

# Transforming Healthcare Delivery: ICT Design for Self-care of Type 2 Diabetes

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## ABSTRACT

In this position paper we present an on-going case study where the aim is to design and implement mobile technologies for self-care for patients with type 2 diabetes. The main issue we are addressing in this paper is how to bridge clinical and non-clinical settings when designing self-care technologies. Usability, User Experience and Participatory Design are central aspects of our research approach. For designing with and for patients in home settings and everyday life situations, this approach has so far not been problematic. However, when it comes to designing with and for user groups located within a large healthcare organization, in a highly institutionalized clinical setting, the situation is different. We have recently introduced the Health Usability Maturity Model (UMM) to our project partners as a potential tool for bringing usability and participatory design issues to the fore as strategic assets for transforming healthcare delivery with ICT.

## Author Keywords

Participatory Design; Usability; User Experience; mHealth; Self-care technologies; Type 2 diabetes; Usability Maturity Model

## ACM Classification Keywords

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

## INTRODUCTION

In this position paper we present an on-going Swedish case study where the aim is to design and implement mobile self-care technologies for patients with type 2 diabetes. The case study is part of a three-year Indo-Swedish research and development (R&D) project, *Health in Hand – Transforming Healthcare Delivery*, where the overall aim is to contribute to transforming healthcare delivery through innovative mobile technologies which support and promote self-care. As the project started in 2014, we are still in the first round of an iterative process of mobilizing user involvement and mapping user needs, while simultaneously exploring existing self-care solutions for type 2 diabetes before deciding how to proceed with iterative prototyping.

The main issue we are addressing in this paper is how to bridge clinical and non-clinical settings when designing self-care technologies. Usability, User Experience and Participatory Design (PD) are central aspects of our research approach. Concerning design with and for patients in home settings and everyday life situations, our user-centered and situated approach has so far not been perceived as problematic. However, when it comes to design with and for important user groups in a clinical setting, i.e. healthcare professionals and hospital staff, who are expected to support and make effective and efficient use of the self-care technologies in their everyday work practice as part of their role in healthcare provision and delivery, the situation is different. It is proving to be a considerable challenge to bring usability and participatory design issues to the fore in a highly institutionalized clinical setting where work practices, legacy systems and traditional division of labor between different professional roles, as well as established ways of communicating with patients, all seem to pose formidable barriers to alternative ways of doing things with technology for supporting self-care. To meet this challenge and lever participatory design in clinical settings, we have introduced a conceptual management tool for bringing usability issues to the fore as strategic assets for transforming healthcare delivery with ICT: the Healthcare Information and Management Systems Society's (HIMSS) Health Usability Maturity Model (UMM), which was developed by the HIMSS EHR Usability Task Force in 2011[1].

In the following, we present experiences so far from the Swedish case study. We then present the HIMSS UMM and how we plan to make use of it in our project. Finally, we conclude the position paper with a short list of questions we hope to be able to explore and discuss further during the workshop.

## EXPERIENCES FROM THE SWEDISH CASE STUDY

The Swedish case study is being carried out in collaboration with the county council, one of the wards of the county hospital medical clinic, and with people living in the region who have been diagnosed with type 2 diabetes and who have volunteered to take part in the study. We are also collaborating with four industrial partners, of which three are small local enterprises. The fourth is a large consultancy

company in the ICT sector with the health sector as part of their customer base.

We are currently mapping out information and communication flows and work practices within the involved hospital ward and between the hospital and their patients with type 2 diabetes. The case study is focused on self-care technologies for type 2 diabetes. This includes supporting secure, effective and efficient communication between healthcare professionals and patients in ways that support good health for the patients, high quality healthcare provision as well as a manageable work situation for the healthcare teams.

Our field studies so far have raised issues about how to design for integrating self-care technologies into a clinical setting focused on hospital-based healthcare delivery. The Swedish county hospital we are collaborating with provides a work environment for its staff where legacy systems, firewalls and local ICT policies limit and restrict what is perceived as possible to change and what is possible to implement. This is not a unique situation in healthcare organizations today, even though the Swedish healthcare sector is in many ways considered to be at the forefront in using technology to enhance healthcare delivery.

Using ethnographic field-study methods (individual and group interviews, observations, shadowing), we are now mapping current work practice and communication flows from the healthcare provider's perspective within the ward of the medical clinic at the county hospital, in parallel with doing field-studies of everyday life for patients with type 2 diabetes. What we have discovered so far from our field-studies in a clinical setting at the county hospital is that there are many problems with the current technologies in use, and not least with the firewall in the hospital, which are causing great frustration among healthcare staff (see Figure 1).

<b>Types of ICT problems encountered by staff</b>
I. Problems related to IS log in and to ID card usage
II. Lack of IT support outside of office hours
III. Lack of integration between different systems, resulting in repeated updating of identical information
IV. Firewall regulations vs communication w patients

**Figure 1. Problems with technologies in in-clinic everyday use**

Just to give one example, which is particularly relevant to our specific case study; many patients are proficient with smart phones and e-mail, and could easily send their blood values etc. via a mobile app or a digital form attached to an e-mail. However, the fire wall and security regulations within the county hospital do not allow this. Instead, patients are expected to use a website which requires a digital ID (which many patients do not have and do not

want to use, or find difficult and time-consuming to use). The designated web site does not allow for communication that includes attached files. This means that blood values etc. are sent in unformatted free text through the web site, resulting in difficulties for healthcare staff to interpret important and potentially health critical information correctly. This is just one of a number of usability issues with existing ICT in in-clinic use that we have encountered in our field studies and that could negatively impact self-care technologies. (Type IV according to our first rough draft of categorization of usability issues, see Figure 1).

Type I Problems related to IS log in and to ID card usage can be further divided into sub-categories, such as problems with having to log in to a multitude of different systems with different passwords repeatedly during every single day, despite the IT department having promised that the personal ID card which is mandatory in order to access the intranet would solve this problem. Another sub-category of Type 1 problems is related to the personal ID card itself: it is necessary to keep the card in the card reader while working with ICT. But healthcare staff are constantly on call, and it is easy to dash off, forgetting the card in the card reader. This is a security risk, as someone else could access the system while you are gone. But it is also a logistic problem, since the ID card functions as a personalized key to locked spaces all over the hospital, such as to different wards, to medicine cabinets and dressing rooms. If you forget your ID card in your card reader in your office, you cannot get through the doors to where you are going, which you often do not discover until you have run through a number of corridors and gone up and down in various elevators to reach where you were going, only to find you forgot your ID card and cannot get through the door. If you are lucky and someone is around who can let you through the door, you still cannot access the information system, should you need to do so, because your ID card – mandatory for logging in on the system, no matter where you are in the hospital – will still be in the card reader on your desk in your office.

The solution would seem to be not to forget one's ID card, i.e. to always keep it at hand. However, there is another subcategory of Type I, where this does not solve the problem. When you try to access the system from a location and a computer which you do not use very often, or instance from an emergency room when you are a doctor on emergency call, the log in process can take an extremely long time. This seems to have something to do with the individual work station rather than with the intranet. In an acute emergency situation, the slow "chewing" of the ID card log in before it allows access to the system could mean the difference between life and death for a patient. This is when you might try to call the IT support function for help. Which brings us to the Type II problem (see Figure 1)..

Type II Lack of IT support outside of office hours might seem like an unlikely problem to encounter in a large

county council hospital saturated with expensive, high-tech ICT solutions, hundreds of employees working at all hours of the day and night and hundreds of hospitalized patients heavily dependent on the technologies in use. However, it is listed by the staff as a both serious and frustrating problem in everyday healthcare provision.

An example of type III problems (see Figure 1) is that identical information about a patient is updated manually in a number of different systems. Not only does this cause extra work and frustration, it is also a security risk in that the information may deviate across different systems.

It quickly became clear to us that if we simply brought in yet another stand-alone application to be tested in a clinical setting at the county hospital, we would be adding to the frustration and heavy work load of the healthcare professionals rather than supporting their work. Thus, we decided to “take a step back” and map the current obstacles and challenges to transformation of healthcare delivery with self-care technologies. We aim to document and discuss current usability issues, and possible solutions to at least a few of these, with the county council IT department before introducing a prototype for self-care of type 2 diabetes in the medical clinic. As one of our industry partners provides several of the central information systems currently in use in the county hospital, the aim is to initiate collaborative efforts towards improvement of the current situation through giving voice and visibility to some of the usability issues experienced in everyday work life by the healthcare professionals. By improving the current situation through one or two modest interventions, we hope to pave the way for user involvement in Participatory Design workshops with patients and healthcare professionals in the autumn of 2014. In this way, we aim to address the gap between clinical and non-clinical settings through participatory design of the first prototype of a self-care solution for patients with type 2 diabetes. In order to gain organizational support and acceptance within the county council for this approach, which is admittedly wider and more invasive in the clinical setting than we had initially planned, we have introduced the HIMSS UMM to our project steering committee and project partners as a tool for change.

### **INTRODUCING THE HIMSS HEALTH USABILITY MATURITY MODEL (UMM)**

After the first interviews and workplace visits at the hospital ward, it became obvious that we needed added leverage for motivating and supporting change from within the healthcare organization itself. The American Health Information Management Systems Society (HIMSS) has recently presented an adapted Usability Maturity Model (UMM) [1, 2] for leveraging user experience to be a strategic asset in health organizations. One of the authors of this position paper has been visiting and collaborating with researchers in the U.S. who have been central in developing the UMM for health organizations and thus has gained insight in to how it is being applied on a large scale with the

aim of “transforming health through IT”. We therefore decided to test this model with our project steering committee as a shared model for moving ahead in the case study. The steering committee, which includes representatives of the public healthcare sector and IT and health service providers as well as of all the involved research disciplines, approved of the idea of using the health related UMM and focusing on usability and user experience as strategic assets in the continued work with defining problems, goals and requirements in the *Health in Hand* project. The service providers could clearly see the benefit of driving this development themselves in close collaboration with the county hospital and on-going research on innovative self-care technologies. On our side, we see the UMM as a potentially powerful lever for highlighting Usability and User Experience on a strategic level in healthcare organizations and thus providing space and support for participatory design that can bridge clinical and non-clinical settings in our case study and beyond.

### **NEXT STEPS IN THE CASE STUDY**

As one of the anonymous reviewers of our workshop paper pointed out, it would be interesting to explore the needs from the “outside in”. How necessary is it for patients who are trying to manage their type 2 diabetes to have access to information which is currently locked in behind the firewall and only accessible for healthcare providers, and primarily, even for these professional users, only in clinical settings? That is actually part of what we plan to study in the next steps of the case study, when we will be doing field studies of patients’ everyday lives and their perceived needs and requirements for mobile support for self-care.

### **TO DISCUSS AT THE WORKSHOP**

Why do self-care technologies need to be designed to work in both non-clinical and clinical settings? Is it a good idea to mix patients and healthcare professionals in the same self-care technologies design workshop? Is the Health UMM a viable tool in a PD toolbox?

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