"It's Better to be Grounded in Reality": a Speculative Exploration of Patient-Centered Digital Phenotyping for Neurological Conditions

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ABSTRACT

Digital phenotyping in clinical research provides objective measures when evaluating neurological conditions, such as ataxias and Parkinson's disease. While the clinical validity of digital phenotyping data is yet to be fully determined, individual research results are not reported back to participants due to 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. However, researchers are calling for individual results to be made available to participants, respecting participants' ownership of their quantified selves and improving transparency of research practices. To investigate how patients with progressive conditions might value seeing their data, we are conducting an interview study with neurology patients who have participated in digital phenotyping. We report initial findings from four participants, who expressed interest in using digital phenotyping data to 1) motivate their care, 2) make perception of their condition concrete, 3) reduce labor in tracking and communicating their condition, and 4) perceive their contributions to clinical research. This work points to exciting potential of patient-centered digital phenotyping to benefit patients' understanding of themselves, and push forward a paradigm of ethical data report-back.

CCS CONCEPTS

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

KEYWORDS

Digital phenotyping, neurology, mobility impairment, Ataxia, Parkinson's disease, ethics

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1 INTRODUCTION

In clinical research, digital phenotyping technology can capture differences in people's motor behavior that are imperceptible to the human eye [21, 28] using the "moment-by-moment quantification of the individual-level human phenotype in situ through the use of personal devices" [7]. Digital phenotyping has shown great promise for researchers and clinicians to objectively and accurately characterize neurological conditions [11, 29], such as ataxias [14, 22] and Parkinson's Disease [2, 24], that are currently subjectively, coarsely, and infrequently measured through clinicians' observations of patients' conditions according to clinical scales [10, 25]. However, in the context of clinical research data collection, individual results from digital phenotyping are often not reported back to patients who dedicate great time and effort to these studies, as research teams worry that viewing uncertain results may inadvertently mislead or discourage participants regarding their health [8]. Additionally, it remains unclear how complex digital phenotyping data should be represented and communicated with patients, as well as how sharing this data might affect future data collection time points in longitudinal studies. The ethics of sharing data with patients are even more complex for progressive health conditions, as the data is likely to show that a person's health is declining.

Despite these challenges, within and beyond clinical research, there is a call for an ethics-focused paradigm shift in whether and how individual research results are returned to participants. This call urges researchers to treat "data ownership as an extension of self-ownership" [16] by respecting participants' "right-to-know" [4], as well as improve transparency of the research process [6]. Additionally, the value of clinical research data has been defined as a combination of "analytic and clinical validity, clinical utility, and

personal utility" [6]. While clinical utility and validity of digital phenotyping in neurology research is still being determined [15, 20, 31], the personal utility of such data must be investigated simultaneously, especially considering the chronic and often progressive nature of these conditions. In digital phenotyping literature, the potential benefit of such data to patients themselves is often discussed but not fully tested [7, 30], though emerging consumer products already report digital phenotyping data such as daily resting tremor metrics to patients [1]. More broadly, digital phenotyping points to future ethical questions that are becoming increasingly timely as sensors proliferate in our pockets: Who should access and own our quantified selves? If disease progression can be predicted, how (if at all) should such information be communicated?

We are conducting a speculative design study with neurology patients with progressive movement disorders (but whose cognitive abilities are largely intact) to explore what value patients anticipate from interacting with their health data. Our participants have taken part in Neurobooth, a novel digital phenotyping study at Massachusetts General Hospital that quantifies impairment through various eye movement, speech, motor, and cognitive tasks [18]. Currently, participants do not have access to their data collected in this study while researchers determine the data's clinical validity and develop reports to succinctly convey useful information derived from complex time series data (e.g., [15]). Our interviews probed participants' current practices in tracking and understanding their conditions. We then asked them to speculate on how they would like to interact with their digital phenotyping data. We ask the following research questions:

RQ1: Data practices. What are patients' current practices in using data to understand their condition?

RQ2: Data representation. What implications do patients foresee in interacting with a representation of their digital phenotyping data?

In reporting initial findings, we contribute patients' priorities around interacting with digital phenotyping data for progressive conditions. Participants indicated interest in using data to 1) motivate their care with positive or negative results, 2) make their perception of their condition concrete 3) reduce labor in tracking and communicating their condition within their healthcare teams, and 4) perceive their contributions to clinical research. While we focus on neurological movement disorders in this study, our findings have implications for individual reporting of research results for digital phenotyping in clinical- and healthcare-related research more broadly.

2 RELATED WORK

The risks and benefits of digital phenotyping and personal quantification for chronic disease have been widely studied, largely on conditions such as diabetes that display frequent and actionable changes to a patient's state [23]. However, in regards to making digital phenotyping data collected in clinic available to participants, "little is known regarding the actual (versus potential and perceived) risks associated with returning individual research results" [6], much less for a progressive disease with limited treatment options. As this research is limited, we turn to related work on self-tracking for patients with neurological conditions to understand how patients already use data to inform their care and how patient-centered digital phenotyping tools can complement this. Mishra et al. [19] investigated the potential benefit of self-tracking for patients with Parkinson's disease and their care partners, finding that self-tracking of environmental, behavioral, and medical aspects of their life can promote positive coping strategies and disease management. Within this, participants noted their avoidance of acknowledging the decline in their condition. Additionally, they worried that their subjective documentation would misrepresent their changing abilities without objective metrics to support it, suggesting that subjective self-tracking alone may reinforce discouragement that deters patients from taking care of themselves. Another study on self-tracking for Parkinson's disease shared that patients found self-tracked data to have "a lack of perceived usefulness", as the data was often not actionable without their healthcare provider [26]. While these studies indicate that self-tracking alone is promising, they also showcase that it remains insufficient, highlighting how digital phenotyping data can supplement patients' understanding of their conditions.

3 METHODS

3.1 Participants and recruitment

So far, we have interviewed four neurology patients (3 female, 1 male) with ataxias or Parkinson's disease who are currently enrolled in a digital phenotyping study. Participants' average age was 59.5 (SD: 13.96, range: 37 - 73). All were diagnosed one to eight years ago. After participating in a digital phenotyping session through Neurobooth [18], 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. Patients who answered "yes" to both questions were reached out to for an interview. All participants were compensated for their time with a digital gift card. Our study methods were approved by the Institutional Review Board of Mass General Brigham under protocol number 2024P000692.

3.2 Procedure

Each participant took part in an hour-long interview on Zoom with two researchers present. Interviews were audio- and video-recorded. During the interviews, researchers asked questions around three main themes:

T1: Health history. How has a patient understood their diagnosis? How has managing their condition changed?

T2: Data tracking. How do patients track their condition or seek further information about it?

T3: Data speculation. How do patients want to interact with their digital phenotyping data? 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 [9] and scenarios used to navigate value tensions [12]:

> Imagine that Neurobooth has 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'.

3.3 Analysis

Using thematic analysis [3] and grounded theory [5], two researchers analyzed the transcripts and video recordings. All videos were open-coded twice, then the lead author consolidated codes into higher-level themes. The codebook included 61 codes in four categories: health history, tracking, speculation, and self-perception. The two researchers who performed analysis agreed on interpretation of participant quotes and the written findings.

4 FINDINGS

We now present initial findings, sorted into four main opportunities for patient-centered digital phenotyping projects.

4.1 Motivating care with positive or negative individual results

While researchers are often apprehensive around sharing results with participants, especially results that may indicate decline, patients we talked to were highly interested in seeing their data, whether positive or negative. This was likely shaped by patients' backgrounds as clinical research participants. Additionally, all participants had a family member or close friend with a similar diagnosis, giving them expectations around late-stage disease progression and management. They also shared high acceptance of the eventual decline of their conditions; P2 shared that he anticipates sharing his mother's Parkinson's symptoms during her decline, saying that *"we're all going to get to that point after a while, whether it's [...] 8 or 108."* Even so, all patients practiced proactive care, to try and slow progression and to maintain independence in their lives. P1, whose father also had ataxia, shared a notably optimistic outlook, 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. Overall, this participant pool represents patients with particularly high health literacy who are naturally more inclined to interact with digital phenotyping data, which likely differs from many other patients.

In regards to the ethics of sharing individual research results, all four patients agreed that they should have and would want access to their data. Patients reported seeking their own health data in the past and imagined that seeing it might motivate their care. Both P4 and P1 had asked researchers for access to their data before. They maintained interest in seeing such data despite understanding researchers' apprehension about how patients might interpret results on their own as signs of improvement or decline. P1 shared that she jokingly made a *"promise"* to researchers in the past that she would not make those conclusions. While thinking of helpful use cases for the data, P2 wanted to see a prediction of his progression and relative metrics within the patient population to anticipate adapting to changes. However, P1 and P4 explicitly did not want to see comparisons of their data to that of other patients. P1, who informally compares her performance on digital phenotyping studies to her past sessions, noted that any comparison to another patient would be unhelpful given the nuance of neurological conditions, saying *"I doubt there's anyone else with the exact same type that I have at the exact same point"*. P4 agreed, saying she would only 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, which may also influence longitudinal data collection. While these findings point to positive use cases of sharing data, P1 acknowledged apprehension around seeing negative results. For example, she would not like to know if she was *"the worst"* on a test, and surmised that her father who also had ataxia but was less accepting of treatment might not want to engage with the tool at all. These initial findings point to the diverse range of patient perspectives, and the need to design carefully to give different patients autonomy over engaging with their data.

4.2 Making perception concrete

No participants in our study practiced formal ways of tracking their conditions observed in other self-tracking studies on neurological conditions [26], such as journaling or using spreadsheets to track symptoms. Instead, participants emphasized the mental effort they put into evaluating key points of their condition. In recounting their diagnosis, each participant described a common life task becoming difficult as a turning point in their condition that led them to seek formal health support. For example, P1 shared the experience of no longer being able to walk in the heels she usually wore every day, while P3 highlighted her decreasing ability to do hands-on work with children as an occupational therapist. Post-diagnosis, lifestyle changes were still only made after patients experienced sudden and sometimes risky changes to their abilities, such as P3 freezing while playing tennis. Participants also depended on others' perceptions of their condition. During appointments, P2 reported depending on his wife to share symptoms that he might have forgotten or not realized. Patients' mental tracking was difficult while experiencing fluctuations in disease state, which P2 described as *"spells"* in which progression *"increases and then levels off, increases and levels off"*. P3 similarly noted variability in her progression, but also worried about inconsistency in her perception of it, as she may feel less able to exercise due to weather conditions like the winter cold and misattribute it to a change in her abilities.

Though these patients exhibited high levels of acceptance regarding the ambiguity of their progression, they still found value in making these perceptions of their conditions concrete. P1 used genetic testing as an example, saying that it was a *"good confirmation of what I already knew"*. P4 shared the difficulty in feeling sure about her symptoms without objective measures and anticipated that seeing data would make such feelings ***"grounded in reality"***. P3 similarly sought quantitative measures of symptoms since *"the testing now seems so subjective"* and she has *"lost touch with what is normal"*. Additionally, P2 was interested in using his data to serve as evidence to support lifestyle changes beyond anecdotal information online. P2 wanted to see differences in results based on patients' different treatment plans, such as medication or exercise routines, so that he could have more validated guidance on how to improve his own care. This patient feedback highlights how digital phenotyping data can give patients more structure around their

condition and potentially provide signs of decline before patients experience a related health risk.

4.3 Lowering labor around tracking and communicating data

The lack of formal tracking mentioned above was attributed to a lack of time, resources, and energy, which is in line with other research around self-tracking for chronic conditions [26]. As P4 put it, *"taking care of myself is a full-time job"*. For all participants, that job also entailed communicating with a provider who did not understand their condition before finding their neurologist. 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 [13]. P3 shared this sentiment, saying that *"I feel like I know more than my [primary care] doctor does"*. This is especially frustrating when P3 wants to be seen as a *"whole picture"*, as she does not expect her neurologist or primary care doctor to have the other's expertise.

Considering the labor required to track neurological conditions and the gaps in understanding that patients experience in their healthcare, returning individual research results to participants can alleviate the burden of tracking while also creating artifacts for their appointments that may help various medical providers understand their condition. 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 Understanding personal impact on clinical research

Notably, when discussing the potential value of digital phenotyping data, P2 was interested in benefits beyond individual personal value, initially reacting to the hypothetical scenario by saying, *"I'm looking more for . . . are these [studies] helping?"* This speaks to P2's interest in seeing his data as evidence of contributions to clinical research and the patient community as a whole. P2 described patients, researchers, and clinicians being on *"the same team"* asking the same *"huge questions"*, leading him to want to see how the research team uses his data and what they might learn from it. This builds on the value of reciprocity practiced in community-based participatory research [17]. P2's sentiment indicates that communicating how individual patient data is transformed and used throughout clinical research processes can be interesting and validating for participants of digital phenotyping projects, most of whom are altruistically motivated by potential "benefit to others" [27].

5 CONCLUSION AND FUTURE WORK

In working towards ethical data report back of individual research results, we begin to understand patients' visions of interacting with their data through four initial interviews with patients who have progressive neurological conditions and are already participating in digital phenotyping studies. These patients expressed interest in seeing their data despite uncertainty around its clinical validity. They also imagined concrete use cases for how this data can inform their care. While these insights suggest positive implications of patient-centered digital phenotyping for a subset of the population, our interviews only scratch the surface of what "ethical" digital phenotyping report back might look like more broadly. For example, patients' preferences for how data is communicated and acted upon may differ according to the severity of their progression, or their personal outlook on their condition. This study is still ongoing and our findings will likely evolve. We seek to further learn from differing perspectives, such as patients who are less interested in clinical research or whose progression is more severe. In doing so, we hope to create ethical data representation tools for digital phenotyping that can serve diverse patient perspectives.

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