

User-Centred Design of a Mobile Application for Chronic Pain Management

Berglind F. SMARADOTTIR^{a,b,1}, Asbjørn J. FAGERLUND^a
and Johan Gustav BELLIKA^a

^a*Norwegian Centre for E-health Research, University Hospital of North Norway, Tromsø, Norway*

^b*Department of Information and Communication Technology, University of Agder, Grimstad, Norway*

Abstract. Chronic pain patients constitute a large and heterogeneous patient group and it is important to build tools and methods that can identify efficient treatment options for each individual patient. It is estimated that 20-30% of the population has suffered from chronic pain and this imposes enormous costs on society and the national welfare programs. The research project *Chronic Pain* addresses the problem of how to provide patients and physicians with relevant, valid and adapted decision alternatives in a shared decision making tool. This paper presents the results from co-creation workshops early in the user-centred design process of the chronic pain mobile application. The end-users contributed in mapping the user needs and requirements, and made paper prototyping of the user interface. The main contribution lies on how a user-centred design methodology can be applied in a clinical development context.

Keywords. User-centred design, chronic pain management, mHealth, decision support, patient-reported outcomes

1. Introduction

Pain can be described as an unpleasant sensory and emotional experience associated with actual or potential tissue damage [1]. Pain lasting shorter than 12 weeks is defined as acute pain and more than 12 weeks as chronic pain [2]. The prevalence of having experienced chronic pain in Europe is estimated to be around 20%-30% [3][4]. Despite recent advances in empirical pain research, healthcare services are still lacking methods to effectively treat many chronic pain conditions [5]. Chronic pain patients can experience reduced quality of life and higher prevalence of depression [6] and this applies enormous costs on the society related to expenditures for wage replacement and welfare programmes [7]. The sustainability of the welfare state is threatened by the lack of cost-effective treatment options combined with the high prevalence of chronic pain [8]. In this context, the research project *Chronic Pain -Decision support for personalised chronic pain care* (2019-2021) addresses the problem of how to provide patients and physicians with relevant and valid decision alternatives in a shared decision making tool,

¹ Corresponding author, Berglind F. SMARADOTTIR, Department of Information and Communication Technology, Faculty of Engineering and Science, University of Agder, Jon Lilletuns vei 9, N-4879 Grimstad, Norway; E-mail: berglind.smaradottir@uia.no.

which also provides realistic probabilities for outcomes, side effects and adverse events. The specific sub-problem addressed in this project is the problem of getting access to patient-reported outcomes (PROMs) and experiences. The project applies a user-centred design process [9] and the outcome will be a patient data collection tool. This paper presents the results from an early project phase, where co-creation design workshops were made together with end-users. The research questions (RQs) stated were:

RQ1: *What are the user needs for a mobile decision support application for chronic pain patients and what elements are suggested for the user interface design?*

RQ2: *What are the benefits and constraints of involving end-users in the application development?*

2. Methods

The *Chronic Pain* project employs a user-centred design approach for the application development [9]. The project will be conducted in five phases: 1) design of the PROMs data collection application in close collaboration with end-user representatives 2) design of the data storage and computation environment, 3) technical development of the PROMs application, 4) building the data storage and computation environment and 5) usability testing together with end-users. The project is in an early phase, and this paper reports from the first phase, where co-creation design workshops were made together with participants from the Norwegian Fibromyalgia Association. The first contact point was an information meeting at the patient organisation, where 14 informants were recruited to contribute in the research project.

Two co-creation workshops were organised at the end of year 2019 and beginning of 2020 together with 5 informants, all female pain patients and with the average age of 52 years. In the first workshop, the informants were introduced to the project aims and the research team. They were informed about the user-centred design process and the expected commitment to the project. The informant's competence on personal devices such as smartphones and tablets were assessed by oral self-report and found to be sufficient for them to utilize the planned functionality. Additionally, a discussion was made of the practical use of activity trackers and how this kind of data could support the mobile application. The second workshop addressed the use of technology for management of chronic pain, the situation today and the performance of the mobile application in a future perspective- *what is needed to support the pain patient's situation?* For this purpose, post-it sticky notes were used, and the informants were asked to write user needs and how they expected the application to function. Afterwards, each participant presented their suggestions to the group. Paper prototypes were created for user interface design suggestions. The research team consisted of people with expertise in human factors in design, psychology, health science, statistics and medical informatics.

The data collection consisted of audio-recordings and annotations from the workshops, which had the average duration of approximately 3 hours. Qualitative methods were used to analyse and categorise the user needs and requirements for the PROMs data mobile application. The Privacy Officer at the University Hospital of North Norway approved the study with project number 02147. The participation in the study was voluntary and the informants signed a consent form.

3. Results

The results target the 1) user needs and functionality and 2) suggestions for the user interface design. The workshop participants agreed about the following functions: a virtual scale for measuring pain and stressed the importance of registering the feature of the pain: *ache, burning sensation, sharp stabbing pain or stiffness*. It was also underlined that pain is subjective regarding sensitivity and intensity. For the frequency of reporting pain, it was agreed on reporting 3 times a day: *morning, noon and evening*, each with an interval of 3 hours. An automatic notification or push notification was suggested 15 minutes before the end of the interval, possibly on a wearable and not only on the smartphone. The participants suggested a function for voice command for registering pain, like “*pain threshold 4*”, in addition to manually entering a score into the smartphone. There was a consensus about that reporting pain also on *good and painless* days was unproblematic.

It was addressed that mobile application had two different aims: individual adaption to the user’s needs and research purposes. For the individual user, the usefulness and ease of use are important factors to consider. The user must have access to own data and being able to view trends and historical data. The participants suggested registration of the following parameters: level of activeness, sleep quality, use of medication, nausea or headache and cognitive problems (*fibro-fog*). At the end of the day there should be a general registration on how the day was with symbols, energy level- what gives/takes energy (*fatigue*) and mental health regarding anxiety, mood and stress level. Regarding impacts on the pain sensation, the consumption of food and drinks and changes in the weather should be noted. A diary function was suggested with free text on actions and treatments. It was also proposed a digital reward such as badge, star or scorekeeping for consequent use of the application.

The participants made paper prototypes on large sheets, with suggestions of the user interface design and the preferred way of interacting with the application, see Figure 1. For all functions in the user interface, Norwegian language was required by the participants.

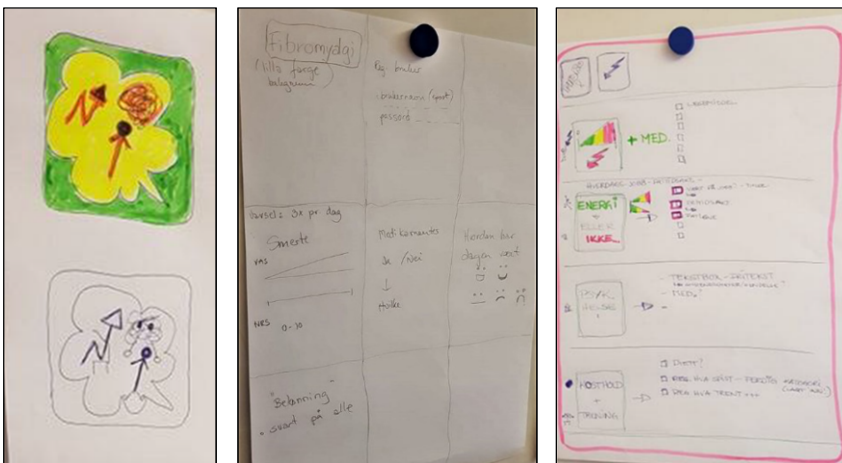


Figure 1. Suggestion for the logo of the application (left) and the functions of the application (middle and right).

4. Discussion

The main contribution of this paper lies on how a user-centred design methodology can be applied for the active contribution of the end-users in a clinical development context. The research questions (RQs) are answered based on the results. RQ1 asked about the user needs. The workshops, which were organised in an early project phase together with end-users, efficiently outlined the user needs and requirements for the application and the context of use, the method was inspired by [9]. The paper prototypes provided a good foundation for discussion, showing the functionalities and actions in a detailed way. Such visual representations are meaningful in user-centred design processes. The outcome of the workshop provided input for the following development phase, which is in progress. RQ2 asked about benefits and constraints of involving end-users. The benefit of involving real pain patients as end-users, is their first hand experiences and descriptions of the user needs. The end-users were considered as full project members, and their contribution aimed at increasing the quality of care, safety, self-management of pain and clinical outcomes for pain patients. The constraint is a time consuming procedure with multiple and long meetings, which might be physically painful for the participants, but adherence to the research project is important for the user-centred process. In addition, human factors experts need to be involved. This study has some limitations, such as a limited number of informants. However, the study participants meaningfully represented the user group of the application. Future research agenda targets continuation of the user-centred design process by conducting quarterly user workshops, and performing iterative user evaluations and deploying the application for an extensive effect study.

Acknowledgement

The authors thank the Norwegian Fibromyalgia Association for collaboration and for the contribution of the workshop participants. The *Chronic Pain* project is funded through the Northern Norway Regional Health Authority with Grants number HNF1463-19 and HNF1445-19.

References

- [1] Merskey H, Bogduk N, Classification of chronic pain, IASP Task Force on Taxonomy, International Association for the Study of Pain Press, Seattle, 2016.
- [2] British Pain Society, Useful definitions and glossary. [cited 2020 May 12]. Available from: <https://www.britishpainsociety.org/people-with-pain/useful-definitions-and-glossary/#pain>.
- [3] Rustøen T, Wahl AK, Hanestad BR, Lerdal A, Paul S, Miaskowski C, Prevalence and characteristics of chronic pain in the general Norwegian population, *Eur J Pain* 8 (2004), 555-565.
- [4] Breivik H, Collett B, Ventafridda V, Cohen R, Gallacher D, Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment, *Eur J Pain* 10 (2006), 287-287.
- [5] Knardahl S, Chronic Pain-are we doing it wrong? *Journal of the Norwegian Medical Association*. [cited 2020 May 12]. Available from: <http://tidsskriftet.no/2001/09/kronikk/kroniske-smertes-gjor-vi-alt-galt>
- [6] Bair MJ, Robinson RL, Katon W, Kroenke K, Depression and pain comorbidity: a literature review, *Arch Intern Med* 163 (2003), 2433-2445.
- [7] Loeser JD, Melzack R, Pain: an overview, *Lancet* 353 (1999), 1607-1609.
- [8] NACHEMSON A, Chronic pain—the end of the welfare state?, *Qual Life Res* 3 (1994), S11-S17.
- [9] Smaradottir BF, The steps of user-centered design in health information technology development, 2016 International Conference on Computational Science and Computational Intelligence, IEEE (2016), 116-121. [cited 2020 May 12]. Available from: <https://ieeexplore.ieee.org/document/7881322>.