Engineering Healthcare Technologies for Broadening the Participation of Patients and Carers

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ABSTRACT

This workshop focuses on engineering the next generation of healthcare technologies for supporting and widening the participation of patients and carers in their healthcare. We will gather stakeholders from distinct disciplines and backgrounds to discuss and reflect on experiences to date with healthcare technologies that support participation. We will also engage in ideation and design sessions with two case studies from the Portuguese primary care reform. The outcome of this workshop will be a research and development agenda based on lessons learned and pointing to the opportunities for new technologies and platforms for broadening the participation of patients and carers.

Author Keywords

Healthcare technology; healthcare system; participation; patients; carers; healthcare infrastructures.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous;

INTRODUCTION

Recent decades have seen a growing development of healthcare technologies that support the participation of patients and carers in their healthcare. These technologies enabled participation in multiple contexts, from medical consultations [4] to self-care activities [7], sometimes even challenging medical processes and procedures that expected more passive roles from patients and carers [3]. Apart from enabling technology-mediated participation, the HCI, CSCW, and Medical Informatics communities have implemented participatory development processes, in which patients and carers were invited to influence the design of their technology [6] and, consequently, their life [5].

There were (and are) good reasons for supporting an active participation of patients and carers. After all, they bring unique experiential knowledge on their medical care [9], the experience of living and managing their condition on a daily basis [8], and the knowhow of caring for themselves and others [2], all of which are crucial for reaching appropriate medical processes and decisions [1]. Moreover, the contribution of patients and carers is especially encouraged in participatory democracies, where the right to participate is granted by the law or constitution.

The participation enabled by healthcare technologies is highly related with the models, components, architectures, configurations, and infrastructures that compose them. For this reason, and as healthcare technologies become prevalent, it is timely to take a step back and critically reflect on the work achieved so far, as well as on the process that lead to achieving those results. This reflection will enable workshop participants to build a shared vision and agenda for future research and development in the area.

AIMS AND GOALS

This workshop aims to bring an international audience to learn from the experiences and perspectives of people from different countries and backgrounds, who have similarly worked to support the participation of patients and carers in their healthcare. Sharing experiences should inspire participants to engineer new technologies that support and widen the participation of patients and carers in new ways.

The workshop will focus both on the work of participants, as well as on reflecting upon two case studies from the team coordinating the Portuguese primary care reform. The invited experts will introduce their current vision and actions for supporting and widening the participation of patients and carers in their national healthcare system. The first case study will bring attention to patient care trajectories and call for a reconceptualization of healthcare technologies that complement medical consultations. The

second case study will present the patient boards that are increasingly involved in the management and evaluation of primary care units in Portugal, but relatively unsupported by technological aids. The case studies will offer the opportunity to discuss different ideas on how to enable a broad participation of patients and carers.

TARGET AUDIENCE
We welcome submissions from researchers, designers, developers, healthcare practitioners, patients, carers, as well as anyone developing, studying, or using technologies for healthcare. We expect to accommodate between 15-20 participants in the workshop.

We will also invite two coordinators of the Portuguese primary care reform, who will provide the basis for discussions around the two case studies.

INVITED CONTRIBUTIONS
Participants will be invited to submit a 4-6 pages position paper using the SIGCHI Extended Abstract Format. Position papers will be lightly peer-reviewed by at least two members of the program committee and selected based on their quality and relevance to the workshop themes.

Alternatively, participants may submit a 500-word motivation letter stating their background and interest to attend the workshop. This submission is mostly suited for non-academics and will be judged by the organizers in relation to its relevance to the workshop.

OUTCOMES
The outcome of this workshop will materialise in two concrete contributions. First, position papers from participants will be made available in the workshop website, summarising examples of current work around participation in healthcare technologies. Second, we will build a shared vision for future research and development in the area, which will contribute to a joint publication to submit for *Interactions* or *Communications of the ACM*.

FORMAT
The workshop lasts a full day and is organised as follows:

- 09:00 - Introductions
- 09:30 - Poster presentations
- 11:00 - Coffee Break
- 11:15 - Mapping exercise of solutions, issues, and challenges
- 12:30 - Lunch Break
- 14:00 - Case study 1: Participation during medical consultations
- 15:00 - Quick summary: emerging themes
- 15:15 - Coffee Break
- 15:30 - Case study 2: Participation in patient boards
- 16:30 - Mapping exercise of solutions, issues, and challenges
- 17:00 - Closing remarks and next steps
- 17:30 - Workshop end

The morning will be focused on the submitted position papers. Each presenter will have between 5 and 10 minutes for presenting their poster, plus 1 to 3 minutes for answering questions. Following all presentations, we will map the proposed technologies, as well as common issues and challenges to participation.

During the afternoon, we will work on two case studies as mentioned above. These two sessions will follow a similar structure. After a 15-minute introduction by the invited experts from the ministry of health, researchers will break into two groups for discussion. In the end of the sessions, there will be a common exercise of mapping the ideas, issues, and common challenges.

ACKNOWLEDGMENTS

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