

The PROfeel 2.0 App: Development in Codesign With Adolescents With Chronic Conditions and Fatigue Maartje Stutvoet, Elise van de Putte, Remco Veltkamp & Sanne Nijhof

Background: Severe fatigue is a common and potentially disabling symptom for adolescents with chronic conditions (e.g., auto-immune diseases, post-cancer treatment). A transdiagnostic method targeting universal mechanisms across disease groups is promising, whilst a personalised approach tailored to individual's needs is key. PROfeel combines both by providing individualised insight into fatigue-associated factors in a trajectory blending on- and offline care. Insight is obtained with repeated questionnaires (Experience Sampling Methodology (ESM)) via the smartphone-based PROfeel app. This leads to face-to-face shared decision making on personalised lifestyle recommendations. As a result, PROfeel can support adolescents with symptoms of persevering fatigue to regain control of their lives. Efficacy of PROfeel is being studied. Although adolescents with chronic conditions and fatigue evaluated the PROfeel trajectory as a whole as feasible and useful, in the design of the PROfeel app user preferences have not yet been taken into account. Leaning on the Double Diamond Model, this study describes the iterative discovery and defining steps taken, involving patients and clinicians as co-designers in the development of the PROfeel 2.0 app.

Methods: In semi-structured qualitative interviews with 1) adolescent users of PROfeel, 2) their important others and 3) health care professionals we evaluate the PROfeel trajectory and explore human facilitators and barriers for future implementation. Interviews are conducted from October '22 to February '23. In January '23, the potential of a persuasive gamified PROfeel was discussed amongst PROfeels target population in focus groups.

Findings: Health care professionals stressed the urgency of an approach to fatigue. Ease of use and time constraints were designated as potential barriers in the use of PROfeel. Recurrent themes in interviews with adolescent users of PROfeel were the difficulty with responding to ESM questionnaires on time and with implementing lifestyle recommendations. Most focus group participants saw gamification of the PROfeel app as a solution for both increasing adherence to ESM questionnaires and maintaining motivation for lifestyle change. The importance of personalisation was pointed out often. Younger participants (12-15 years) were interested in minigames, scores and themes, while older participants (16-18 years) were less interested in games and stressed the relevance of linking the app design to the primary motivation of usage of the app: regaining control of their life by gaining insight into fatigue.

Discussion: Showing feasibility was the first step in the development of PROfeel. Irrespective of efficacy, to adopt PROfeel in clinical practice, PROfeel should answer the needs of its users (i.e., adolescents and health care professionals). Qualitative studies are key to explore those needs. Translating the diverse needs (e.g., minigames vs. no minigames) into one app design remains a challenge. This challenge shows the necessity of continued patient participation as co-designers in subsequent development stages in order to develop and deliver a more engaging and motivating PROfeel 2.0 app.