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How to Design Successful Participatory Design Workshops for Digital Health Solutions?

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Abstract. Participatory design (PD) is increasingly used to support design and development of digital health solutions. The involves representatives of future user groups and experts to collect their needs and preferences and ensure easy to use and useful solutions. However, reflections and experiences with PD in designing digital health solutions are rarely reported. The objective of this paper is to collect those experiences including lessons learnt and moderator experiences, and to identify challenges. For this purpose, we conducted a multiple case study to explore the skill development process required to successfully design a solution in the three cases. From the results, we derived good practice guidelines to support designing successful PD workshops. They include adapting the workshop activities and material to the vulnerable participant group and considering their environment and previous experiences, planning sufficient time for preparation and supporting the activities with appropriate material. We conclude that PD workshop results are perceived as useful for designing digital health solutions, but careful design is very relevant.

Keywords. Participatory design, user-centered design, experiences, digital health intervention, user involvement

1. Introduction

Digital health interventions are increasingly developed using participatory design (PD) or user-centered design. These iterative design approaches place the individual in the center of the design; they differ in their central focus. User-centered design tries to understand the user, focusing on their needs and limitations. PD is "a process that includes the stakeholders in the early stages of design" [1], which increases their sense of ownership. PD is known to be effective in involving vulnerable user groups into the

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design process in a creative and reflective manner. Active participation allows them to concretely express their needs. In health informatics, this design approach becomes important since it is assumed to increase acceptance and usefulness of digital health solutions by end users. PD lends itself to user-centered design innovation and fits within the research field participatory health informatics (PHI) that provides resources and delivers tools supporting active participation, and focuses on individual-centered care, individual-centered self- management, and individual-centered decision making. PHI also assesses accessibility, usability, individuals' technology acceptance, experience, and satisfaction, tool appropriateness and quality [2]. While PD is becoming state of the art in developing digital health solutions, reflections and experiences with PD are rarely reported. The objective of this paper is to collect those experiences from three cases including lessons learnt and moderator experiences, and to identify challenges.

2. Methods

We conducted a multiple case study to explore the skill development process required to successfully design a solution involved in the three cases. Specifically, we aimed at obtaining a rich understanding of PD experiences. We considered three cases -of PD where we ask the moderators of the PD workshops to answer questions related to their experiences. The questions included aspects such as: challenges occurred, participant engagement, usefulness of the PD workshop results for the design / development of the digital health solution, time management, threats of the approach, and potentials for improvement. We selected three cases from health informatics in which the common point are the communication challenges with the participants that have to be handled in the design phase.

3. Experiences from three cases

3.1. PD workshop with people with intellectual disability

Several PD sessions involving people with mild to moderate intellectual disability were conducted in Valencia (Spain) within the MOVE-IT project aiming at exploring participants' perceptions, preferences, attitudes on the use of digital health solutions for physical activity promotion. Two psychologists, a physical activity expert, an occupational therapist, a physiotherapist, a logopedist, and two experts on PD designed the workshop and adapted activities to individual's skills and abilities. Several digital exergames prototypes were used as study cases to discuss usability, accessibility, personalization, gamification, and behavioral change techniques. Several canvas and accessible topic cards were designed to facilitate the discussions. 4 sessions of 70 minutes average duration were conducted in 2 occupational centers in Valencia. Three people with intellectual disability participated in each session (N=12) guided by a moderator. 2-3 members of the occupational center staff supported the moderators.

Participants appreciated to participate in the workshop and to give their opinions and preferences about a digital solution. The moderators paid special attention in trying to connect with participants from the beginning of the session to let the participants feel comfortable (e.g. by structuring the sessions similarly to others that were done regularly at the centers). Participants were engaged with the activities and liked to discuss

technological topics with the moderators. The support of the occupational center staff was extremely important to overcome communication challenges. The workshop results helped identifying relevant functionalities of the designed exergames.

The main obstacle was communicating with people with intellectual disability. Several abstract concepts such those related to behavioral change were discussed but were complex to understand by participants; providing examples of straightforward applications helped. It was sometimes unclear whether participants appropriately understood the abstract concepts or just said "yes", and it was challenging to promote deep discussion of a topic. Participants often focused on the specific characteristics of the given examples instead of the concepts. Due to cognitive fatigue, several participants easily lost their attention and it was difficult to keep them involved in the activities.

3.2. Data driven workshop

Process mining is a set of techniques to discover, analyze, and monitor a process (clinical processes, logistic analysis, patients' behaviors, etc.). Existing data from health information systems are analyzed and aggregated in dynamic visualizations. Using these technologies participatory workshops are conducted, called Interactive Process Mining Data Rodeos lasting from 30 minutes to 2 hours [3]. Experts in process mining (Process Miners), information technology staff of the institution (IT operators that are familiar with the data available in the Hospital Information System), and healthcare professionals or medical service managers are involved. The main objective is to co-create Interactive Process Indicators (IPIs) that will support domain experts in understanding the studied processes. During these sessions, the Process Miners coordinate an in vivo analysis of the processes using process mining techniques for understanding how the process is carried out, discovering actions performed, and their behaviors [4]. These techniques allow the Process Miners to select the best views representing the process (based on data provided by IT operators) that are understandable for domain experts.

To facilitate successful communication in these sessions, Process Miners must rapidly become familiar with the domain experts` terminology. They must also be familiar with the most important aspects of the study case (the process, the pathway(s), the key performance indicators, etc.). Keeping participants' interest and engagement highly depend on the Process Miners` skills. The first sessions are intended to make the domain experts aware of the process mining methodologies, and what they can expect from data rodeos. The moderator's task is to identify a general process that offers a rough overview of the process. This process will then be developed throughout subsequent sessions, leading to the co-design of a production-level indicator that might be used to analyze the process in actual daily practice. Co-design is essential for ensuring that domain experts truly understand and have trust in the final IPI. It is best to avoid delving too deeply into data curation in the initial stage. The IPIs' impact on the data quality allows for identifying data quality problems that may be caused by information system errors or process inaccuracies. This enables IT professionals to update data or address flaws in the hospital's health information systems. It also enables domain experts to understand the quality of data and how it influences the final indications.

3.3. PD workshop with persons at risk for suicide

As part of the SERO suicide prevention program a mobile app is developed to improve the self-management of suicidal individuals [5]. The concept of the app was developed

together with participant groups consisting of 8-10 participants (health professionals, persons at risk and their relatives) who provided requirements engineering and gave feedback. Methods used included brainstorming, mockup software (Figma), prototypes, usability tests. There was one iteration per functionality of the app that was provided as a minimal viable product for testing, evaluation, and feedback. In the three PD workshops, participants were split into two working groups with one moderator per group; the workshops were held online with a duration of 1 hour: 10 minutes common introduction; 40 minutes group work; 10 minutes presentation of the group works. The purpose of the workshops were collecting requirements, expectations, soft factors (colors, overall appearance, message to be carried, ...). The interaction between the participants was supported using Miro boards.

Participants had difficulties to become activated, in formulating ideas and to prioritize functionalities. The individual views on some of the project's objectives were completely divergent among participants. For the developers it was difficult to weigh the opinions of the participant groups engaged (e.g. range the input from professionals higher than those of affected persons).

The participants were very interested and found the workshops productive; it was the first time they participated in such a workshop. They extremely appreciated that they could contribute to the development of the app. The results from the workshop directly influenced the functionality and the design of the app. Design decisions were based on facts from a group of participants and not on mere opinions of individuals who had decision-making power. Threats of the approach are that the participants might not be diverse enough. To avoid influencing the participants with moderator opinions, the moderator only asked questions and dug into the details without taking a position. Care was taken to ensure that the questions asked could not be answered merely with yes or no, so that the people concerned could describe their thought processes. In addition, the underlying motivations of statements made were collected. The efficiency of the process could be improved, in particular the coordination of all involved parties.

4. Recommendations for successful PD workshops

The three cases demonstrated that PD workshops are very useful for design and development of digital health solutions, even when vulnerable groups are addressed. Given the nature of PD workshops, multiple different ideas can be collected. This leads to the problem that developers have to decide which input to consider since the input might be conflicting, or the budget is restricted and selections have to be made. For projects where applications are developed, it is possible to orientate on the specified project goals. Participants sometimes have unrealistic expectations. It is important to meet these expectations realistically and yet not to curb their enthusiasm. Good information, also about the course of the project and the results, is essential. Opposing opinions and statements from participants must be absorbed and processed. We derive the following recommendations for the workshop design: 1) Prepare for the terminology used by the participants when discussing technical concepts, 2) Adapt workshop to participants' skills and abilities: Guide discussions using carefully predefined topics, 3) Follow an iterative process (data rodeos), 4) Allocate sufficient time for preparation of the workshops.

So far, there is no comprehensive assessment available that studies the effect of joining PD workshops from a participant perspective. Our results show that participants highly appreciate the involvement. A careful preparation of PD workshops is essential

and very time consuming (roughly estimated approximately 5 times longer than the effective participatory phase). It is important to consider the peculiarities of the involved participants and create an environment that makes them feel comfortable. This can be achieved by building upon their experiences with other workshops or conducting the workshops in a well-known environment. Projects have problems in identifying a sufficient number of participants for PD workshops and even more complex, to find a diverse set of participants. An existing pool of the individuals willing to participate in PD workshops would make recruitment easier. A user group available throughout the entire project would be useful. Involving health professionals in PD workshops has to consider their time restrictions and flexibility is needed when other duties of the health professionals are ranked higher than participating in PD workshops. To ensure a positive "participant experience", we recommend giving them the opportunity to express their opinion, to simplify PD activities and adapt them to their abilities and skills and finally, create new technological solutions that can be relevant for them.
Engagement can be supported using: 1) Use of materials to facilitate the discussion (e.g., canvases, cards), 2) Use of study cases to contextualize the discussions (examples of exergames, features implemented in other solutions, etc.), 3) Use of interactive data visualization techniques to provide relevant information (provision and validation). A careful selection of supportive tools is essential to avoid accessibility and usability issues. When using IT, the participant`s digital literacy has to be taken into account.

5. Conclusions

Considering input from future users and experts in the field has potential to deliver solutions that are well adopted by the users and can support the healthcare treatment. The experiences from three case studies demonstrated this and there might be more successful examples. Given the feedback from the involved user groups, it might be interesting to assess, which effect the involvement has on their adherence and adoption. Do they change their behavior already as a reaction to the participation or do they adhere more to the developed solution? These and similar questions might be addressed in future. Another future research question could concern cultural differences and their impact on the success or challenges of user involvement and the impact of hierarchies among the participants (e.g., physicians of different hierarchy levels and nurses participating in a workshop).

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