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Experiences Using Patient and Public Involvement in Digital Health Research for Multiple Sclerosis

Tiia YRTTIAHO[a,1] , Minna ISOMURSU[a] and Guido GIUNTI[ab]
[a] *University of Oulu, Finland*
[b] *Delft University of Technology, Delft, The Netherlands*

Abstract. Patient and public involvement (PPI) is increasingly used for improving quality of the research. There are many barriers in translating PPI into practice, including lacking examples of good practices. Frameworks that have been developed in one setting do not readily transfer to other settings. In this paper, we examine the implementation of PPI in the context of a digital health research project that explores the design, development and use of mHealth for persons with Multiple Sclerosis taking an iterative user-centered design approach. **Methods**: Instrumental case study to describe the PPI process on a digital health research project. **Results**: Overall experience was positive. We found 3 roles for PPI involvement: strategic members; design and development partners; and expert members. Challenges lay on unclear PPI terminology; managing roles and expectations; and ensuring accessibility.

Keywords. patient and public involvement, Multiple sclerosis, digital health, mhealth

1. Introduction

The promise that delivering healthcare through mobile devices (mHealth) holds relies heavily on its adoption. One of the greater challenges that digital tools face is properly meeting the users' needs, failure to do so often results in misused or underutilized solutions [1,2]. There is evidence that involvement of users in the design and development of digital solutions increases the chances that the end result is valuable and meets the needs of the users [1,2]. There have been steps towards an active involvement of patients and other stakeholders in the design process of digital health solutions, but this is still not the norm [3]. The National Institute for Health Research has defined public involvement in research as "research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them", in which public includes patients, other people and organizations that use health and social care services [4]. Patient and public involvement (PPI) is an emerging approach to increase inclusiveness in health research. The use of PPI can improve research actions since researchers "don't know what they don't know" at the beginning of their projects. This is also the reason why no one knows

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[1] Corresponding author: Tiia Yrttiaho. University of Oulu. P.O. BOX 8000, FI-90014, Oulu, Finland. E-mail: tiia.yrttiaho@oulu.fi

beforehand how much more information is gained through PPI and therefore impact can seem unpredictable [5].

Patients and public have been involved many ways in different stages of research[6]. Crocker et al's [7] meta-analysis found that PPI interventions increased the odds of participant enrolment in clinical trials, especially if people involved had lived experience of the condition that was studied. PPI is a known concept especially in UK where it's also requirement for public research funding; this practice is becoming common in other parts of Europe like the Netherlands and Scandinavian countries [8].

There are many barriers in translating PPI policy into practice, including lacking examples of good practice [8]. Frameworks that have been developed in one setting do not readily transfer to other settings: there is a risk of tokenism and neglecting democratic values [6]. Successful involvement is built on equal partnership, where everyone is acknowledged, rewarded and valued [9].

Multiple Sclerosis (MS) is one of the world's most common neurologic disorders of the young adults leading to severe disability [10], and it requires significant active support. There are cases of pwMS involvement for digital health before where it has improved the quality of the research and lead to impactful changes [11,12]. In this paper, we examine the implementation of PPI in a context of a digital health research project called More Stamina. The project explores the design, development and use of mHealth for persons with Multiple Sclerosis (pwMS) taking a iterative user-centered design approach [13].

2. Methods

In this paper, we use the More Stamina project as an instrumental case study, to describe our PPI process and, based on our experiences, provide insights to better guide the use of PPI in MS mHealth projects.

More Stamina is a Research to Business project of the University of Oulu, funded by Business Finland. The team behind it is multidisciplinary, composed of physicians, psychologists, software engineers, interaction designers, information systems specialists, business developers and others.

3. Results

3.1. Patient Roles

Throughout the project, we examined how we could involve patients in all activities and phases. Through this process, the following 3 roles emerged:

- **Strategic members**. A pwMS sits on the project steering group, participating in strategic planning and decision making.
- Design and development partners. Two pwMS worked in design and development activities as members of the project team.
- Expert members. Specific roles which required professional skills involved pwMS. E.g., a User Research Professional who is a pwMS participated in interview data analysis.

3.2. PPI Process

We started PPI in this research without prior experience of PPI. Our first actual PPI activity was a test to explore possibilities of patient involvement through a pilot interview using our **strategic member**. In this session they let us know that the length was too much for them and it raised our awareness, prompting further work on this PPI line. The process began with a planning workshop among the research team, where we familiarized ourselves with the principles of PPI and discussed how it could be integrated as an essential element in our project. We nominated a person to be responsible of PPI activities and to act as contact point. Internally, we established PPI guiding principles and discussed how would we approach potential "patient representatives", what kind of reimbursement model should we use, how should PPI activities be designed, etc. A specific PPI budget and hourly fees were settled as per patient association guidelines.

We approached pwMS through a local MS association, which already had an appointed patient representative. We were able to connect with other pwMS who had prior experience working as patient representatives and they were invited to join the project. A second patient representative was found through the first's extended network. A total of 2 patient representatives were recruited as **design and development partners**.

We designed an onboarding process where the first meeting was reserved for mutual learning and getting to know each other. The research team presented the project scope, previous research and our partner institutions; pwMS gave us context on their history with MS. We used this meeting to inquire the patient representatives about their preferences and validate types of tasks. To reduce the risk of overburdening, an initial estimation of PPI activities was agreed: monthly meetings, with a maximum session length of 2 hours. There was also a clear preference of keeping online sessions short and leave more time for face-to-face encounters. PPI activities were determined to consist of hands-on workshops and occasional consultation. COVID-19 restrictions played a role so some in-person sessions had to be rescheduled as online meetings. In order to keep our patient representatives up to date when no active tasks were required, they were added to project's monthly newsletter and internal mailing list.

In-person meeting were held in the premises of University of Oulu, as it has accessible entries, toilets, parking, and good public transport. It was checked beforehand that meeting rooms were accessible, and we mapped unobstructed routes so we could guide them. This map was sent to patient representatives before each meeting.

In the 5 months that patient representatives have been involved in our project, we have consulted them on several instances. For example, in a task about mapping the MS patient journey through qualitative interviews to healthcare professionals and pwMS. **Design and development partners** went over the preliminary materials to be used in research, the pwMS recruitment plan, and the creation of the More Stamina tutorials that would be beneficial to participants in our research. Later, a pwMS acted as **expert member**, going over the collected data and providing insights.

3.3. Challenges in PPI for Digital Health Research

3.3.1. Unclear Terminology

Early in our process it became clear that different terms have been used interchangeably although they are not such similar concepts: consumer involvement, patient engagement or co-production. It was often difficult for pwMS to differentiate between PPI and traditional design activities, such as usability testing. Terminology got further complicated because of the multilingual nature of the team and how PPI terminology differs between languages.

3.3.2. Roles and Expectations

Even though in our project we tried to be clear and open with the patient representatives, it still left us moments of confusion. It has been a challenge to inform our patient representatives and keep their roles and expectations clear, while at the same time avoid confusing them with unnecessary information.

The PPI process has been new to our team, so roles also have been defined as we have worked together. Our main role in PPI has been supporting and empowering patient representatives and creating collaborative atmosphere so they are able to contribute. We have been listening to their hopes and asked for feedback.

3.3.3. Accessibility

MS-disease can cause changes in motor and cognitive functions, and it can also cause disabling fatigue. Keeping this in mind, we invested extra time in removing accessibility barriers (e.g., ensuring wheelchair access and considering session length). Accessibility is more than just accommodating for physical limitations. In our case, not only information had to be accessible, but also technology. Any use of digital tools during remote sessions took extra planning to minimize the burden a tutorial could become.

4. Discussion

Successful PPI lies deeply on a shared understanding and power balance [9,14]. It is important to generate an atmosphere of equality among the team, which may not be easy to accomplish, as healthcare contexts carry inherent power-asymmetries. This is something that in digital health projects can be compounded with the added potential disadvantage of digital literacy. PPI literature indicates how remuneration is useful not only as means of compensation, but also to even out possible power difference between patient representatives and the rest of the research team [6].

Terminology issues might be slowing the spread of PPI good practices. NIHR remarks that involvement, engagement and participation are used interchangeably and gives them definition that differs from involvement [4]. Biddle et al [8] also noted that there was inconsistency in terms and purpose of PPI.

Unclear information and lack of preparation has been reported to impair patient representatives ability to contribute [15]. Our information had to be understandable also for people without healthcare or research background, so it was important avoid professional jargon and too technical language [14].

The literature highlights the importance of clarifying the expected types of tasks and time commitment [14]. Clarity of roles is considered important in PPI [14], yet it seems to be still a common issue [14,15]. Active involvement in research activities can be a burden for patient representatives [15], and this was even more sensitive for MS [12]. It was interesting to observe that pwMS were very skilled in estimating how much time they would be able to contribute. When this was clearly agreed, they felt it was a fair situation.

A common complaint of PPI in research is that it takes more time [15]. Setting up a project's PPI process certainly requires time, knowledge, and resources. However, we think that using this time early in the process was beneficial by giving us a better understanding of needs and the potential value of the solution.

5. Conclusions

Our positive experience is aligned with previous literature. Valuable insight was gained from PPI that guided research actions. Even in situations where our patient representatives had nothing to add, it helped in validating our approach. The process clarified the use of PPI, which will make further PPI actions more efficient in the future.

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