Democratizing Data-Driven Healthcare

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The miniaturization of mobile and wearable devices has opened up new possibilities for continuous health monitoring. For instance, in the case of Parkinson's disease (PD), wearable sensors and mobile applications have enabled the tracking of motor fluctuations outside of traditional clinical settings. However, despite promising results, digital endpoints have been largely confined to the research arena and their real-world application is still limited. Our research in designing data-driven healthcare for PD is focused on three key aspects: data availability and clinical utility, agency and negotiation, and data minimization.

Data availability and clinical utility. There is a vast amount of studies showing the correlation between wearable device-derived metrics with PD clinical scales and disease staging. Still, these are mostly off-clinic controlled studies which leave the question: how is this data going to be presented to clinicians and how will it be useful? To bridge this gap, we designed Datapark, a platform for capturing and analyzing accelerometer data from clinical assessments and everyday activities [2]. Dashboards were co-created with multidisciplinary care teams, such as nurses, physiotherapists, speech therapists, and neurologists, and the platform was deployed in a tertiary care institution for five years. This embedded research project has enabled us to devise new goals together and share a mental model about the future of data-driven technologies, in part related to the following points.

Agency and negotiation. The traditional model of healthcare is highly transactional, with clinicians having full control over data collection and intervention. Unfortunately, adherence to long-term monitoring and intervention programs is often low, as patients do not always see the value in using monitoring devices in their day-to-day lives. However, many people already use devices that could be of potential interest for clinical care, which suggests that they are willing to record and share their data if they see value in doing so. To address this issue, we propose a paradigm shift where patients become holders of data that is meaningful to them. For example, a smartwatch with an app that tracks running can provide a variety of metrics related to fitness, such as kilometers, energy, and speed. This data can be made available to clinicians, who can analyze it from a different perspective, such as step variability and other promising gait micro-characteristics. By negotiating with the patient, clinicians can ask them to respond to a questionnaire after each run to provide additional context and insights. This patient-centered approach allows for a more personalized and meaningful way of collecting and using data. By empowering patients to take control of their health data, we can increase engagement and adherence to monitoring and intervention programs. With this paradigm shift, patients can become active participants in their care, and clinicians can use the data to provide more personalized and effective treatments.

Data minimization. Lastly, our work has also been focusing on data minimization and privacy. First, by giving more agency to people and control over their data, we will be reducing the amount of information that is left on shared repositories, hopefully making it more manageable and useful, while safeguarding users. Second, we have also been exploring, in the cue.band project, alternatives that restringe data collection to what users are interested in [1, 4]. An example would be a wearable that is streaming data into a buffer but only stores data (e.g., the last 30 seconds) when explicit input is given by the user. This would enable scenarios where users could report events and make data available (e.g., freezing of gait) after they have happened without having to have all their days stored. Third, we have been exploring approaches to intelligent systems that build on small data and value personalized information rather than large-scale datasets [3].

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