would like to interact with a representation of their deep digital phenotyping data, such as visualizations that show raw, summarized, individual-level, or population-level results. We asked the following research questions:

RQ1: Data practices. How do people with neurological conditions use data to understand and manage their condition?

RQ2: Data representation. How do people with neurological conditions seek to interact with a representation of their deep digital phenotyping data?

We draw on philosopher Annemarie Mol's work on ontologies in medical practice [78] to analyze our findings. Mol conceptualizes ontologies of disease as realities created through practices and experiences, which may differ widely from one stakeholder to another, but can still coexist. We first highlight how participants' personal ontologies of their disease and its progression shape the value they see in *accessing* data in the first place, even if it is experimental. We then analyze

how, in the process of caring for themselves, participants encounter different and sometimes conflicting ways that neurological conditions are understood by themselves and others, including by family, other people with neurological conditions, physicians, and researchers. We describe how patients view deep digital phenotyping data as an improvement upon personal tracking due to its comprehensiveness. As a result, they view it as a tool that can uniquely help different ontologies of neurological conditions coexist to improve well-being and management—not just for themselves, but also for their disease community.

In the rest of this paper, we start by situating our work in the literature on technology for neurological conditions and data sovereignty. We then describe our study design and methods, followed by our findings highlighting how patients imagine data to support the coexistence of different ontologies of neurological conditions. Our contributions to CSCW and HCI are three-fold. First, we foreground how people with neurological conditions have a stake in their deep digital phenotyping data, and how they envision the utility of this data in relation to multiple stages of disease and stakeholders. Second, we discuss the implications of our findings for shaping patient-driven clinical research practices. Third, we discuss how we might design deep digital phenotyping tools for a multiplicity of patient contexts. By following calls to practice data sovereignty, we envision a future in which patients have increased agency over their data and can use it to inform their care.

2 RELATED WORK

In this section, we provide background on research on technology design and data-driven tools for neurological conditions, highlighting the particular intersection of personal, clinical, and research applications that deep digital phenotyping sits within. We also summarize work on data sovereignty and the particular challenges of practicing it in the clinical context. We end by providing background on Mol's theory of multiple ontologies, which we use to structure our findings.

2.1 Neurological Conditions, Patient Data, and Technology Design

CSCW and HCI researchers have increasingly investigated the potential of emerging technology to support people with movement disorders, with a significant focus on Parkinson's disease and a small but growing body of work on ataxia—the conditions we focus on in this study. There has been a foundation of work seeking to understand information-seeking and care coordination among people with these conditions. Nunes and Fitzpatrick [83] describe the everyday self-care practices of people with Parkinson's, noting the complexity of seemingly routine tasks like taking medication, and the active work of compromise, self-acceptance, coping with stigma, and advocating for one's care with clinicians, that is often overlooked in medicalized views of Parkinson's. Jacobs et al. [47] studied how caregivers coordinate care for children with ataxia telangiectasia, noting the additional information-seeking required among caregivers when healthcare providers lack experience with a rare disease.

Prior work has thus noted the value of more tailored technologies to support these populations. In the context of Parkinson's, for example, research has discussed opportunities for technology to support management and improvement of motor, non-motor, cognitive, and psychosocial symptoms [71], with the ultimate goal of improving quality of life as well as supporting a sense of autonomy and independence despite the uncertainties of the disease [88, 110]. Other technologies for these conditions are assistive or rehabilitative, supporting people in completing desired activities or maintaining and improving functioning. Examples include customized utensil grips [58] and dressing aids [114], as well as smart walkers [79], exoskeletons [23, 105], and multimodal games [46, 56, 68, 80] that help with rehabilitation, balance, and visuo-spatial perception. Other work has

sought to support collective forms of support, such as community-created health information services and social support [2, 34, 72, 81, 116].

More recently, research has investigated applications of data-driven tools for people with Parkinson's and ataxias. These applications tend to be for personal use, supporting patient and clinician interactions, or clinical use. Within the realm of personal use such as self-tracking and Internet of Things applications, prior work has shown that self-tracking of environmental, behavioral, and medical aspects of their life can promote positive coping strategies and disease management [71, 77, 93]. Sharing data with others with mobility disorders could also help inform self-care practices [55]. Researchers have emphasized the need for symptom monitoring and sensemaking tailored to the complexities of Parkinson's [110], highly customizable data collection to reduce effort to gather data, support for self-experimentation, and diverse interaction modalities to ease engagement [71]. Prior work also notes challenges in tracking, including the time it takes, inaccurate tracking technologies, and not knowing what data might be most insightful [93, 110, 115]. Studies have also noted how people with Parkinson's may not always be able to accurately perceive their symptoms or discern them from comorbidities or aging [77, 110], potentially making self-tracking alone unreliable for this condition. Prior work has offered alternatives, such as crowdsourcing assessment of speech patterns as a form of self-monitoring [70].

Other research has examined sharing data with clinicians in the hopes of improving care. In some prior studies, people living with Parkinson's found self-tracked data to have "a lack of perceived usefulness" without support from their healthcare provider in making it actionable [104]. Mentis et al. [74] showed the benefit of using hand movement sensor data after deep brain surgery for co-interpretation of a patients' movement by patients and clinicians. Still, there are power dynamics involved in interactions with clinicians, including experiences with not being able to lead discussions about one's health, hearing assessments of data that do not align with patients' lived experiences, or needing to prevent and push back on adverse clinical decisions due to care teams' inexperience [104, 115]. Mentis et al. [73] explored how self-tracking data generated by people with Parkinson's can be interpreted by patients and clinicians during clinic visits to collaboratively create disease management goals. The authors propose that when patient data is introduced to clinical settings, patients should be given agency over data interpretation such as through annotation capabilities.

A subset of work also looks at data-driven tools for clinicians specifically, largely focused on technical advancements in diagnostic and assessment tools, such as quantifying impairment through gestures [101, 107], smartphone interactions [35], and gait or stride video analysis [90, 119]. This work looks at the particular observational or quantitative measures that would be helpful for clinical assessments, as well as the interactions that can best support accurate assessments. These approaches are referred to as digital phenotyping, defined by Gupta [40] as "the characterization of an individual's phenotype, or set of observable traits, using everyday consumer devices such as general-purpose smartphones, smart watches, and personal computers."

More recently, clinical researchers are using *deep digital phenotyping* [31] to examine conditions more holistically and comprehensively through complex technological systems not always accessible to patients, such as a combination of motion, speech, and eye-tracking sensors, expanding the set of symptoms that can be captured and analyzed through data. Deep digital phenotyping has shown great promise to eventually help researchers and clinicians objectively and accurately characterize neurological conditions [40, 109], such as ataxias [53, 85] and Parkinson's disease [15, 95], that are currently subjectively and coarsely measured through clinicians' observations of patients' conditions according to clinical scales [37, 96]. Deep digital phenotyping data is created by patients, who are often recruited through their nurses and clinicians, and primarily used by researchers not directly involved in patient care. While researchers have suggested that this rich data can address

the shortcomings of personal tracking options [29, 111], it is currently not shared back to patients due to researchers' apprehension about how complex data types should be represented, the manner in which results should be communicated to patients, and the possibility of uncertain results being misinterpreted [25]. As this data is uniquely comprehensive and institutionally supported, our work examines how clinical research, even while still ongoing, can support not only insights for researchers but also benefits for patients.

2.2 Data Sovereignty and Health

Across CSCW, HCI, and beyond, there have been numerous calls to ensure that people who generate data have greater ownership over it. This has been captured by the concepts of data sovereignty [45] and data governance [76]—that is, individuals' decision-making power and control over their data and accountability for decisions related to the collection, quality, and accessibility of data. Data sovereignty has been supported by policy, with, for example, the European Union's General Data Protection (GDPR) Laws [1] and the Health Insurance Portability and Accountability Act (HIPAA) [6] ensuring people's rights to access, modify, erase, or move their data. Scholars have proposed various models of data governance, highlighting concepts such as dynamic consent [8, 18, 118], privacy-risk quantification [9], consent verification monitoring [94], and data cooperatives [43]. However, there have been documented challenges in implementing these models, including barriers to understanding how data is being used (even when attempts are made to be transparent) [92] and lack of compliance with or poor handling of GDPR requests [59].

In health, data sovereignty is uniquely characterized by the sensitive nature of data, as well as the potential benefit data-sharing can have in advancing health research. Prior studies have noted how people with Parkinson's have interest in using their data as well as concerns around how their data may be used by private companies for profit [55, 69]. More broadly, perceptions of data as sensitive or intimate can be dynamic, based on the insights they enable [30, 38, 69]. This has implications for researchers seeking to develop data-driven personal health interventions. Gómez Ortega et al. [41] offer the framework of Sensitive Data Donation to approach research. They propose that researchers involve participants in engaging with their data throughout a research study, from conception to analysis. In doing so, participants can bring experiential, emotional, and social context to their data [86]. Other studies, including with people with Parkinson's, also point to how research may only over time lead to useful findings, requiring more longitudinal plans for data reuse and reporting back findings to participants [55, 77, 110]. Other adaptations on the part of researchers may include proactively bringing up potential privacy issues with those donating their data [55, 69], learning to work with more heterogenous datasets to accommodate greater choice in data donation [39], and using data cooperatives or personalized data management interfaces to reduce the burden on individuals to manage their data [16, 43, 55]. Work in environmental biomonitoring also recommends reporting back results based on their certainty and actionability, encouraging actions when possible or further research when needed [54].

Looking at research within formal health settings, the possibility of enabling data sovereignty is potentially limited by the unique protocols of medical institutions and clinicians' perceptions of the impact that research results might have on patients. Compared to researchers in informal care settings, clinical researchers are particularly concerned with their "responsibility to protect participants from uncertain, perhaps poorly validated information" [25]. However, prior work stresses the need to prioritize data's personal utility alongside its clinical validity, as "a research result that lacks clear clinical utility may still have personal utility or meaning to a participant" [25]. Multiple studies speculate on the personal benefit of returning research results [29, 111], though the effect of doing so remains insufficiently tested. Cox et al. [28] explored the effect of returning clinical trial results for cancer patients and discuss that there is "some evidence to suggest that

receiving results can cause distress for a minority of individuals, however this does not appear to consistently translate into regret about receiving results". This highlights the need for our work to determine how people participating in clinical research view the effect of accessing data and how they want to use it.

2.3 Multiple Ontologies of Disease

To frame our work, we draw on the idea of multiple ontologies, particularly as put forth by philosopher Annemarie Mol. In *The Body Multiple*, Mol [78] defines an ontology as a "set of practices," and examines how differences in practices lead to disease being "done differently". Mol focuses on atherosclerosis, a condition in which substances build up in artery walls and may lead to blocked blood flow. She observes how patients, clinicians, surgeons, and pathologists develop distinct ontologies of atherosclerosis through their practices. For example, the reality of disease is studied and communicated in distinct ways—patients describe the pain that atherosclerosis causes to communicate their lived experiences, clinicians and surgeons feel pulsations in a patient's limbs to make care recommendations, and a pathologist examines an artery under a microscope to understand underlying biological mechanisms. Mol notes how despite these ontologies of disease being very different, they coexist in the same hospital, whether through the work of **coordination** to connect them, **distribution** to keep them separate, or **inclusion** to shape and influence one another. While they coexist, they still may be in tension, such as a patient valuing the entirety of their experiential knowledge compared to clinicians only asking about specific symptoms.

We use this concept of multiple ontologies of disease to understand how different ontologies of neurological conditions are practiced by different people, including participants, their family, clinicians, and researchers. This allows us to highlight how participants view the potential of using deep digital phenotyping data to help these ontologies coexist and sometimes work together. Prior work has drawn upon the notion of multiple ontologies to coordinate patient and clinician ontologies of disease during appointments through sensor-based tools [74]. In this work, we describe how patients view their ontologies of neurological conditions as different from other stakeholders', and how deep digital phenotyping tools can variously help with crossing or pushing boundaries, ultimately facilitating connection and inclusion of different ontologies.

3 METHODS

The goal of our study was to understand the motivations of participants in a deep digital phenotyping study to access their data, and what they saw as the perceived utility of this data.

3.1 Setting: Neurobooth

Neuroboothis a scalable platform capturing time-synchronized multi-modal human behavior in an outpatient Neurology clinic setting. Patients with an upcoming appointment with their neurologist are recruited to complete a 40-minute session in Neurobootheither before or after their clinical visit. The session is held in the Neuroboothbooth, which consists of a seat in front of a monitor that displays instructions for participants to follow. Participants can also take part in Neuroboothwhile sitting in their personal wheelchair. Before the session begins, researchers place five accelerometer devices on a participant's legs, torso, and wrists. During the session, participants perform eye movement, cognition, speech, and motor tasks while wearing these accelerometers. Participants are audio- and video- recorded as well, which is used to extract speech and eye tracking data. Through deep digital phenotyping, Neuroboothaims to precisely and sensitively measure key behaviors affected by neurodegenerative diseases and develop models to quantitatively predict disease progression over time.

3.2 Recruitment from Neurobooth

After participating in Neurobooth, patients filled out a survey asking if they would be interested in viewing a report of their data from the study and being contacted for a future study around such a report. Only patients who answered "yes" to both questions were reached out to for an interview. In the consent form and phone call briefing, patients were assured that their choice of whether to participate in the study would not affect their other medical care. All participants were compensated for their time with a USD 25 digital gift card. Our study was approved by our institution's Institutional Review Board.

3.3 Participants

We interviewed 12 patients with ataxias, Parkinson's disease, and multiple system atrophy who have participated in Neurobooth. Participants' ages ranged from 37 to 75. Participants were comprised of 9 females and 3 males. All participants identified as white. Participants were diagnosed 1 to 20 years ago. We sampled for a diverse severity of progression, as indicated by Patient-Reported Outcome Measure of Ataxia (PROM-Ataxia) [96], which captures patients' quality of life through Likert scale survey questions about their symptoms, care practices, and mental health. While PROM-Ataxia was designed for ataxia patients, all participants had completed the survey and had a PROM-Ataxia score. A higher PROM-Ataxia score, out of a maximum of 280, indicated that a patient had more physical and mental difficulties in their daily lives. In this study, we considered a PROM score of 90 to indicate high-severity progression. Four participants were low-severity, with PROM-Ataxia scores lower than 90, and eight participants were high-severity, with PROM-Ataxia scores higher than 90.

3.4 Procedure

To accommodate participants' accessibility needs, all interviews were conducted online on Zoom. Participants' most salient needs in the study were minimal movement, as many participants had limited mobility, and a quiet environment, as many participants had varying levels of slurred or altered speech. Each participant took part in an hour-long semi-structured interview with the first author or sometimes both the first and second authors. Interviews were audio- and video-recorded.

During the interviews, we spent the first portion getting to know the patient and understanding their preferences for how to discuss their condition. Then, we asked questions around three main themes. While our full interview guide is included in the appendix (Section 8), below is a summary of the three themes we asked participants about:

- **T1: Health history.** How has a patient understood their diagnosis? How has managing their condition changed throughout the progression of their disease?
- **T2: Data tracking.** How do patients track their condition or seek further information about it?
- **T3: Data speculation.** Do patients want to see their Neuroboothdata? How do patients want to interact with their Neuroboothdata? What are the foreseeable positive or negative implications in doing so?

In "Theme 3: Data speculation", we presented participants with the following hypothetical scenario to guide their speculation, inspired by participatory speculative design practices [32] and scenarios used to navigate value tensions [44]:

> Imagine that Neuroboothhas a new feature that can use the data it collects to answer any question you have about your condition. For example, you can view your data, understand your diagnosis, see changes in your condition over time, and compare your condition to others'.

Based on this scenario, we asked participants to share their gut reactions to the hypothetical tool, what use cases it might be most helpful for, and foreseeable positive or negative implications of the tool.

As we build on Mol's theory of ontologies, we note the methodological limitations of this speculative design study. Mol defines ontologies as "a set of practices" and observes these practices directly in a hospital setting. In our study, we observe practices *indirectly*, relying on participants to reflect on their past behavior and speculate on what they might do in the future. While both of these activities do not fully capture reality, we draw on patchwork ethnography [33, 42], which asks how "lives and commitments demand new ways of collecting data" and sees the limitations of some methods more as "openings for new insights" [42]. In the context of our study, our methods allowed us to accommodate our participants' mental and physical needs. Additionally, participants were able to seriously discuss their health- and clinical research- related experiences outside of a hospital setting and in the comfort of their own home. Nevertheless, we recognize additional methods to accessibly observe "practice" beyond traditional paradigms, such as those proposed by Chronic Illness Methodology [51].

3.5 Analysis

We used reflexive thematic analysis to make sense of our data [20, 22]. After familiarizing ourselves with the data, the first and second authors inductively open-coded the transcripts to capture the underlying needs and values of participants, such as the codes *"desire for positive external perception"* and *"need for control"*. Half of the transcripts were inductively open-coded twice. Then, the first author consolidated codes into higher-level themes, such as how participants' needs and values differed in their interactions with different stakeholders, and re-coded all of the transcripts to capture these patterns throughout the entire dataset. The first and second authors worked with the rest of the research team to merge multiple interpretations of participant quotes, as authors' held diverse patient-centered perspectives as medical providers, clinical researchers, and computer science researchers. The authors finalized themes around how data can be a form of communication between patients and 1) themselves, 2) other patients, 3) health providers, 4) family and friends, and 5) the research community. In contextualizing the findings within literature, we found that the notion of multiple ontologies helped highlight the motivations behind participants' desire to use data to mediate different relationships, leading to our findings structured around the utility of Neuroboothdata in helping ontologies co-exist.

4 FINDINGS

Our findings, summarized in Table 1, present the role of data in bridging different ontologies of neurological conditions practiced by participants and others they interact with, following Mol's [78] concept of multiple disease ontologies. We first highlight how participants' personal ontologies of their disease and its progression shape the value they see in accessing data in the first place, even if it is experimental. We then analyze how, in the process of caring for themselves, participants encounter different and sometimes conflicting ways that neurological conditions are understood by themselves and others. We describe patients' existing data practices aiming to bridge these ontologies, their shortcomings, and patients' speculations on how different representations of deep digital phenotyping data, such as individual-level, or population-level- results, could uniquely help different ontologies of neurological conditions coexist to improve well-being and care.

Theme	Overview
4.1 Future Outlooks Shape Perceived Utility of Data	Patients' disease outlooks, such as how deterministic they are about their condition, shape their engagement with data.
4.2 Understanding One's Condition through Data	Individual-level data can help patients concretely track their ambiguously-changing symptoms.
4.3 Communicating One's Condition to Others through Data	Individual-level data can help patients address misconceptions about their condition with clinicians, friends, and family.
4.4 Using Data to Learn About Disease Community	Population-level data can provide reliable and relevant insights about similar patients' progression and care practices.
4.5 Using Data to See Contributions to Clinical Research	Population-level data can show patients their contributions to clinical research and disease community.

Table 1. Overview of themes.

4.1 Future Outlooks Shape Perceived Utility of Data

As we speculated on data with our participants, they often shared their outlooks on the progression of their condition, which can be understood as a driving force of their personal ontologies of disease. Patients' acceptance of their condition affects their engagement with healthcare and their health outcomes [4, 26], and we find that acceptance also shapes engagement with data.

As a whole, our participants shared particular health behaviors. All participants took initiative in managing their condition through dedicated care practices, including exercise, physical and speech therapy, medication, and research on their condition more broadly. They all had participated in clinical research, indicating high health and data literacy. Half of them also had family members with the same genetic condition, giving them expectations for what late-stage progression and disease management might look like. However, perspectives on disease progression fell between two broad outlooks: 1) those who were non-deterministic and believed they could influence disease progression, and 2) those who were more deterministic and believed their progression was set in stone. Participants' disease perspectives were along various points of this spectrum.

P11, a former nurse, addressed the connection between future outlooks and data when asked whether she wanted access to data that may indicate decline. She hypothesized that other participants' emotional reactions to the tool might be rooted in their acceptance or fear of their future progression:

> *"[How you answer is] how you feel about life and death, you know? Is [my condition] going to kill me? Or will it impair me so much I don't want to be alive? Or, I think I can handle everything except this [indication of decline].".*

Participants with non-deterministic mindsets about their condition believed in the ability for their care practices to stop or slow progression—this is a perspective that was shared by most participants. For example, P11 wanted access to her data to proactively shape her physical therapy routine to slow the recent rapid progression of her slurred speech. P1, whose father also had ataxia, shared a notably optimistic outlook on the future of her condition and viewing data related to it, sharing that she was able to *"unlearn"* her father's idea that *"you can never reverse anything"* after seeing her own positive results in physical therapy. These participants had already tried accessing their

digital phenotyping data, as both P4 and P1 had asked researchers about this previously. They maintained interest in seeing such data despite understanding researchers' apprehension about how participants might interpret results on their own as signs of improvement or decline, prioritizing the value it would bring over their emotional reaction to it. P1 said she jokingly made a *"promise"* to researchers in the past that she would not make any *"wild assumptions"* about the results. P6 advocated for participants to own their data and be trusted with deciding how they wanted to engage with it:

> *"That information belongs to the patient. [...] I think that there are also people who can look very clear-eyed at the situation and say, this is what I want to know. Don't make me jump through hoops to get it. Don't tell me I can't."*

P8 similarly said that she would not want to be *"shielded"* or *"protected"* from her own data. P11 agreed, but emphasized the need for contextual and empathetic communication of results since the *"same number"* will mean *"something different to every person."*

Others with deterministic mindsets around progression displayed how data might be interpreted differently, as they showed less interest in tracking their condition generally and in viewing their digital phenotyping data in particular. One factor was how optimistic participants were about change. P5, a participant with ataxia who said multiple times that he was *"screwed"* based on his diagnosis, shared that he did not track his condition aside from medication intake. Relatedly, P5 would *"look at [data] if someone wants to show it to me, but I'm not in any way inclined to"* since *"it won't change anything"*. Another factor was how secure participants were in their care regardless of data. P12, a participant who has been managing ataxia for more than 20 years, tracked her condition but shared a similar disinterest in seeing her data—she felt *"secure"* in her understanding of her condition, stating that she *"already knows"* how she's going to progress. She shared that her faith helped her accept this view:

> *"My faith is very strong and it gives me somebody to yell at, it gives me somebody to cry to, gives me somebody to believe in. Every single time that something different either changes within my body or changes within my life, like this disease takes one more thing from me, one more ability from me, I feel like I have to go back and grieve every single thing [...] You have to give yourself the time, the space, and the process to say, yep, this is what's going to happen. And I'm going to get there, and I'm going to be okay, and I'm going to find joy on the way."*

These findings highlight the different realities shaped by practices around self-care and coping, and how these realities shape interest in data. Many participants noted that they knew other patients who would not be interested at all in the tools that could be produced from deep digital phenotyping data. In the rest of the findings, we share the perspectives of participants who were mostly interested in seeing their data, but procedures for sharing data with neurology patients more broadly must respect these diverse perspectives.

4.2 Understanding One's Condition through Data

Over time, participants' ontologies of their own condition varied greatly, which shaped their tracking practices from pre-diagnosis to the present day. They emphasized the validation that diagnosis brought, though the lack of definitive measures post-diagnosis made them depend on intuition and other people to understand themselves and make life changes. Participants engaged in personal tracking, such as documenting symptoms through notes and calendars, to coordinate their care with their experiential knowledge of their disease. However, we found this self-tracking was laborious and inconclusive, adding to prior work on the limits of self-tracking for people with neurological conditions due to their ambiguous symptoms and comorbidities [110, 115]. Given

these gaps in understanding their condition and self-tracking, participants imagined that viewing individual results from comprehensive deep digital phenotyping can provide validating measures post-diagnosis to support self-perception and care practices.

4.2.1 Using Data to Stabilize Self-perception. Across participants' disease histories, they had to continually update their understanding of their own abilities through personal and outside perspectives, attempting to coordinate ontologies of disease without sufficient tools to do so. While prior work focuses on self-tracking to manage conditions post-diagnosis [55, 110, 112], our participants highlighted the importance and difficulty of tracking symptoms pre-diagnosis, as they sought diagnosis for up to 35 years. During this time, their symptoms were only perceivable by themselves, leading many participants to document their experiences in order to make sense of incomprehensible symptoms. For example, P6 noted down any sudden unexplainable change to her body, whether it was a worsening cough or reduced sensation in her legs, starting in her late twenties. She continued to do so until her official diagnosis 35 years later. P5 noted the emotional difficulty of experiencing inexplicable change to his abilities when others could not perceive them, saying that initially it was *"something only I knew"*; prior work has studied this rare inner world that chronic disease creates [64]. To deal with this solitary experience, participants described documenting their symptoms in detail. P7 did research on the *"completely ambiguous"* and *"endless possibilities"* of what her condition might be. She remembered that she *"wrote down everything, because I didn't know what was going on."* Receiving a diagnosis helped participants focus on the right symptoms and care practices after years of doing research around many different diagnosis possibilities, as P4 said:

> *"I convinced myself that I had some terrible disease, not that Parkinson's is great, but I thought I had Lou Gehrig's disease. So I'm thinking, oh, yeah, I'm gonna die [...] [My doctor] did the standard tests and he said you have Parkinson's and I'm like, oh, thank goodness. So for me, it was like, okay, that's great. Now what do I do?"*

While diagnosis was a relief, it was the only point at which they received answers about their condition and an idea of what to expect in the future. P12 emphasized the labor she continued to have to do to understand herself post-diagnosis, as she *"lived in the library every day"*, *"to figure it out because no one's going to figure it out for you"*.

Participants saw potential for their individual results from deep digital phenotyping data to provide reassurance post-diagnosis in the face of ambiguously changing symptoms that are hard to track. This was especially relevant for participants with late-stage progression. As P6 put it, *"you don't even recognize your body anymore"*, reflecting past work on people with neurological conditions who are unable to identify changes in their symptoms [77]. P11 recounted a surprising fall she experienced recently: *"I fell down. I have no idea why. That's happened to me twice. Usually I know when I'm going to fall."* Other participants described the knowledge they were doing things *"too quickly"* (P5) and having to listen to their body when it told them *"slow down, you're doing too much"* (P9). Not being able to adapt to their changing abilities led to serious injury during mundane daily tasks. P5 experienced this when *"the door [...] didn't close entirely, so I spun around really quick to push it, and I went back and– timber!– I broke a collarbone."*

Similar to what has been reported in past self-tracking studies [112], participants tracked their symptoms through notes or calendars to keep up with their changing abilities. This data was often inconclusive or laborious to engage with, especially with the known difficulty of differentiating between neurological condition symptoms and comorbidities [110]. Falls were the events most often tracked by participants, but P7 noted that she only did so because that's *"every doctor's first question,"* displaying how clinical questions shape personal tracking. While participants attempted to make connections between their experiences, symptoms, and research, sometimes they would

frustratingly conclude that *"there's no rhyme or reason"* (P10) to what they were observing. In the midst of updating their perception of themselves and without conclusive data to depend on, participants largely based major life changes on intuition, such as P7 recently stopping to drive since she said it was *"too scary"* at night. Participants also depended on others' perceptions of their condition, as has been previously reported [47]. During appointments, P2 and P7 said they depended on their partners to share symptoms that they might have forgotten or not realized. During our interview, P5's partner interjected to remind him of a fall he had not mentioned to a researcher.

The comprehensive nature of deep digital phenotyping data allowed participants to imagine how such data could meet their symptom- and progression- specific needs around symptom tracking, giving them more agency in understanding their condition. Generally, participants were interested in using their individual results to make their perception of their condition *"grounded in reality"* (P4) and *"more real"* (P9), compared to depending on their intuition and outside perspectives. While personal health informatics focuses on presenting data that is *actionable* [111], some of our participants highlighted their desire to use data just to develop a "conceptual understanding" [110] of their condition without a desire to use it to inspire change. P3 sought quantitative measures of symptoms since *"the testing now seems so subjective"* and she has *"lost touch with what is normal"*. P6 noted that seeing any data around progression would be better than *"convincing myself that I'm doing okay"*. P7 saw data bringing a *"fresh perspective"* to her abilities, especially in regards to symptoms that strangers may notice before her or ones that *"I haven't accepted myself"*, such as her slurred speech: *"My speech pattern is getting worse, but the people close to me don't see it because it changes everyday. But the ones that I just meet, they can hear it right away."* Similar to P7's idea, other participants wanted objective measures around specific symptoms related to important or frequent actions in their day to day life. P6 wanted to ask the tool *"Am I still steady when I'm turning rapidly to the left or the right?"* and to be able to evaluate other motions she performs, like walking backwards, that can't be currently performed in Neurobooth. P3 wanted to tailor the tool's mouse-based task to the fact that she uses an iPad to help with her arthritis. P9 wanted to understand her reaction time through data, since she already tries to interpret the way her neurologist assesses her reaction time through tests that consist of having her hand follow his: *"when I have to follow [my neurologist's hand in clinic], [...] I notice one of my hands is not fast."*

Related to their self-perception, participants also recognized their *"denial"* (P6) of the support they might need, such as mobility aids, to avoid dependence on them [24, 27]. They imagined that deep digital phenotyping data could help them with accepting their condition and necessary life changes by showing them the reality of their abilities. In the midst of denial of their condition and using mobility aids, clinical credibility and support was key in acceptance. P6 said that she was once *"fooling herself"* when resisting becoming an *"old lady with a cane"*. She reflected that her health experiences have allowed her to accept the support she needed, saying that the *"greatest thing"* that her neurologist has done for her was help her get past the *"emotional aspect"* of using a cane, and imagined that viewing concrete individual deep digital phenotyping data around her health could similarly help her accept aspects of her condition. Multiple participants shared this sentiment, with P7 saying that viewing individual results that indicated decline could help her *"know something is wrong with me that I haven't accepted myself"*. The combination of improved self-perception and acceptance that deep digital phenotyping can deliver to participants may be able to inform proactive life changes, instead of participants depending on intuition and outside perspective to guide them.

4.2.2 Using Data to Explore Effects of Care. Sometimes, participants did find that data provided clear insights, especially when trying to understand how changes in care impacted their symptoms. For

these participants, tracking information beyond the body in order to contextualize their experiential knowledge was most important, as has been found previously [110]. This was most relevant for medication, exercise, and physical therapy. P8, for example, tracked her falls and her exercises on the same calendar, sharing that *"I'm making sure I'm exercising daily, it's a lot longer between falls"*, giving her positive feedback that her exercises were paying off. P2 tracked medication intake, though only noted down its effects when they were not positive in order to report it back to his doctor.

Participants imagined that objective individual results from deep digital phenotyping could similarly motivate their care. Past studies have found that analog self-tracking can be a strong source of self-motivation in disease management [112], and participants imagined that deep digital phenotyping could further accomplish that. P4 saw deep digital phenotyping data as being able to provide *"alarm bells"* for significant progression, which may indicate the need to change her care practices. For example, she wanted to know *"if there is something that is changing and I'm not noticing"* to tailor her physical therapy to that symptom. P2 agreed, saying that he would use results to know if he *"should be doing different exercises, such as more strengthening rather than cardio."* More generally, he just wanted to see his progression to have more understanding of the relationship between his care practices and symptoms, wanting to see whether *"things I'm doing are really making a difference or not."* Multiple participants saw data potentially providing gamified motivation, with P4 saying she would want to *"compete"* against herself. P1 added to this further, speculating that even seeing negative results from digital phenotyping might motivate her to beat her *"score"* during the next session. While we focus on participants' perspectives, their ideas that suggest gamification of research results entail considering how incorporating such ideas may also influence longitudinal data collection that aims to capture natural behavior.

4.3 Communicating One's Condition to Others through Data

While participants worked to understand their own conditions, they were subject to others' ontologies of their disease—including those of coworkers, managers, family, and doctors—that were based on misunderstanding. They reported having limited ways to bridge this understanding, such as showing dismissive doctors their self-tracked symptoms over time, pointing to opportunities for individual results from deep digital phenotyping data to add the reality of their disease to others' perception, supporting participants' self-advocacy.

4.3.1 Using Data to Address Misunderstandings From Coworkers and Family. Participants shared the ways that others misunderstood their conditions and their inability to communicate their ontologies of disease to those around them, leading them to imagine how deep digital phenotyping data may enable others' accurate and empathetic understanding of their symptoms. Others' misunderstandings often consisted of judgments of participants' cognitive abilities based on their physical symptoms. Multiple participants shared that they were asked whether they were *"drunk"* (P5, P9, P12) at work because of their worsening balance and slurred speech, an example of the stigma that people with neurological conditions are subject to [83]. P12 said that her boss *"brought me into the office to talk to me about my drinking"* when her walking symptoms got noticeably worse. This misunderstanding applied to family members as well. P9 recounted family associating slurred speech with worsening cognitive symptoms that led to P9 feeling abandoned and misunderstood: *"They don't understand our speech and our walking, but we're still there."* In the face of this misunderstanding, participants did not have approaches to explaining themselves, but instead just accepted that *"other people in my family don't understand"* (P7). P7 related this specifically to misunderstandings around what she is able to do: *"As far as they're concerned, ah, I saw her a year ago, she can do this. They don't realize a year later, I might not be able to now."* Given this,

participants saw deep digital phenotyping data as a way to address misunderstanding through an artifact that explains their condition with their individual results. P7 imagined that results that communicates the changes in her abilities might be helpful to communicate her decline to her family *"if it was in a simple enough language that I could explain it to people."* As health data is already largely inaccessible to participants without provider support [104], this requires continued exploration into how the complex data types generated from deep digital phenotyping can be made understandable considering varying health and data literacy levels.

4.3.2 Using Data for Self-Advocacy with Dismissive Doctors. Participants shared ways that their care teams had misunderstood them as well, putting labor on participants to advocate for themselves with providers who did not understand their condition before finding the *"right people"* (P5), including their current neurologist. Pre-diagnosis, participants described the tiring experience of talking to multiple dismissive providers who were *"not believing what patients are saying about themselves"* (P12). P6 described the experience of going from allergists to different clinicians regarding her ataxia symptoms as a *"40 year bread-crumb trail"*, leading her to meticulously track her symptoms through an ongoing document that she shared with the many providers who became part of her diagnosis journey. This misunderstanding continued even after diagnosis. P1 shared that during her initial diagnosis, her primary care provider had to *"go home and google"* ataxia, putting her in the position of having to educate her clinician—a challenge reported by other rare disease patients [47]. P12 had enough negative experiences such as these, saying that she *"pulled away from the medical side of things"* for two years, trusting her knowledge of her own body instead: *"I've always felt like I can listen to my body well, so I didn't keep up with health care."*

Considering the gaps in understanding that participants experience in their healthcare and participants' difficulty in addressing them, deep digital phenotyping data has the potential to produce artifacts for self-advocacy to help patients' multiple providers understand a patient's condition, especially since these data already exist in the clinical realm. In medical settings, P3 imagined using her individual results to be seen as a *"whole picture"* by her primary care doctor since *"'everything's not Parkinson's"*. Doing so would entail further exploration of how digital phenotyping data can be made accessible to people with differing medical knowledge, including providers from different practices and areas of expertise, as well as complement patients' goals in communicating their lived experiences to others.

4.4 Using Data to Learn About Disease Community

Participants sought to learn about other patients' ontologies of disease to supplement their knowledge about themselves, seeking to include other patients' ontologies in their own. Half of our participants had family members with the same condition, giving them an idea of what to expect in late progression and what disease management might look like. The other half was left looking for community and answers through in-person and online connection. However, participants were not sure how stories of others related to their own condition. Given this, participants thought that the large deep digital phenotyping datasets collected through their neurology clinic would contain verified population-level results from participants who shared their diagnosis. Participants saw population-level results as an opportunity to get credible, relevant advice from other Neuroboothparticipants who shared their condition.

4.4.1 Using Data to Find Relevant Care Practices of Other Patients. When faced with the difficult *"full-time job"* (P3) of navigating their condition, participants looked to others for advice. As P3 said, *"I often wonder [...] how do other people do this?"* While some participants had family members with the same condition to answer these questions, others had to turn to communities in-person and online. Compared to prior work that has focused on social support for chronic illness through

online communities such as Patients Like Me [118], participants pointed out how family members who shared their condition gave them built-in disease community and expectations around disease management. P12 shared that her sister who also has ataxia *"does experience a lot of the same stuff,"* giving P12 a dependable point of comparison. P9's twin sister who also has ataxia makes her experience *"easier"* since they can *"compare what we tried."* Participants without family members who have their same condition found disease community elsewhere. P8 described the positive experience of running support groups. P8 saw these groups as most beneficial for newly diagnosed members who *"present things they've gone through"* so *"everybody can figure what's going on"* together, emphasizing the value of "social sensemaking" [89].

Regardless of whether or not they had family members with the same condition, participants looked for other patients' stories in-person or online. They shared the helpfulness of reading others' experiences with disease, but also the difficulty in determining which stories were relevant to their own and the credibility of anecdotal stories. P1 shared that Facebook support groups *"have been really helpful to see people with the same diagnosis or similar ones at different stages."* However, access to these stories without an idea of how their own disease might follow suit could be overwhelming. P11, who lives in a care home for people with Parkinson's disease, shared that seeing others at later stages of progression is stressful:

> *"It's good to be in a place where they know Parkinson's, but it's not so good to be in a place where they are because you see what could happen to you. I see people walk around, shuffle in their walkers."*

P10 shared this sentiment when discussing her online research on others' experiences, saying that she usually could *"never know how far along they are"*, which would help her relate the stories to her own. P1 noted that even when she reads medication advice of people she can relate to, anecdotal experiences can vary widely: *"there's always people who are like 'that doesn't do anything' and people who are like 'it's a miracle.' "*

Given the difficulty of finding dependable advice from other patients online, participants wanted more credible advice, as has been shared by others with Parkinson's disease [55]. Participants thought that deep digital phenotyping data could help them find this advice through population-level results, as it collects comprehensive data from many other patients. P2, who depends on his doctor for *"credible conversation"* to tell him what works for other patients, imagined that seeing others' deep digital phenotyping data might make care advice more concrete beyond anecdotal stories online. Others specified that contextual information about other participants' disease would be especially helpful alongside quantitative measures of treatment effects. P2 and P10 wanted to see differences in progression based on other participants' varying treatment plans, such as medication or exercise routines, as well as the disease context of such participants, such as how far along in their progression other participants are. The combination of this information would allow participants to feel confident in the measures they were seeing and discern whether participants' experiences were relevant to their own, so that they could have more validated and relevant guidance on how to improve their own care.

4.4.2 Using Data to Contextualize Progression and Prepare for the Future. Participants also thought that population-level results from deep digital phenotyping data could help contextualize their progression in relation to others. On their own, participants were not sure of how they were doing, as described in Section 4.2 and in past work [77, 110]. As P6 put it, *"you can convince yourself of things both positive and negative. 'Am I getting better? Am I getting worse? Am I staying the same?' "* In this ambiguity, participants saw value in having *"somebody who was like me or similar to me that I could compare to"* (P4). Similar to preparing for the future with their own data, seeing data on others' progression could help them anticipate their own as well. P2 saw data as helping him learn

what is *"average for most people"* about his condition: *"as changes happen, I'd realize that it's part of the normal progression and not something different or new."* This concept of *"normal"* was especially relevant for late-stage participants (P6, P10, P11) who had experienced more rapid decline recently, as they wanted context on how fast their progression was compared to others at their stage.

Beyond understanding their current disease state and changing their care practices, participants wanted to use comparative data to prepare for the future proactively and accept their condition. They hypothesized that with comprehensive data on progression from multiple participants, they might be able to see predictions of their own progression based on participants with similar diagnoses and symptoms. P6 said that if clinicians have predictive data, they should share it with her, saying that *"I want to rely on my medical providers to be aware of the medical issues and [...] warn me of them if there's something that's coming up that they can see."* P10 compared this data to a cancer diagnosis, suggesting that this data would influence his care practices: *"with information, you can hopefully do something about it ."* P7 described predictive data as a *"magic ball"* that she would *"love to see."* However, P7 noted the tension between *"accepting and anticipating the reality of [my] condition,"* since data that reveals her future progression may also discourage her about the eventual worsening of her symptoms. P11, whose Parkinson's symptoms do not align with the most common ones, wanted comparative and predictive data to answer questions like *"What should I expect in terms of dexterity and speech? Does it typically progress like this? If it's atypical, am I getting worse faster, or is it a slow moving problem?"* P6 noted that the extent to which such data would be useful was unclear, as it would be difficult to *"live with your awareness of mortality every day."* Multiple participants who indicated interest in seeing this data noted that there was a foreseeable point at which they would not want to see predictive data, comparative data, or data that indicated decline, but they were not able to articulate such a point without seeing example data.

4.4.3 Resisting Comparison Based on Uniqueness of Condition. Even with the comprehensive nature of deep digital phenotyping data, multiple participants did not want to see comparisons of their data to that of other participants as they recognized the *" many different [...] versions"* (P8) of their disease, making other participants' data irrelevant to their own symptoms. P1, who informally compares her performance on digital phenotyping studies to her past sessions, noted that any comparison to another participant would be unhelpful given the nuance of neurological conditions, saying *"I doubt there's anyone else with the exact same type [of ataxia] that I have at the exact same point."* P12 was also disinterested in seeing other participants' data, but largely because she had done so in the past and felt secure enough in her understanding of her condition that she no longer needed to engage in comparison.

4.5 Using Data to See Contributions to Clinical Research

Beyond gaining knowledge about themselves and others, participants were also interested in learning more about the ontology of their disease formed by clinical research practices. Participants were motivated to participate in clinical research to benefit their disease community and already sought out ways to see the impact of their research involvement. They saw report-back of population-level results from digital phenotyping data as an opportunity to learn more about the clinical research community and their contributions to it.

Participants who participate in research are largely altruistically motivated by potential "benefit to others" [106], a sentiment participants in our study shared. Participants engaged in clinical research to care for their disease community in the long term, especially to *"find a cure"* (P10) alongside researchers and clinicians. P2 described participants, researchers, and clinicians as being on *"the same team"* asking the same *"huge questions."* P12 accepted that her contributions to

clinical research would largely be beneficial to future generations and not herself, saying that *"we're really just giving them information so that [...] hopefully they'll be able to do something for the next generation."* P6 shared this perspective, saying that her religious background that values the *"sanctity of the body"* helps her realize the importance of *"having this condition at a point in time where [my data] could be hugely helpful to researchers."*

Prior work has shown that people with neurological conditions who participate in research seek more reciprocity in their research experiences by seeing the impact of their participation [55], a sentiment our participants shared. Some participants were unsatisfied with reports of aggregated data from clinical research studies they had participated in previously, though most participants had not been given their research results in the past. Instead, they learned about broader clinical research, especially through official organizations such as the National Ataxia Foundation (P1, P5, P6) and the Michael J. Fox Foundation for Parkinson's Research (P4, P10, P11). P2 recognized that his work to understand clinical research is not sufficient on its own, leading him to discuss research generally with his doctor:

> *"I take with a grain of salt because I'm not a doctor, so I don't understand a lot of that stuff. So I rely on [my doctor] to kind of keep me up to date on what's the newest and latest. We've discussed the idea of deep brain stimulation and things like that."*

P10 similarly said that he likes to *"pick my doctor's brain"* and *"spew questions"* about research when he sees his neurologist. His own research results have rarely been returned to him, and when they have, they were *"nothing too memorable."* P2 had this experience as well, only given an option to view an online report of the findings of studies he's participated in. P3 saw results she's been given about past studies as unhelpful due to the nature of the study itself, showing how the value of results starts with study design: *"I feel like the study wasn't a good study to begin with [...] they were comparing 'how is it making me feel?' to 'did I want to pedal faster?' "*

Participants' interest in learning about clinical research, their dependence on clinicians to do so, and their own dissatisfaction with the research results they've gotten access to shows potential for population-level digital phenotyping data to help participants learn about the clinical research community and see their contributions to it. When discussing the value of deep digital phenotyping data, P2 was interested in research-focused insights, initially reacting to the hypothetical scenario by saying, *"I'm looking more for . . . are these [studies] making a difference [or] helping?"* P4 was similarly interested in knowing how the study would contribute to drug trials in the future. This speaks to participants' interest in seeing their data as evidence of contributions to clinical research and the disease community as a whole, leading them to want to see how the research team uses their data and what researchers might learn from it. Building on the value of reciprocity practiced in community-based participatory research [65], which calls us to ensure that research practices benefit participants as well, we see that communicating how individual participant digital phenotyping data is transformed and used can be interesting and validating for participants.

5 DISCUSSION

Aligning with Mol's description of disease ontologies as disease being "done differently", our findings highlight participants' practices to understand themselves and communicate with others about their condition. Participants revealed the shortcomings of available tracking methods to address these issues, and imagined the way that data could support relationships between different ontologies of disease, such as those conceptualized by care teams, coworkers, others in their disease community, and clinical researchers. Along these lines, Mol posited that disease ontologies could be **coordinated** to be "fused into a composite whole", or **distributed** so that "each variant has a site of its own" and could be used effectively by different people. We now discuss how the ontologies

we've uncovered may be coordinated to shape patient-driven clinical research practices such as study design and future questionnaire work. Then, we return to our second research question around patient priorities in data representation. We discuss the way we can distribute ontologies through data tools that enable multiplicity of interpretation by incorporating patients' experiential knowledge and mediating patients' relationships.

5.1 Coordinating Ontologies: Shaping Patient-Driven Clinical Research Practices

The deep digital phenotyping data collected through clinical research studies like Neuroboothsits in the unique intersection between clinicians, patients, and researchers, creating potential for such data to meaningfully address the combined needs of all three parties better. Mol [78] refers to this as **coordinating** disease ontologies, either through adding ontologies (combining ontologies that don't overlap) or calibrating them (helping overlapping ontologies influence one another). As clinical research practices are largely shaped by clinician and researcher interests, there is room for such practices to be more coordinated and calibrated with patient interests. To practice reciprocity [65] and data sovereignty [41], approaches to do so should be integrated throughout the life cycle of research to sustain investment and interaction between clinical research projects and the people participating in them, as described below.

5.1.1 Trusting Patients with their Research Data and Sharing Back Results Incrementally. In clinical research, data practices and study design are typically determined by researchers. Though participants generate the data that enables this research, they typically do not have access to their data or the learnings from it. This data is not shared back with participants due to researchers' apprehension about how complex data types should be represented, the manner in which results should be communicated to participants, the possibility of uncertain results being misinterpreted, or even how doing so may impact the scientific integrity of the study itself [25]. Our participants recognized these concerns themselves, but had varied reactions to the perceived utility of their data based on their personal outlooks on the future. While prior work has reached varied conclusions on the psychological effects of viewing clinical research results [28, 29, 111], many participants in our study who had non-deterministic outlooks on their condition were open to viewing results, even those indicating a decline in their abilities, since they valued the way that data might motivate their care practices or help them accept their disease above the emotional impact it might have. Other participants, specifically those with deterministic or secure mindsets, acknowledged that they might not want to see certain data, or their preference to not engage with it at all. These perspectives highlight participants' desires to be trusted to decide if they want access to their data, as well as with their interpretation of it. The current practice of holding off on sharing back results before determining the emotional and psychological effects of it prioritizes clinical interpretation of participant needs and might perpetuate clinical knowledge power asymmetry [103]. Allowing participants to decide whether they would like to see their data is a crucial step in understanding how to return research data ethically and give participants greater agency in research. Past studies that have shared back individual-level motion sensor data from hand motion sensors [74, 75] or gait sensors [19] have shown that such data could be validating and rewarding for patients. With the generation of increasingly detailed and comprehensive quantitative data in deep digital phenotyping, sharing back data can be incremental, whether in terms of individual- vs. population-level or type of symptom, to investigate the value of specific parts of the data. For example, some participants were interested in their data related to their balance, while others were more interested in understanding their slurred speech. Data related to patient interests can be prioritized as report back is explored.

5.1.2 Co-Designing Studies Alongside Patients. Sharing back data also entails making data useful for participants, which can be accomplished by aligning researcher and patient questions at the study design stage, as recommended by the Sensitive Data Donation framework [41]. This is also a way to practice the value of reciprocity suggested by community-based participatory research [63, 65], as desired by our participants and in prior work [55]. While past studies have explored making researcher-designed sensor data useful for patients [74], our study showed that participants were not interested in certain data if they thought the study itself was irrelevant to their experiences. In a workshop study on data governance with people with Parkinson's disease, Kulkarni et al. [55] advocated for reciprocity in research through "participant-driven data generation", possibly using data cooperatives that allow patients to voice their needs collectively [16, 43]. Using participatory design studies that have included people with Parkinson's Disease as a model [72], clinical researchers can consult patients proactively to understand how research questions and practices can fit participants' personal questions as well. For example, participants in our study wondered about how data could help them understand contextual movement that cannot be performed in the study booth, such as walking backwards or turning around. In conducting these participatory research practices, McNaney et al. [72] emphasize the need to avoid tokenistic inclusion and to allow for a range of contributions from participants who have different engagement levels. In clinical research, researchers can approach this by first incorporating questions around participants' interest in data into questionnaires already being conducted. Such questionnaires might be those on patient-reported outcome measures [96], or pre- and post- study feedback surveys that ask participants to reflect on their study experience. These touchpoints also create opportunity to continually solicit participant perspectives and dynamically inform study practices. In the long term, clinical research studies can benefit from structures such as data cooperatives, which may look like engaging patients as study partners or oversight groups, which is already being done for some clinical trials [10, 36, 62, 99].

5.1.3 Combining Patients' Experiential Knowledge with Quantitative Measurement. Digital phenotyping data has potential to complement patients' experiential knowledge, especially if the data collection is shaped by participant preferences, which can be useful for patients, researchers, and clinicians. Currently, there is a disconnect between how participants value their holistic experiential and bodily knowledge, and how clinical settings do not support the full interpretation of these experiences [115], a perspective shared by our participants. This was most salient when participants described doctors not taking their symptoms seriously or their frustration with clinician questions (e.g., about falls) that do not feel the most relevant to their daily experiences. At the same time, clinicians treating multiple sclerosis have suggested that gait sensor data would benefit from additional patient context, such as information about their daily life [97]. Outside of clinical experiences, the limits of self-tracking options have been found to limit patients' ability to investigate their own condition [82]. This becomes incredibly frustrating for people with neurological conditions when it becomes difficult for them to recognize their own bodies as their symptoms gradually change, as reported by participants in our study and in prior work [77, 110].

In the face of this, the movement data generated by motion and vision sensors presents an opportunity to "image the unseen" [102] in terms of participants' movement. Combined with their bodies as a source of knowledge [61], patients can "develop a 'materialized epistemology' that reunites sensual with ideational knowing" [117]—or, in Mol's [78] words, calibrate patient, clinical, and research ontologies of disease. During clinician-patient interactions, co-interpreting sensor data has been shown to be useful for actively reflecting on motor symptoms during clinic visits and taking the burden of reflection off of patients [74, 75]. These tools can be helpful for patients on their own as well, expanding the agency patients have over the perception of their

condition. For example, with access to deep digital phenotyping data, patients can have the option of which symptom to further quantitatively investigate, beyond commonly available data such as gait and tremor data or their own limited tracking. Visualizations of digital phenotyping data that replicate a participant's motion in a digital avatar, which have been created using data from patients with Parkinson's disease for clinicians to analyze [50], can serve our participants' desires to get another perspective on their movement. Participants' recognition of how quantitative measures can complement their perception also points to the potential of using this data to observe treatment effects in clinical trials, as researchers have suggested [84].

5.2 Distributing Ontologies: Designing Data Tools for Patient Context

Aside from being **coordinated**, ontologies of disease can be **distributed**, or made useful to different individuals, at different points of time, and in different contexts. The increased comprehensiveness and detail of deep digital phenotyping data is an opportunity to address gaps in personal and clinical tracking that have been observed by our participants and in past work. We now return to our second research question and discuss how different representations of digital phenotyping data—whether raw, summarized, individual-level, or population-level results—can be made relevant for various patient contexts, such as through enabling multiple interpretations based on patient priorities and mediating relationships.

5.2.1 Enabling Multiplicity in Interpretation of Digital Phenotyping Data. Deep digital phenotyping studies like Neuroboothenable collection of comprehensive data regarding cognitive, speech, visual, and motor abilities that can be used to serve diverse patient perspectives, as our participants described. Researchers have suggested moving away from systems that are meant for a singular interpretation and towards designing systems in which "multiple, potentially competing interpretations can fruitfully co-exist" [98]. Kaziunas et al. [52] applies this idea to technology for chronic disease and presents a "caring-through-data" lens that acknowledges "a wider range of human experiences between people, data, and technologies." Taken together, these ideas call for health tools to honor the multiplicity of patients' health experiences and perspectives, such as the way that our participants' future outlooks shaped the perceived utility of their data.

One way we can understand the multiplicity of patients' data needs is considering how they are shaped by time. Our participants described their changing tracking habits and desires based on their progression. They reflected on their increased need to track their condition pre-diagnosis, or their interest in seeing data regarding symptoms that have progressed rapidly at late-stage progression. Prior work has studied the temporal nature of health tools and how they can better integrate into patients' care [11]. In chronic disease, it is especially important to design tools that fit patients' changing needs during fluctuations in disease state [48, 83] and support self-care in their daily lives [83, 87]. Marcu et al. [67] identified a temporal spectrum of health information technology, ranging from tools that support time-critical short-term needs to those that support flexible long term services. Progressive neurological conditions would particularly benefit from technologies that fit on the flexible end of the spectrum, as such conditions progress slowly with less actionable events as compared to those observed in other neurological and chronic conditions, such as strokes or diabetes. This creates opportunity for integrating more interpretation and reflection into the management of neurodegenerative disease.

Given the temporality of health tools and the diversity of patient needs, we can consider how patients might want to see their digital phenotyping data at varying time points and at varying levels of interpretation. Participants speculated that each type of data representation (raw, summarized, individual-level, or population-level) has distinct value. They identified different ways they would like to engage with data on their own, and emphasized the value of understanding the data

without taking action based on it, contrary to the focus of health informatics work for chronic conditions [67, 91]. For example, while participants acknowledged the ambiguity of their symptoms, a finding shared in prior work [77, 110], the way they would like to view data to become aware of their symptoms changed based on their progression. Those earlier on in their progression desired more individual-level data and more interpretation or summarization of it to navigate their developing symptoms, while those later on in their condition wanted more raw individual-level data to track specific symptoms based on rapid progression or social perception of them. While some participants additionally wanted community-level data to motivate their care, many of them simply wanted to understand themselves to fill gaps in their perception, reflecting the awareness-oriented sensemaking of people with Parkinson's disease to build "conceptual understanding of disease" that Vafeiadou et al. [110] presents. This understanding can help prepare patients for the future, as our participants speculated that individual-level measurements of their decline can be used to aid them in accepting their condition, as prior work on self-tracking has also suggested [77]. This temporality of data desires is reflected throughout our findings, supporting the idea of designing for multiplicity through various representations of digital phenotyping data. To do so, we can take inspiration from past health studies in HCI—for example, representing raw movement data [74], summarized health statistic data [91], individual-level symptom tracking data [77], and population-level environmental exposure data [21]— and use these techniques to shape deep digital phenotyping data to dynamic patient needs.

5.2.2 Mediating Relationships with Others. While work in health informatics largely focuses on the patient-provider or patient-caregiver relationship, we expand the view of what kind of relationships data can mediate for patients. Prior work shows that tools surfacing patient values can create shared goals and improve patient relationships with providers [12, 13, 97] and care partners [14]. Our work identifies how deep digital phenotyping data can further serve patients' values in relationships other than those with their providers. There is especially potential to connect them to other patients through relevant and validated advice regarding the impact of treatment, in line with prior work that has identified patient needs for more credible care advice [55]. However, the introduction of data tools to such relationships will change the nature of them, highlighting the need to proactively study the ethics and dynamics of relationship-mediating tools with additional stakeholders. For example, prior work has found that introducing technology to relationships with care partners can place increased burden on them [100]. More broadly, when sharing data beyond the medical sector, researchers have emphasized the need for participants to maintain consent and awareness around how their data is being used [69]. Mediating relationships with digital phenotyping data requires further investigation into other individuals' ontologies of disease and how their priorities can better align with the participant needs we have uncovered here.

6 LIMITATIONS

We conducted an interview study with 12 neurology patients at a large medical institution. Our participants' perspectives do not represent their entire disease community, or those with chronic and progressive conditions in general. Additionally, as we recruited from an existing pool of patients already involved in clinical research, our participants were largely those who had high health and data literacy, dedicated involvement to engaging with their care, and financial resources to access high-quality care. As it has been shown that designing for privileged users can widen disparities in health outcomes [113], especially for older adults and people with disabilities, more work is needed to investigate the needs and perspectives of a diverse user group along various demographic variables and identities, such as income, ethnicity and race, or health and data literacy.

7 CONCLUSION

Amidst the increasing datafication of healthcare, deep digital phenotyping is being explored in clinical research to gather comprehensive data that can improve understanding of neurological conditions. However, participants currently do not have access to this data due to researchers' apprehension around whether such data is interpretable or useful. This study focused on patient perspectives on the potential of deep digital phenotyping data to benefit people with neurodegenerative diseases, such as ataxias, Parkinson's disease, and multiple system atrophy. We presented an interview study (n=12) to understand how people with these conditions currently track their symptoms and how they envision interacting with their deep digital phenotyping data. We described how participants envision the utility of this deep digital phenotyping data in relation to multiple stages of disease and diverse stakeholders, especially its potential to bridge different and sometimes conflicting understandings of their condition. Looking towards a future in which patients have increased agency over their data and can use it to inform their care, we contribute implications for shaping patient-driven clinical research practices and deep digital phenotyping tools that serve a multiplicity of patient needs.

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8 APPENDIX

Below is the interview guide researchers used for semi-structured interviews in this study.

8.1 Theme 1: Health history

First, I'd really like to understand your condition, how you've navigated it, and how you've managed it in the past. Please share to whatever extent you feel comfortable, and what you think would be important for me to understand during this conversation.

- Can you please tell me about your condition? How would you like me to understand your condition?
- When were you diagnosed? What was the process of understanding your diagnosis like?
- How were other people involved in helping you understand this diagnosis?
- How did you adapt your lifestyle to changes in your condition?
- How were other people involved in making these changes?
- What has changed over time in managing your condition?
- What is important for you to take care of now vs. at the start of your condition?
- What is important for you to understand about your condition regarding your day-to-day life?
- What are unanswered questions you have about your condition?
- How do you try to answer these questions?
- What motivates you to manage your health and overall wellbeing?
- What are your aspirations around managing your health?

8.2 Theme 2: Data practices

Thank you so much for sharing that with me! Now, I'd like to move on to talking about health data and information around your condition specifically. We are interested in talking about data such as blood pressure, falls, your day-to-day abilities, though we'd like to hear about whatever type of data is most interesting for you.

General questions

- Are you interested in tracking your condition? What inspires you to track your condition?
- What types of data or information do you track to understand your condition?
- Is there data you track during a clinician visit?
- Are there types of data or information that you seek online to help you understand your condition?
- Are there types of data that you are not interested in tracking?
- What is important to note as your condition changes? Is there another way you note those down, even if informally?

Collecting data

- How do you keep track of data or information that is important to you?
- What makes data "important"?
- What tools do you use to do this?
- Do you do this with another person? How do you work together to do that?

Integrating data:

- What do you do with your data once it is collected?
- What is immediately notable to you within this data?

Reflecting on data:

- How do you explore your data?

- What questions do you ask about data that you've collected?
- How do you use this data to answer those questions?
- Is there an aspect of the data that you would not like to engage with?

Acting on data:

- How does this data affect your understanding of your condition?
- How does this data affect your management of your condition?
- How does it affect your day-to-day?
- How does it affect your emotional state?

8.3 Theme 3: Data representation

Thank you for sharing all of that! I'd now like to move into the last part of our interview. Now, I'll be sharing a hypothetical scenario about a decision-making tool that we'll use as a basis for the next part of our conversation.

> *Imagine that Neuroboothhas a new feature that can use the data it collects about you to answer any question you have about your condition. For example, you can view your data, understand your diagnosis, see changes in your condition over time, and compare your condition to others'.*

- What is your gut reaction to this tool?
- Would you use this tool?
- What would the most helpful use of this tool be?
- What questions would you ask it?
- What might some positive implications of this tool be?
- What might some negative implications of this tool be?
- What would you add to this tool to amplify the positive implications?
- What would you add to this tool to protect against the negative implications?
- How would you like to use this tool with your doctor? Your family?
- What if this tool could tell you how your condition is progressing? Or how it might progress in the future?