

Design of the CAPABLE Prototype: Preliminary Results of Citizen Expectations

Astri Letnes Janson^a, Anne Moen^b, Kristin Skeide Fuglerud^c

^a *Division of Diagnostics and Technology, Akershus University Hospital, Lørenskog, Norway*

^b *Institute of Health and Society, University of Oslo, Oslo, Norway*

^c *Department of Applied Research in Information Technology, Norwegian Computing Center, Oslo, Norway*

Introduction

Having access to and opportunity to an overview of all personal health-related information is important to citizen health empowerment. Today, citizens can access subsets of their health information through dedicated, secure portals, manually enter information into specific apps of their choice or keep paper logs. The result is a mix of paper documents and digital snippets of exchanges and data in incompatible formats. This may be supplemented with ad-hoc strategies for interpretation and management. There is currently no simple way to collect, complement and control health information from multiple sources, institutions, services and systems, and thus no way to get a good overview and understanding of its implications. CAPABLE aims to create a tool that enable citizens to actively utilize their clinical and personal health information to manage medication, improve nutrition, and facilitate health services coordination.

Materials and Methods

The CAPABLE prototype development is based on user-centred design (UCD). In the first phase to understand user needs, values and context, 57 citizens have participated in two focus groups (n=13), five personas workshops (n=15), a design workshop with five groups (n=24), a pluralistic usability walkthrough (n=4), and a paper prototype user testing (n=1). Among the project partners are health advocacy groups (NGOs) and municipalities, which are recruiting participants. They ranged from adolescence to elderly, with and without disabilities, had a variety of health problems, different digital health literacy and different roles: pupils, workers, next of kin and retirees. Thematic analysis of detailed field notes from the activities has been performed.

Preliminary Results

The results show how citizens have a wide range of expectations toward the CAPABLE tool – both affirming and contradictory to each other, ranging in level of detail and developmental implications. However, the overall expectation from all citizens is for the CAPABLE tool to be easy to use, requiring only small amounts of work or efforts for a citizen to utilize it. They expect that everything that can be automatic to be automatic. This overriding theme has three main expressions:

- a) Citizens expect to utilize existing personal health information in digital form in the CAPABLE tool.

Providing citizens with a registration tool for health information has very limited value for users. They expect to be able to collect information that already exists in various digital platforms.

- b) Citizens expect to have access to checklists and resources where they can personalize content.

Citizens want a structured way to record and store questions and experiences before health appointments and to note what they have learned from health personnel, but they do not want to write everything down in full text. Providing information, checklists and templates they can personalize to their specific needs seems to be a usable and useful way to complement health information.

- c) Citizens expect to guard their health information from the community and choose to share parts of their information from trusted parties in the CAPABLE tool.

Citizens are conscious of how health data needs to be protected and guarded, and the threats of not doing so. At the same time, they would like functionality to share their health information with people of their own choice, select what to share, to decide for how long the shared information is accessible for others.

Discussion

Results from the user-centred activities provides some fundamental design implications for the CAPABLE tool. They are:

- a) A successful prototype has opportunities to gather and use personal health information in digital form, and interoperability with existing health information systems are crucial.
- b) Citizens propose checklists as a way to prepare for health encounters. Unstructured note-sections are expected to be laborious and limiting use. Checklists provide an important starting point to personalize and annotate, as one size does not fit all.
- c) “Privacy by design” is important from a legal perspective, and paramount for citizens’ maintained trust. The tool needs to provide easy and flexible ways to control and share personal information, and avoid unintended or unforeseen incidents.

Acknowledgments

We thank the participants and project partners for their contributions, and the Research Council of Norway for funding.

Address for correspondence

Astri.letnes.janson@ahus.no