

## POSTER ABSTRACT

# **A digital companion (eCARE-PD platform) for people living with Parkinson: A co-design study**

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Integrated care model for people living with Parkinson disease (PwP) offers the promise of meeting complex needs in a person-centred way that addresses fragmentation and improves quality of life. Digital health technologies could play a role in the development of integrated care models for PwP with the potential to improve communication with the health care team and support self-management practices in a personalized way. There is evidence indicating that digital health technologies can be effective or at least promising for supporting self-care in the context of an integrated care model for PwP. However, engaging PwP's, caregivers and health care professionals in the design of technologies which could provide personalized provision of tips and care resources to PwP's is crucial to ensure that tailored health communication generated by the technology meets their needs and expectations.

For this study, we used a co-design approach involving 4 main iterative phases: (1) preparation (2) mapping (3) test and use, and (4) co-production of solutions and final requirements. This approach used mixed methods (e.g. Participatory Design workshops, usability and acceptability survey, Design critique sessions) to directly engage people in the design of the technology. Purposive sampling was used to select participants for the study. Sampling criteria were developed in collaboration with the Parkinson clinic to ensure variation in terms of gender, stage of PD, age, time since diagnosis, living area (urban/rural).

The study allowed us to identify design principles to be integrated in the development of the eCARE-PD platform. These principles incorporate the expectations of future users, which were expressed during the iterative phases of the co-design process: (a) 6 Key design requirements based on users' needs and expectations (i.e. Customizable & flexible, meaningful, responsive & adaptable; informative & interactive, collaborative, tailored); (b) 6 main issues raised by the users during a test at home and key features for improving the design of the eCARE-PD platform, and (c) collective solutions to design an interactive, meaningful, tailored, empathic and socially acceptable technology. The results of the successive phases of the co-design process allow us to underline the progressive constitution of a technology defined over successive iterations as a digital companion supporting the self-care process at home and having the capacity to generate tailored digital health communication.

In this study, we demonstrate how the co-design approach allows the conditions for the social acceptability of this technology to be negotiated and progressively defined. In addition, personalized care is necessary to optimize care management models tailored to individual's needs involving digital health technologies. Our study underlines that a digital companion based on tailored digital health communication and enhanced by a recommender system (e.g., using a

Machine Learning algorithm) can help select tailored care tips, suggest personalized care plans that are most relevant to users.

As our results reveal, bringing the experience of PwP into the co-design process contribute to create a digital health technology that suggests the need to move toward a new way to tailor content for supporting self-care in the context of integrated care model for PwP.