Design of the CAPABLE Health Empowerment Tool: Citizens' Needs and Expectations

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Abstract. It is important but difficult for citizens to gain a proper overview of their health-related information. The CAPABLE project aims to create a digital tool that enable citizens to actively utilize their clinical and personal health information to manage medication, improve nutrition, and facilitate health services coordination. 57 participants have participated in various user-centered co-creation activities. A key finding of citizen's needs and expectations is that citizens are positive about such a tool provided it is easy to use and requires minimal work. Especially, opportunities to collect and utilize already existing digital health information, having access to personalized and relevant checklists and personalized resources, and be able to share health information with health personnel and others according to their own trust and privacy preferences. Involving other stakeholders to ensure integration with other systems is of principal importance to fulfil citizens' expectations of integration and automatization.

Keywords. User-centered design, inclusive design, mHealth, automatization, personalization, privacy, medication management, interoperability

1. Introduction

Today, citizens can access subsets of their health information through dedicated, secure patient portals [1], but content can be fragmented and access unequal [2], or requiring users to manually enter information into the apps of their choice [3]. Apps are usually targeting one specific condition, e.g., diabetes [4], heart failure [5] or cystic fibrosis [6] to mention a few. Over time, most people experience many health issues leading to health encounters, many of which produce information and knowledge that may be of relevance and importance for self-management and the best possible follow-up of treatments. The result is that citizens ends up managing a mix of paper documents, digital snippets of information exchanges or data in incompatible formats, supplemented with ad-hoc strategies for interpretation and management. The extent of health information exchange varies considerably, and is only partly achieved in some countries [7]. For citizens, there is currently no simple way to collect, curate or complement nor control health information from multiple institutions, services and systems, making it quite challenging to retain a good overview and understanding of its implications.

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We anticipate that easy access to and overview of all health-related information will contribute to increased empowerment and improved digital health literacy, which in turn can contribute positively to health status [6]. In our ongoing project, CAPABLE, we aim to support citizens' ability to manage their health and participate in health-related decisions. We are creating a mobile tool to enable citizens to actively utilize their clinical and personal health information to manage medication, improve nutrition, and facilitate health services coordination. To counteract current inequality in health services provision [8], we emphasize and pay special attention to the needs of vulnerable groups, people with disabilities, complex and or chronic conditions, and those with low health literacy. The research focus for the user-centered design process we report from was: what are the citizens' needs, values and the social context for developing the CAPABLE tool? What are the expectations of citizens for such a tool?

2. Method

The development of the CAPABLE tool is based on an inclusive user-centered design approach [9], emphasizing user involvement from the very beginning and throughout the full development and deployment cycle. Involving users in the design process contributes to increased applicability, accessibility, acceptance and adoption of the designed solution. It is considered especially efficient and influential in the early stages of the development process since the costs of making changes increases as the development continues [10]. We follow an interpretive research approach and utilize different user-centered methods. The variety and flexibility of methods allowed us to further investigate certain issues and questions, helping to clarify and identify recurring themes and topics. 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). Municipalities affiliated with the project (n=3) recruited participants through existing municipal councils (elderly, disability, youth), and non- governmental disability and health organizations (n=3) recruited via their members. Participants represent citizens, from adolescence to elderly, with and without disabilities, with varying degrees of health problems, digital health literacy, and in different stages of life: pupils, workers, next of kin and retirees. We conducted a thematic analysis based on detailed field notes from all the activities.

3. Results

The analysis showed a wide range of expectations toward the CAPABLE tool – both affirming and contradictory to each other, ranging in level of detail and developmental implications. An overall, very common expectation was for the CAPABLE tool to require only small amounts of work to utilize it since many citizens experienced that creating an overview of their health information could be labor-intensive.

Providing citizens with a tool that requires them to register all their health information comes with little value, according to the participants in our research. They expected to be able to utilize the information that they are aware of already exists digitally. Presupposing imported digital health information, citizens expressed a willingness and eagerness to log additional, relevant health parameters related to their health challenges to gain knowledge and overview. In general, citizens are well aware

of the national summary care record "Kjernejournal" containing information from the last 3 years [1]. When they see themselves as healthy or have few or straightforward health issues, they find information about themselves in "Kjernejournal" as sufficient, but if conditions are more complex, they told that information could be incomplete or missing, requiring them to recall incidents from years or decades ago when asked.

Citizens anticipated that the CAPABLE tool could help them to manage experiences, questions and information before and after consultations with health personnel. To keep documentation to a minimum, citizens anticipate that checklists relevant to diagnosis, conditions or medicines could be useful. They pointed to examples of resources and information from the public health authorities or NGOs. However, CAPABLE tool should facilitate modifications in the resources it to their specific needs, according to their experiences and knowledge.

To support their memory in relevant situations, our participants would like to store health information in a secure place, where they can access it when they need to. At the same time, participating citizens were conscious of how their personal health data needs to be accessible for them, but not for their community. If functionality exists, they want to share their information with people of their own choice. The attractiveness of sharing relevant information, and decide how much information to share, for which treatment purposes and period, was high and seen as a feature for personal control.

4. Discussion

Citizens' expect to utilize their health information with as much automation as possible comes with three main implications for design, discussed in the following.

4.1. Collecting Already Existing Digital Information

Our findings confirm previous research, which consistently find that ease of use, usability, accessibility and readability are key factors for successful adoption and use of eHealth systems [3,11-13]. Our participants go even further by emphasizing the need for and attractiveness of integration and utilization of existing digital health information. To collect existing digital health data, as we propose for the CAPABLE tool, the citizen could ask for access to personal health information from electronic sources, and save a copy of their health information for personal use, annotation, complementation, or even sharing personal health data at the person's discretion. This approach complements established communication lines and should maintain data integrity in the source. CAPABLE build extensively on HL7 FHIR® resources to foster interoperability, the international leading interoperability standard, also recommended by the Norwegian Directorate for eHealth [14]. Above all, the CAPABLE tool will give the citizens an opportunity to maintain personal health information in one system, which was also a principle finding in Floch et al. [6].

4.2. Curating Personal Health Information

Personalization can contribute to making the application relevant and reduce the amount of work for each user. Kwon & Kim [15] differentiate between two types of personalization: *implicit*, based on previously collected consumer data, or *explicit* where

the consumer proactively specifies elements. In the CAPABLE tool, using an implicit approach could be possible as a starting, focal point of reference. Assumptions of health conditions can be delineated from a medication classification system, e.g. if a citizen take Carbamazepine, epilepsy is quite likely. However, the citizen might use the same drug for neuropathic pain or bipolar disorder. Moreover, the citizen may need information for conditions that cannot be deduced from the medication list. Therefore, explicit personalization would be a better strategy. As discussed by Li [16], incorrect information makes people more likely to interpret content as non-personalized, meaning that efforts to make content personalized in the CAPABLE tool can be futile. To balance these trade-offs, we propose a procedure where the citizens explicitly are asked to confirm deductions about health conditions. Further, we propose functionality where the citizens can select between predefined checklists and texts, and then add text alternatives that they miss to curate or adjust information to be meaningful for them.

4.3. Controlling Health Information

"Privacy by design" is important to comply with a legal perspective, but also paramount to the citizens' maintained trust and willingness to use the CAPABLE tool. Recent research has found that many mHealth apps run the risk of jeopardizing the privacy of its users [17] because they do not conform to the General Data Protection Regulation (GDPR). CAPABLE needs to provide citizens with an easy and flexible way to control and share their information, while at the same time avoid unintended and unforeseen incidents. For sharing information from CAPABLE with health personnel, we plan to use SMART on FHIR to integrate CAPABLE with other health information systems if the citizen chooses to do so. This is well-aligned with The Norwegian Directorate of eHealth advice for our setting – that SMART on FHIR based on HL7 profiles is the most promising framework for application integration in EHR's [14].

4.4. Limitations

Although this research has involved a relatively large number of participants, the current emphasis has been on the users of health services and their representatives. There is a need for further work to integrate this with the needs and expectations of other types of stakeholders. In addition, the views reported here reflect those who were willing to take part in this research project. People who were not interested or not able to participate may potentially have different viewpoints. A strength of the study is the combination of methods and the involvement of a wide diversity of citizens.

5. Conclusion

User involvement from citizen stakeholder assessment shows that it is of paramount importance to create and offer novel functionality going beyond "yet another registration tool". Providing novel opportunities to collect and actively use digital personal health information to minimize text entry, be able to curate and annotate to meet personal needs and relevance, and ensure interoperability in privacy preserving manners could foster innovation that really empower the citizen. This user centered design approach has

informed the first step in designing the CAPABLE prototype. Based on the experiences, we will create a first prototype, piloting with approximately 50 additional users. Finally, we will carry out a large-scale feasibility trial with a proof of concept version of CAPABLE. The main challenge ahead is involving other stakeholders to meet the needs and expectations articulated from citizens.

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