SCAUT: Using patient-generated data to improve remote monitoring of cardiac device patients

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Abstract
The main problem with remote monitoring of cardiac device patients relates to inefficient communication. This is because patients and clinicians are separated in space and time. In the SCAUT project (2014-2018) we experiment with asynchronous interaction and explore how different types of patient-generated data can improve collaboration. The types of data that patients generate using the SCAUT patient app includes symptom experiences (categories/audio/numeric values), context (activity level/audio), medication list and travel information. We find that it is very important to consider how the data that patients enter can become useful for patients and clinicians simultaneously.

Author Keywords
Patient-generated data; remote monitoring; cardiac device patients; symptom tracking; aligning concerns.

ACM Classification Keywords
H.5.m. Information interfaces and presentation (e.g., HCI): J.3 Health

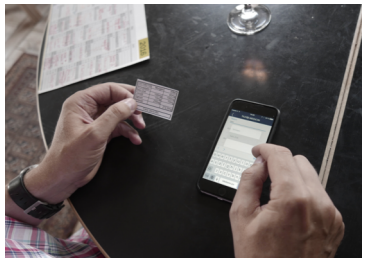

Figure 1: A patient with an implanted cardiac device entering his own medication list (PGD) in a prototype of a patient mobile app in the SCAUT project

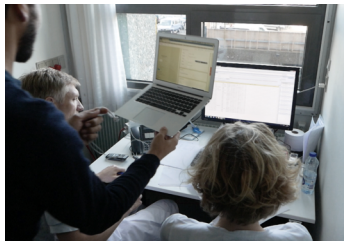

Figure 2: A design intervention in the remote monitoring clinic, experimenting with making PDG useful for clinicians

Introduction

In 2001, remote monitoring of patients with an implanted cardiac device was introduced (e.g. pacemaker, ICD or ICM). Today it is standard of care for millions of heart patients. The positive consequence is that patients are more effectively monitored, the clinic can manage more patients and patients no longer need to travel to the clinic. However, for clinicians the downside is that they now must get in touch with, and talk to patients over the phone [5]. For patients, the downside is that the logic in remote monitoring is "no news is good news", which sounds good for some but for many, it creates uncertainty and anxiety [6].

Since 2008 (www.cith.dk) we have worked with ways to asynchronously connect the remote monitoring clinic with patients at home [2]. In our current R&D project (2014-2018) called SCAUT, which is short for Self-, Co-, and AUTo-detection of deterioration (www.scaut.dk) – we aim to improve patient experiences and workflows in the remote monitoring clinic, at the same time. For this we experiment with asynchronous communication based on various types of patient-generated data (PGD).

Project and Methods

The SCAUT project is set up as a participatory design project with a commercial aim and with long term and large scale user involvement [1]. We have established a living lab (a technology, co-design and test environment) in Copenhagen, Denmark where 70+ cardiac device patients, 8+ clinicians, designers, software developers, and researchers are brought together to design, develop, and test early versions of working prototypes.

The participatory process is organised in learning cycles where we co-design and develop a prototype of a patient mobile app (figure 1) connected to a clinician website. The prototypes are developed in an iterative and agile software development process with short sprints and a rapid introduction of new or re-designed features. The features are sketched and informed by fieldwork observations and interviews as well as by workshops and design interventions (figure 2) in patients' homes and in the clinic. By this interdisciplinary approach, it becomes possible to explore and experiment with optimal ways for patients to generate input that supports an asynchronous collaborative practice – which benefits both clinicians and patients.

The problem with remote monitoring

The main problems for clinicians in the remote monitoring clinic are related to the patient not being physically present when being monitored. This leads to problems of proximity such as a) interpretation of remote transmissions of data coming from the cardiac device, and b) coordination and education of patients [4].

The hidden extra work for clinicians includes that they need to call, email or send letters to patients when there are e.g.

- Alerts from transmissions -> input from patients is missing and takes time to collect
- Missed transmissions -> getting a hold of patients and notifying them, takes time
- Questions from patients -> explaining the same many times is redundant work

The main problems for patients are

- Feeling left out since they rarely hear anything from the clinic
- Anxiety due to not being sure if everything works as it should
- Not understanding what the cardiac device has recorded and how it relates to their symptom experiences

The goal of tracking & sharing PGD

The PDG that patients can input in the mobile app are designed to create more efficient communication and collaboration with clinicians at the remote monitoring centre. Aligning data or information exchange between the clinic and the home is pivotal. It is a design rationale that all features, where inputting PGD is possible, must be aligned to support both patients and clinicians. This is partly inspired by Grudin [3] who argued that cooperative systems needs to support shared motives for use: *"... the best solution is to try to ensure that everyone benefits directly from using the application"* (p. 87).

information, it supports the needs of clinicians – and vice versa. If patients need "clinician generated information" such as personal feedback on device transmission, we work to ensure that clinicians get what they need to make a fast and useful reply.

Type of sharing

The app is designed primarily to support asynchronous communication – to speed up communication and coordination. PGD can be both patient-initiated and clinician-initiated.

Type of data to be shared

The app supports various PGD types including

- Patient-reported outcome data (PRO)
- Symptom experiences (categories/audio/numeric values)
- Context data (activity level/audio)
- Messages in free text
- Medication list (see figure 1)
- Personal and information on relatives (picture, phone no., address, GP)
- Travel destination and dates

Current major challenges

The current major challenges include

- Making symptom tracking useful for both patients and clinicians at all times (right now it is mostly useful for patients in that they can use it to raise concerns)
- Ensure that PGD such as two-way messages in free text can become useful for clinicians
- Finding ways to educate patients and clinicians or develop a new culture around the asynchronous communication between patients and clinicians
- Designing ways for clinicians to take action on patients' individual PGD

Workshop participants

Jonas Moll has a background in computer science and a PhD in Health Informatics. He co-leads the SCAUT project with Tariq Andersen who has an MSc in software development and a PhD in Health IT Design

Research – also from 2012 from the Department of Computer Science at the University of Copenhagen.

They both carry out fieldwork, software development, co-design and innovation management in the project. Their contribution to the workshop includes

- Deep understanding of PDG in remote monitoring
- Long experience with participatory design of patient-centered tools that support PGD
- Establishing and maintaining a living lap using agile software development for experimenting with PGD in use (in the clinic and in patients' homes)

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