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Involving Patients into the LifeChamps Project: Preliminary Findings

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Abstract. Patient involvement in research has been highlighted as a major requirement for the development of products and services that cover actual patients' needs. However, there has not been an agreement on a commonly used standard for patient involvement in research, at least not in the EU, partially because of lack of common terminology and implementation methodology. Within the standardization activities of "LifeChamps: A Collective Intelligent Platform To Support Cancer Champions", this qualitative study was developed to discover patients' views for their engagement in research. This is an ongoing qualitative study of semi-structured interviews of cancer survivors aged over 65 years of age, exiting the feasibility studies of the LifeChamps project in Stockholm and Thessaloniki. Findings from the thematic analysis of this study are expected to indicate requirements for involvement of patients in research studies as participants.

Keywords. Shared decision making, patient involvement, public Involvement, patient centered care, research design, interviews, patient involvement standard

1. Introduction

Providing person centered care (PCC) is a growing imperative across health care. In 2020 a new standard was released aiming to provide the minimum requirements for person-centered care, in patient involvement in health care [1]. The main component of person-centered care is the shared decision making and the partnership between patients, their families and carers, and health professionals. The standard was initiated and led by University of Gothenburg and was examined for its applicability during the LifeChamps research and innovation project [2].

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As digital technologies around health and well-being are advancing, they create potential new healthcare service offerings for patients. Co-designing the development and implementation of such solutions together with patients in iterative processes would allow researchers and developers to ensure that they tackle actual patient needs aptly and efficiently [3]. In LifeChamps (https://lifechamps.eu/) we sought to assess patient and public involvement in the organizational level of the study but also on a patient level. Several standards exist to introduce specifications and requirements of involving patients into research, such as the UK standard for public involvement in research [4], however to our knowledge, not on a European level. Our aim was therefore to elicit requirements of patient involvement (i.e., on the organisational level and public space) into research & development (R&D) projects that aim to design healthcare solutions and products in the European context.

2. Methods

A validated instrument 'Patient Engagement in Research Scale' (PEIRS) was identified and guided the design of the interviews in the study to fit the aim of the project [5]. PEIRS was originally developed as a 37-item questionnaire based on a mixed quantitative and qualitative study in Canada by Hamilton CB et al, that generated the PEIRS framework of meaningful patient participation in research [6]. Based on the PEIRS framework two researchers from Sweden - Karolinska Institutet and Academic Primary Health Care Centre in Region Stockholm - and two from Greece - Aristotle University of Thessaloniki generated open ended questions in English (Table 1) for semi-structured interviews with study participants of the LifeChamps project. The questions were later piloted and re-assessed with two additional researchers, and two clinicians. The questions were translated to Greek and Swedish.

Patients that participated in the preliminary data collection study and feasibility study of the LifeChamps project in Thessaloniki, Greece and Stockholm, Sweden were invited for phone interviews via Teams. Ethical approval was acquired from both Swedish (Registration No. 2022-00562-01) and Greek (Registration No. 267203/2022) pilot sites. The patients consented to participate.

The aim was to collect personal feedback from the patients that can be thematically analyzed into requirements for involving patients into research projects. The qualitative thematic analysis of the interviews is being performed with an inductive approach [7]. First, recordings were transcribed verbatim and the transcripts were sent to the participants for proofing. Data are being reviewed independently by two authors (E.K. & E.R.), for the initial pattern identification. The authors then will iteratively develop and apply initial codes to the transcribed data. Last, the authors will combine these codes to identify themes and sub-themes emerging from the data. All authors will review, name, and define themes, and sub-themes according to an iterative process until consensus is reached. Representative quotes will be selected to highlight themes and sub-themes.

Table 1. List of questions and helping questions of the semi-structured interviews in English.

Main questions	Helping questions
1.Please describe how would you understand your participation into the LifeChamps project, for example in activities such as providing feedback for the mobile app?	a) Could you please describe step by step your involvement into the project?
2. Where there any challenges did you face in the previous examples of your participation? Example, lack of guidance, difficulty in the communication, for instance in communicating the task, something that you remember as challenging.	a) Previously, you described all these steps of your involvement. Was it something that you considered challenging in particular to these challenges? b) This could refer to workshops you were invited, did you feel heard? c)How about the process of using the sensors at home, did you have any challenges? d)How would you describe your workload?
3. Please describe your experience of communicating with the research team of LifeChamps.	
4. Can you describe what kind of support, or supporting material did you describe from the project?	a) By support, we mean your experience with training materials, readings, research team members answering your questions and guiding you through the tasks.
5. Can you describe the ways you were ethically or materially rewarded for your contributions to the LifeChamps project?	a) What would you have liked, in order to feel valued for your contribution?
6. Please describe the benefits you received from your contribution to the research project, for yourself. Please describe the benefits you received from your contribution to the research project for the public and the society.	
7. If you were invited to contribute to another project in future, would you like to do anything different? anything additional? (additional, maybe you would like to be more part of the research team, meet the team, receive updates from the research project, select your tasks?)	

3. Results

Seven patients from the Swedish pilot (4 men and 3 women) and four patients from the Greek pilot (2 men and 2 women) were invited to participate in the interviews. Four patients from the Swedish pilot (mean age 77.5), and four patients from the Greek pilot (mean age 68.25) accepted to participate and interview data were collected.

Anticipated results from the thematic analysis include themes similar to the PEIRS framework. That could be an indicator of applicability of the framework in the European population, although this is expected since the questions of the semi structured interviews were generated from PEIRS. The identification of new themes is also anticipated; it would be interesting to examine if they overlap with themes in Standards for patient involvement such as the European Standard for Patient Involvement in health care, minimum requirements for person-centered care, developed by the University of Gothenburg [8].

Preliminary results cannot be generated at this phase of the study since the thematic analysis is ongoing and results from patients from the feasibility study that agreed to participate in the interviews are being expected.

Feedback from the interviewees indicates an overall patient satisfaction in participating in research. However, patients perceived technical challenges as a barrier to their contribution. The majority of the patients discussed that they would be willing to be involved in future research projects. Future studies will specifically elaborate on our results following a thematic analysis.

4. Discussion

Qualitative data from this study could assist ongoing research on the development of standards for patient and public involvement in research. There is no commonly accepted standard being used so far within the EU and ongoing efforts from other academic groups such as the University of Gothenburg [8] could be assisted from the insights of this study. Moreover, the results of this study can contribute to research studies that seek to differentiate patient involvement in research as partners and as participants. As highlighted by Kristin Liabo et al., there is still confusion in research regarding patient involvement as partners and as data providers of data [9]. Within LifeChamps we have actively engaged patients and the public as partners on an organizational level mainly through European Cancer Patient Coalition (ECPC) who has been an active consortium partner of the project participating in the design and dissemination of our work as wells as by getting in contact with national patient organizations who helped us with small focus groups in Sweden, Greece, Spain and UK for the co creation of the consortium's AI solution. Patients as data providers have been involved in LifeChamps within our qualitative study of 70 cancer survivors and 23 family caregivers for exploration of care needs [10].

5. Conclusion

The qualitative methodology of the study is anticipated to give insights regarding the experiences and expectations on research involvement of older cancer survivors that participated in a feasibility study of an AI health assisting tool. It is expected that the findings of this study will contribute to the future and ongoing development of standards for patient involvement in research.

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