

Understanding Diverse Needs to Design Personalized Data-Driven Health Interfaces for People with Parkinson's Disease

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Data-driven digital medical devices (DMDs) are being developed to support patients in self-management [13] and in daily living with Parkinson's Disease (PD). Given that their use is closely entangled with the everyday life of patients, there is a need to include the perspective of various healthcare professionals (HCP) and people with PD (PwP) in the design and development of health interfaces [12, 13]. For co-design, various phases can be proposed (c.f. [7]), such as ideation and contextualization, conceptualization, prototyping, and evaluation.

A key challenge of co-designing DMDs and health interfaces in this context is the diversity of PwP, which is relevant for defining user requirements and for personalization. In the workshop, I aim to discuss possible user requirements and design decisions for a patient interface, namely an electronic diary. The diversity of user requirements could be around the experience and access to digital tools [14], digital competence and eHealth literacy [5], contextual/environmental factors [15], medical aspects like disease stage [10], preferences of control and privacy [15], interaction design [16], and others. Based on a range of user requirements, design decisions need to be taken. Interaction and communication design of a patient interface could be more or less agent-like [9], there could be digital, analogue and hybrid solutions, health information could be provided for various levels of eHealth literacy to ensure transparency and trust [15], fitting different contextual requirements, and ensuring various control and privacy preferences. As demonstrated in recent CHI research, co-designing personas with PwP can be effective for engagement in the design process, and to discuss diverse needs [11]. Personas might also be useful to identify early adopters [3]. For data-driven DMDs, personas could be also a starting point to identify characteristics for personalization.

Another relevant aspect to be discussed is an understanding of needs and design from a multidisciplinary research context. As discussed in previous Human-Computer Interaction (HCI) research, a joint definition and approach to target both clinical benefits (from HCP point of view) and user-centered requirements (from PwP and HCP point of view) is needed [3]. Further, there is certainly room to include other types of requirements in the future (e.g., related to financial and cost-related aspects). When designing dialogues (e.g., [1]) and language, patients often use colloquial language to describe symptoms rather than medical terms [17], which requires a negotiation and translation of patient-centered and clinician-centered point of views, e.g., through mapping requirements to data points. Prompting and engaging users requires conversation design [1]. Here, communication sciences could be of relevance [6], as well as experiences from Human-Agent Interaction or Human-Robot Interaction [4, 8, 15]. Studies can be then conducted in an exploratory way (e.g., to gather needs in an open-ended way), or as confirmatory research (e.g., to assess goals in a pre-defined manner) [2]. This needs to be defined carefully to design effective personalized health interfaces that fit clinical and everyday practices of diverse users.

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