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How to Retain Participants in User-Centered Design? Towards Recommendations for Minimizing Dropouts

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Abstract

Dropout and fatigue is present in most research projects. The present project Chronic Pain includes Fibromyalgia patients and applies a user-centered design approach. Surprisingly to the research group, two years into the project there is zero dropout. As a step towards designing a survey to investigate the patient adherence to the project, the characteristics of the user-centered design process are described in this paper.

Keywords:

User-Centered design, Chronic Pain, Patient Dropouts

Introduction

Dropout is a well-known phenomenon in almost every activity that aims to keep an intact group of individuals over a period [1]. User-centered design (UCD), a multidisciplinary approach based on active involvement of users to improve the understanding of user requirements [2], often relies on retaining users throughout a design process. Dropouts of participants can adversely affect the iterative design process. To replace dropouts, the project management will need to accommodate new members that need to be introduced to formal and informal group rules and catch up on the technological aspects of the process. Therefore, UCD-processes should be planned in a fashion that minimizes the risk of user dropouts. The present project Chronic Pain aims to create a tool for patient-reported outcomes measures in a mobile application requiring the maintenance of a group of participants to be retained for two years [3]. Expecting dropouts to occur over time, the project recruited a reserve pool of participants to replace initial participants as replacements. Due to the Covid-19 pandemic, remote workshops were implemented to allow the UCD-process to continue when physical meetings were no longer possible [4]. Surprisingly, the project has to date experienced no dropouts. A survey is planned to explore if the experience from this project can be transferred to other projects to reduce the risk of dropouts and investigate what factors contributed for the participants to remain in the project group. This paper presents the characteristics of the user-centred design process that might have contributed to the lower-than-expected dropout rate and proposes a way to measure it in the group.

Methods

The UCD procedure

The project employs an iterative UCD procedure designed for health technology development [5]. The procedure has several steps: mapping user needs and expectations, paper prototyping, digital mock-ups, prototype demonstration and user testing and feedback. Presently, the project is about to enter the user testing phase.

Participants

The participants were recruited from the local division of the Norwegian Fibromyalgia Association in Troms county, Norway. The association's members were invited to a seminar in March 2019 that included a presentation of the project, chronic pain lectures and discussion. At the end of the seminar, those interested in participating in the UCD-process were invited to sign a consent form. In total, 14 members volunteered to participate. Of these, six individuals were drawn using a random number generator (random.org) to be included in the initial UCD-group, keeping the rest of the patients in a reserve pool to replace dropouts. The included six participants were female with a mean age of 54 years (SD 8.25), mean time since diagnosed with Fibromyalgia 15.1 years (SD 10.25) and mean time since onset of pain was 27.8 years (SD 4.87). On a 0-10 numeric rating scale, the group on average self-reported their interest in technology as 6.6, while the technology skills were reported as 6.

The characteristics of the UCD process

To map the characteristics of the UCD-process, meetings were conducted in the multidisciplinary research team. The experiences and documentation from the process so far were shared and discussed, with an emphasis on separating between patient aspects (characteristics of the patients that cannot be manipulated by the UCD-process) and process-aspects (the parts of the process that can be manipulated by how the UCD-process is planned). The meetings resulted in a consensus-based set of characteristics that described the patient group and the UCD-process.

Results

Patient-aspects

1. Group homogeneity: The participants had a common health condition and were all recruited from the same patient organization. They were all female and the age variance in the group were relatively small.
2. Low research fatigue: On several occasions the patients have expressed their gratitude that someone finally is conducting research on Fibromyalgia.

Process-aspects

1. Dedicated time at the start to involve the patients in establishing group rules on how to resolve differences, absence and communication with the research team.
2. One dedicated resource person for group management, other than project lead. Low threshold for contacting the research team.
3. Sharing research results with the group, not only with the research community.
4. Visualising results on workshops, interactive if possible.
5. Rigorous note taking during workshops to be able to refer to suggestions and reflections later.
6. Social interaction between researchers and patients. All physical workshops are planned with a generous break where a fellow lunch is served.

Discussion

The described patient-aspects are outside the reach of direct manipulation by the researchers but may have contributed to the no dropouts rate in the project. Psychological group formation partially relies on the members identifying as being in a group [6]. The patients in the present project were already in a patient organization together, and this may have facilitated their ability to form a group. Furthermore, perceived benefits and low costs are assumed to reduce fatigue in research [7]. There are some indications that the patients are drawn from a population with low research fatigue, and the projects' ability to demonstrate progress to the patients is likely to maintain it at a low level. In order to investigate whether the process-aspects in the present project have contributed to eliminating dropouts, a patient-survey is planned. The process aspects can be formulated into functional statements, for example "Getting the latest research findings presented to me was important for me staying in the group". The degree to which the patients agree to the statements can be answered on a five point binary Likert scale [8]. A free text option will be available where the patients can share additional insights and experiences.

Conclusions

The results from the future survey will be incorporated into a set of recommendations for future UCD-processes that aim to minimize participant dropout.

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