

User involvement in the design of a data-driven self-management decision support tool for stroke survivors

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Abstract—Many chronic conditions can be better managed by patients themselves with the use of decision support tools. This becomes even more necessary in the case of multimorbidity (i.e. presence of multiple chronic diseases) or in conditions where several underlying risk factors need to be managed and monitored in order to avoid relapse or the reoccurrence of an event, like in the case of stroke. However, despite the fact that these decision support systems are becoming prevalent, little is known about the best practices in designing for end-users - patients and their carers. The aim of the present paper is to report on the process of involving users to inform the design of a novel data-driven self-management mobile decision support tool for stroke survivors, called CONSULT. User involvement was facilitated through the use of a two-phase participatory design approach. During both phases a total of 44 stakeholders participated, including stroke survivors, carers, healthcare professionals and researchers. The paper documents the findings of the participatory design process, in the form of design recommendations, and describes their implications for user interface design.

Keywords—human factors, human computer interaction, decision support, healthcare

I. INTRODUCTION

Research has established that many chronic conditions can be better managed by patients themselves with the use of actionable digital health interventions [1]. Specifically, research

on decision support systems (DSS) for self-management, that integrate heterogeneous sets of health data (e.g. ePROs, EHRs and clinical guidelines) and harness the power of artificial intelligence (AI) methods and techniques, is progressing across a wide range of chronic conditions, for instance from cardiovascular heart disease and cancer to mental health [e.g. 2,3,4]. Such systems can provide patients an evidence-based approach for just-in time and personalised medical and emotional self-management and monitoring of their condition. In the long-term, it is envisaged that the adoption of these systems by patients can reduce the burden placed on the health and social care system, including use of healthcare resources and unnecessary visits to the GPs or the outpatient clinics [2,5].

Self-management and health monitoring becomes even more necessary in the case of multimorbidity (i.e. presence of multiple chronic diseases) or in conditions where several underlying risk factors need to be managed and monitored in order to avoid relapse or the reoccurrence of an event, like in the case of stroke. Stroke can occur either due to a blood clot (ischaemic) or a burst blood vessel in the brain (haemorrhagic). There are several risk factors associated to a stroke, including hypertension, diabetes, atrial fibrillation and smoking [6]. Figures show that the number of people with stroke is increasing in low and medium-income countries while it is likely to increase also in high income countries due to changes in life-style [5]. Stroke is one of the

primary causes of disability in adults [7] and the chances of another stroke are increased for people who have had a stroke before [8]. Therefore, interventions are needed to help stroke survivors and their carers to manage recurrent stroke risk, as well as the physiological and emotional side-effects of their condition during the course of their life.

Harnessing the power of modern technology to prevent secondary stroke, support stroke survivors and improve their quality of life has become the focus of several research projects with some positive outcomes documented in the literature [5]. Different types of technologies, ranging from social networking sites (SNS), Virtual Reality (VR) and Artificial Intelligence (AI), have been implemented as a means of supporting self-management for individuals after stroke. Recently, the wide availability of wearable sensor devices has made possible the development of a new generation of data-driven collaborative decision support tools. Thanks to the ability of these tools to process, using AI, large amounts of heterogeneous health data (e.g. routinely collected data from sensor devices, structured data in electronic health records, as well as data from clinical guidelines, documented literature and clinical trials) it becomes possible for patients themselves to get more personalised and tailored to their needs treatment plans, advice and assistance for better self-management and secondary stroke prevention [9,10].

However, despite the fact that these technologies are becoming prevalent, there is little known about what is the best way to translate their functionality into a design for end-users (e.g. stroke survivors and carers) both in terms of usability and patient safety. It is well documented in the literature that the design of self-management digital health interventions without regard for human factors can have adverse effects on patients' safety [11] and hinder the effectiveness and the level of adoption or acceptance of these technologies among patients [1]. Therefore, involving users in the design of decision support tools for disease self-management is important to ensure that the technologies are user-centred and relevant to the needs and expectations of their beneficiaries.

The aim of the present paper is twofold. First, to report on the user involvement process used to inform the design of CONSULT, a novel data-driven self-management mobile decision support tool for stroke survivors. Second, to present implications of the findings in the form of user-centred design recommendations.

While some general recommendations for the design of self-management digital health interventions for stroke survivors have been reported elsewhere [12,13], the present paper goes a step further by documenting original knowledge about key human factors and design considerations that are unique to data-driven self-management decision support tools for stroke survivors, including, human - AI agent interaction and personal health data visualisation.

The paper is structured as follows. First, a short description of the CONSULT project is presented. In the third section we document the participatory design approach. The following two sections summarise some of the findings of the user involvement process and their implications for design respectively. The final section presents some conclusions and recommendation for further work.

II. THE CONSULT PROJECT

CONSULT (Collaborative mOBile decisioN Support for managing mULTiple morbiditiEs) is motivated by the increased availability of commercial wireless sensor technology that make it possible for patients to monitor a wide range of health and wellness data at home, including blood pressure and heart function. However, such sensor data is currently not integrated in electronic health records (EHRs) and personalised treatment plans; treatment plans do not adapt dynamically to changes in patient circumstances; and a record of patient decisions and responses to daily care is not routinely captured in a standardised way, preventing learning about treatment effectiveness from such a record [14].

Specifically, the CONSULT project explores the feasibility of employing a collaborative decision-support tool to help stroke survivors self-manage their treatment plans. The CONSULT system exhibits the following characteristics:

- integration of data from wellness sensors, patient Electronic Health Records (EHRs), Health Care Professionals (HCPs) input, and clinical guidelines to produce a care plan that is tailored to the patient's individual needs;
- application of computational argumentation that processes the data from these heterogeneous sources and identifies reinforcing and conflicting information. Argumentation [15] is a well-founded formal methodology of reasoning with roots in philosophy and has been applied in artificial intelligence (AI) and multi-agent systems (MAS). In argumentation, conclusions are drawn by analysing evidence that supports (or refutes) the conclusions. As opposed to other systems, argumentation-based systems have the ability to explain why a decision was made in a particular context;
- interaction with patients, or their carers, via argumentation-based dialogue to ensure understanding of the health data and information gathered as well as the decisions made [14].

III. USER INVOLVEMENT IN THE DESIGN

Following a participatory design approach [16], user involvement was split into two phases. During both phases a total of 44 stakeholders participated, including stroke survivors, carers, healthcare professionals and researchers. The purpose of the first phase was concept generation and user requirements specification. The findings of the first phase were used to generate mock ups and a low-fidelity demo version of the CONSULT user interface. The goal of the second phase was to actively involve participants in the decisions made about the user interface design through a set of feedback activities. The findings of the second phase were fed into the design of the first working version of the CONSULT decision support tool. Figure 1 depicts our participatory design framework.

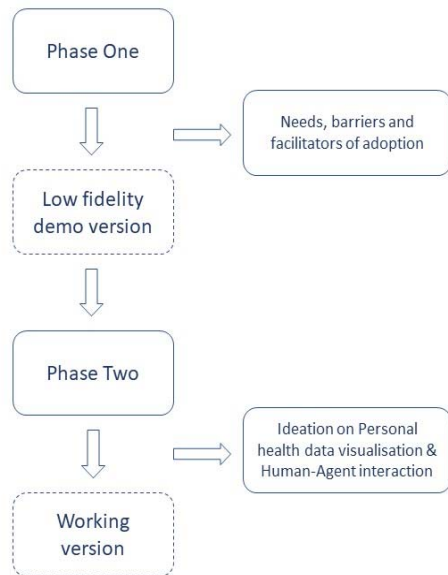


Fig. 1. User Involvement in Design Process

A. Phase One

A total of 34 stakeholders participated in the first phase. Fourteen participants were stroke survivors (i.e., men and women with a range of underlying risk factors, disabilities, conditions and length of time since stroke) and carers. Patients and carers were selected purposively using a maximum variation sampling strategy, thus making sure that a diverse mix of stroke survivors in terms of risk factors, years since stroke, experience with the use of digital health services and mHealth apps would participate. The rest of the participants were healthcare professionals (N=11) and researchers (N=9) who were also selected purposively. Stakeholders in phase one participated in focus groups (n=26) and face-to-face interviews (n=8), to understand and assess their views on facilitators and barriers to widespread deployment of a collaborative decision support system.

The focus group consisted of 26 participants (10 stroke survivors and carers, 7 healthcare professionals and 9 researchers). Participants were introduced to the purpose of the study and to the concept of “self-management” and “wireless sensors”. This introductory session was followed by two separate focus group discussions guided by a topic guide with: 1) stroke survivors and carers and 2) healthcare professionals to identify stakeholders’ needs, facilitators and barriers from a collaborative DSS. Each group had a facilitator, moderator and note-taker. The two groups came back together as one larger group for further discussion and priority setting. In addition to the focus group, face-to-face individual interviews were conducted with eight stakeholders (4 stroke survivors and 4 healthcare professionals), who were unable to attend the focus group, using the same topic guide to ascertain their views on barriers, facilitators and needs from a collaborative DSS. Interviews lasted 40-60 minutes. Focus groups and interviews

were audio-recorded and qualitative data was analysed thematically to identify emerging themes [17].

B. Phase Two

While phase one produced rich information about the user needs, including issues that can help or hinder the deployment of a decision support tool for self-management, the second phase of the user involvement process was focused on understanding users’ preferences and needs when it comes to the design of the information and user interface of the CONSULT. Specifically, phase two served two main objectives: 1. To collect feedback from patients and carers about a demo version of CONSULT designed following the evidence generated from phase one; 2. To examine user requirements and co-create design specifications related to the visualisation of personal health data and human-agent interaction (in this case, human – agent interaction refers to humans interacting with the decisions, explanations and information produced by the argumentation engine). To address these objectives a focus group was organised with 10 participants (stroke survivors and carers) who were recruited purposively using a maximum variation sampling strategy. During the focus group participants were randomly split into two groups of five and asked to perform a set of activities related to the two aforementioned study objectives, including: providing feedback about their likes, dislikes, concerns and ideas regarding the demo version, selecting among different types of visualisations for the presentation of personal health data, and finally, sharing their ideas on how the information and decisions produced by the argumentation engine can be best communicated to users. Each group was joined by three researchers (one mediator and two note-takers). Data was collected using audio-recordings as well as user-generated output, such as post-it notes and sketches (Figure 2). Qualitative data was analysed thematically [17].

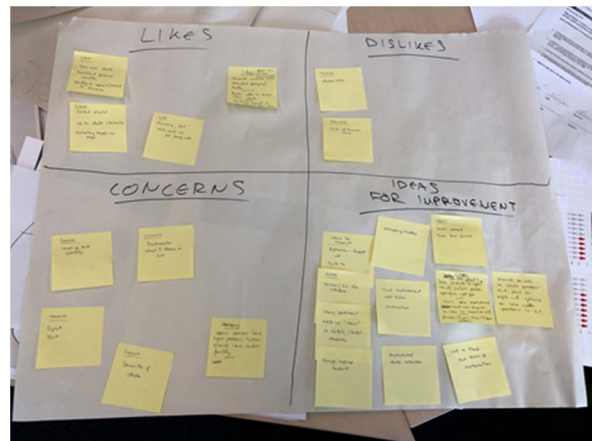


Fig. 2. Example of User Feedback

IV. SUMMARY OF FINDINGS

A. Phase One

The results of the thematic analysis for phase one showed several design factors influencing the adoption of a self-management decision support system for stroke survivors. The key factors were the following:

- Personalisation. The decision support system should be tailored to the patient's needs and individual characteristics, including medical history (such as demographics, co-morbidities, risk factors). Also, it should provide personalised advice, based on a patient's medical history and risk factors (e.g. blood pressure), such as adjusting medication, providing evidence-based recommendations on how a patient can maintain healthy life-style (e.g. stress control, diet, exercise);
- Real-time monitoring. The system should support real-time monitoring and information on patient's risk factors (e.g. blood pressure, heart rate, atrial fibrillation);
- Alerts. The patient should be alerted promptly when a certain value exceeds a certain threshold (e.g. high blood pressure or arrhythmia);
- Communication with healthcare professional. The system should provide the opportunity for patients to book an appointment or communicate with a healthcare professional.
- Profiling. The system should be designed to accommodate the needs of both "passive" and "active" users. The former group characterises patients who would like to get a quick picture or overview of their health state, without getting into detail for each individual risk factor. The latter category of "active" users is typical of patients who need the full picture and would like to monitor their health data regularly.
- Emotional self-management. In addition to physiological monitoring, the decision support system should also support the self-management of emotions, (e.g. stress, depression).
- Behaviour change. The system should integrate behaviour change theories and techniques as a means of keeping users motivated to use it. Common behaviour change techniques, such as goal setting were favoured by the participants in the focus group.
- Relevance of content to patients' needs. When asked about the type of measurements that the system should display to patients, the most common responses were: blood pressure, heart rate, heart rhythm, oxygenation, stress, breathlessness, sleep quality, blood sugar/glucose, activity, mod, pain, cognition, memory and speech.
- Multimodal human-agent interaction. The conversation between the human/patient and the AI agent should be supported both using voice and messaging chatbots, thus taking into account the presence of different stroke-induced language and physical (such as hand mobility) impairments with which many stroke survivors have to cope with.
- Anthropomorphism and mapping between the chatbot and the real world. Participants in the focus group felt that the conversation between a patient and a chatbot (voice or messenger) should mimic the way a patient communicates with a healthcare professional. For example, when a stroke survivor complaints to a GP about a back pain, the GP asks the patient several questions in order to determine the cause of the pain and therefore the type of treatment. Such questions may require from patients to provide details about the location of the pain, the character of the pain (e.g. continuous or cyclical), its duration and severity. The inability of a chatbot to collect information that normally a health care professional would have asked a patient to provide may lead a patient to question the quality of an advice generated by the decision support system even if it is proven to be the correct one.
- Explanations. The conversational agent/chatbot should be able to provide the patient/carer with explanations about the reason why a specific decision was made. For example, why did a decision is made to suggest a change in the treatment plan, such as a change in the drug dosage. In addition to explanations about decisions, the user should also be able to make questions about the meaning of specific measurements, for instance what does an increase of systolic blood pressure from 125mmHg to 142mmHg really mean for the specific patient?

Design considerations for the visualisation of personal health data were the following:

- Overview-Preview. Participants in the study preferred to have a summary/overview of all their measurements/results in a single screen. For each measurement the most recent value should be displayed. In addition, colour or alerts should be used to denote measurements with values outside the normal range that required attention. Patients who needed to access their longitudinal health data for a specific measurement, in order to get a more detailed picture/preview of their readings, should be able to do so by selecting that measurement from the overview screen/page.
- Data visualisation. Participants preferred physiological measurements, like blood pressure and heart rate, to be presented as line graphs. In addition, graphical reference ranges should be used to contextualise the values of a given measurement, thus showing when a specific value was outside the normal range. Moreover, participants felt that it would be beneficial if data could be queried further to show trends, such as average values at specific intervals during the course of the day, or before/after an

B. Phase Two

Design considerations were grouped into two broad categories: human – AI agent interaction, and personal health data visualisation. In the case of patient interaction with the AI agent, participants preferred this to happen in a dialogic or conversational way. For example, instead of reading a set of recommendations and information about the decisions made by the argumentation engine, participants preferred to be able to start a conversation, that would allow them to seek further information and explanations. Specifically, in relation to human-agent interaction the following design themes emerged during the qualitative analysis of the data collected:

event/activity. For example, does blood pressure tend to get higher at certain times during the day (e.g. morning, afternoon or evening)? Did an abnormally high heart rate occur due to having an exercise? In the latter case the system should provide users the opportunity to tag values with additional information.

V. IMPLICATIONS FOR USER INTERFACE DESIGN

User input from the two-phase participatory design process was fed into the design of the user interface of CONSULT. Specifically, the interface has two main components: a dashboard component that visualises longitudinal personal health data, presents tailored health recommendations to patients for disease self-management, and communicates the effect of different treatment and preventive interventions on their health risk (e.g. the risk of experiencing another stroke); and a conversational agent (chatbot) component the role of which is to provide patients with alerts and explanations about their health state (e.g. an increase in systolic blood pressure beyond the ideal reference range), present treatment recommendations for self-managing their condition (e.g. which over the counter painkiller is the most indicative of reducing their backache given their current blood pressure levels, treatment plan and clinical guidelines), or, to allow users to perform, in a dialogic environment, simple health information seeking tasks (e.g. in the form of getting links to authoritative health literature and websites about a specific medication, measurement or condition).

A. The Dashboard Component

The dashboard component of the Consult contains an overview and a preview interface. The overview interface (Figure 3) displays a summary of the most recent measurements for all types of personal health data collected by the patient (e.g. blood pressure, heart rate, sleep activity, pain, stress, mood). For the representation of this information in the dashboard we used a tile-based design where each tile communicated information about a specific type of health data (e.g. blood pressure). Each tile contained the latest measurements, as well as the date and the location of this measurement. Moreover, we used color to make clear immediately to the user when a specific value was outside the normal range. For example, in the case of blood pressure, the green color was used to indicate that a specific measurement was within the specified normal range, the orange color indicated pre-hypertension levels, while the red required attention. By selecting a tile from the overview interface the user can access longitudinal health data about the specific measurement at the preview interface (Figure 4). A typical preview interface provides users the opportunity to view their data at specific time intervals (e.g. hourly, daily, weekly, monthly yearly), as averages or all raw measurements (using line graphs in the case of averages and scatter plots in the case of raw measurements). Also, for each time interval the user was displayed with additional descriptive information, like the average, minimum and maximum value.

In addition to personal health data, the dashboard provides users the opportunity to use a risk calculator and visualise (using cates plots) the effect of specific treatment and life-style interventions on their current risk of experiencing another stroke. Moreover, there is a tab in the dashboard dedicated to

displaying health recommendations to patients. These recommendations can be either tailored to the needs of the specific patient (e.g. treatment recommendation based on current blood pressure readings, clinical history and clinical guidelines) or population level recommendations (e.g. diet recommendations based on clinical studies that involved patients with similar characteristics with the ones of the user of the CONSULT). Recommendations are grouped into thematic categories (e.g. blood pressure, heart rate, mood or sleep).

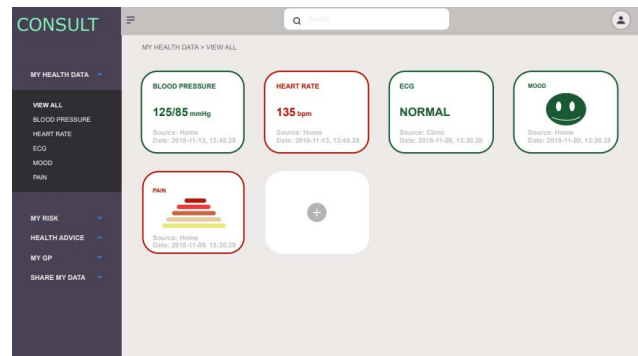


Fig. 3. The Dashboard (Overview) for Android Tablet

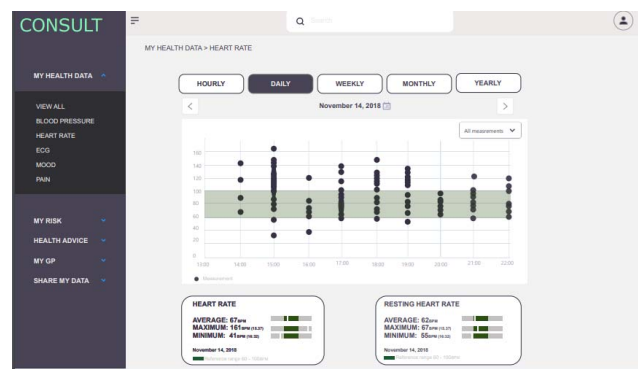


Fig. 4. THE Dashboard (Preview) for Android Tablet

B. The Chatbot Component

The conversational component (Figure 5) of the CONSULT application serves three main purposes. First, to provide a patient the opportunity to seek immediate evidence-based advice about a specific health problem, for example, getting relief from a back ache or a head ache while the patient is on a treatment for lowering her blood pressure or cholesterol. Second, to alert the patient about an irregularity in one or more of her recent measurements and initiate a conversation the purpose of which is to find a possible solution or advice the patient to contact a health care professional. Third, to search and display relevant authoritative information to the patient about specific information seeking needs. The chatbot can trigger or link to data and information displayed in the dashboard (for example, to suggest from a patient to review her blood pressure readings in the event where an irregular measurement has been detected). Also, health recommendations made to the patient during the

conversation are recorded in the health recommendations page of the dashboard along with the explanations as to the reasons why and how did these recommendations/decisions were made.



Fig. 5. The Conversational Component (chatbot messenger)

VI. CONCLUSIONS

This paper detailed the evidence based design of the user interface for a self-management decision support system for stroke survivors. This evidence was generated from the application of a two-phase participatory design approach with 44 participants. Given the lack of empirical evidence in this area of interface design, the present paper contributes new knowledge in the form of design considerations that designers of decision support systems, for the self-management of chronic conditions, should take into account. The next stage of the CONSULT's design life-cycle is the application of formative and summative user evaluation methods (laboratory based usability tests and in-the-wild naturalistic studies) in order to understand in more depth how human factors can influence the design of this type of decision support systems.

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