Transforming Healthcare Delivery in Sweden and India

Sara Eriksén
Blekinge Institute of Technology
SE-371 79 Karlskrona, Sweden
sara.eriksen@bth.se

Ashok Jhunjhunwala
IIT-Madras
#331, ESB, IIT-Madras, Chennai 600036, India
ashok@tenet.res.in

Jenny Lundberg
Dept. of Design Sciences, Lund University
Box 118, SE-221 00 Lund, Sweden
jenny.lundberg@design.lth.se

Suma Prashant
Rural Technology and Business Incubator
Module 6, IITM Research Park, Chennai, India
suma@rtbi.in

ABSTRACT
Participatory design for development (PD4D) is – or should be – a concern in any context where multiple stakeholders are involved in design of socio-technical systems with the aim of transforming current practices. In this paper we present an on-going collaborative Indo-Swedish research and development project in which we are using a Participatory Design approach to transform current healthcare delivery with innovative mobile technologies. Although conditions vary considerably between the case studies in India and in Sweden, many of the challenges we are facing are similar. Transforming healthcare delivery demands changes in agency, work organization and work practices which involve many different categories of current as well as potential future users, including patients and their families. Our ambition is to explore participatory design of mobile technologies for development in a healthcare delivery context in both Sweden and India through reflective cross-disciplinary and cross-cultural collaboration in the on-going case studies in our joint project.

Author Keywords
Participatory Design, Mobile technologies, Healthcare delivery, mHealth

ACM Classification Keywords
H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION
In this position paper we present an Indo-Swedish research and development (R&D) project in which we are using a Participatory Design approach with the aim of transforming current healthcare delivery with innovative mobile technologies. In this project, design-oriented case studies of mobile interventions in healthcare are being carried out in parallel in India and in Sweden. The involved research teams in both countries are multi-disciplinary, including researchers in computer science and software engineering, telecommunication systems and health sciences. According to Winschiers (2006:76), "[c]rossing disciplinary or cultural boundaries implies that one should reconsider established assumptions, concepts and habits that were previous taken for granted. Thus as much as designed products have to be evaluated in the local context so do design methods, techniques and tools." In the project *Health in Hand – Transforming Healthcare Delivery* we are focusing on local design of design methods, techniques and tools that promote participatory design for mHealth development, in case studies in India and in Sweden. During the final year of the project (2016), we aim to focus more specifically on comparing and evaluating the impact of local, participatory design of mHealth, and on how continuing evaluation of mHealth in use can be supported by PD tools and methods as well as by mHealth technologies. Basically, all the involved researchers share an interest in socio-technical prototyping (Gonsalves *et al.*, 2011) which aims at taking context into account in leveraging useful and sustainable ICT solutions that are accessible for rural areas and other challenged (social/cultural/ infrastructure) segments of society. Imbalances in access to technologies, distribution of skills and experience with using ICT, etc. make this an issue not only for developing countries but for socially and infrastructurally challenged groups in all countries. The *Health in Hand* project aims to work across disciplinary as well as cultural boundaries, in and between Sweden and India.

In the following, we first present the Indo-Swedish R&D project *Health in Hand – Transforming Healthcare Delivery*. Thereafter, the ambition of addressing and collaborating across both disciplinary and cultural boundaries in the project, locally in each country as well as from an Indo-Swedish research collaborative perspective, is discussed. We then briefly present the on-going case studies in Sweden and India. Finally, we high-light some of the issues which have surfaced so far in the on-going case studies which we believe could be interesting to discuss further at the PDC workshop on Participation for Development.

THE PROJECT
The Indo-Swedish R&D project *Health in Hand – Transforming Healthcare Delivery (VINNOVA Reg.No. 2013-04660)* is one of 6 projects which were awarded co-funding by the Swedish Governmental Agency for Innovation Systems (VINNOVA), the Swedish Research Council (VR), and the Department of Biotechnology (DBT), Government of India, within the *Indo-Swedish Innovation Call: Health and Disease Prevention 2013.* The project will run for 3 years (2014-2016). Project

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leader in India is professor Ashok Jhunjhunwala, Indian Institute of Technology Madras (IIT-M). Project leader in Sweden is professor Sara Eriksén, Blekinge Institute of Technology (BTH). The Swedish multi-disciplinary research team is distributed across two Swedish universities, Blekinge Institute of Technology (BTH) and Lund University (LU). The Swedish research team is collaborating with IITM and Rural Technology and Business Incubator (RTBI), Chennai, India, around design, development, implementation and evaluation of innovative mobile technologies for health promotion and disease prevention. RTBI is an incubation center at IIT-M with the mission to design, pilot and create successful business in the rural space, leveraging information and communication technology. RTBI's mhealth initiatives aspire to develop and implement simple, affordable, and scalable mobile phone-based solutions to facilitate healthcare delivery in India (www.rtbi.in).

The project has a multi-disciplinary approach, with a focus on health and health promotion on one hand, and design and development of technology that facilitates the delivery of health promotion and healthcare on the other. We are using an iterative Participatory Design approach, combining design-oriented action research, evidence-based health practice, method and tool development for measurement and evaluation of quality of service, usability (Capozza *et al*., 2014; Georgsson *et al*., in press (a); Georgsson *et al.*, in press (b)), user experience and end user adaptation as well as for measuring how these services impact health. We are focusing on supporting situated, formative evaluation which can be used together with PD methods and tools to inform continuing design in use of mHealth technologies. Additionally, studying issues concerning up-scaling and commercialization of mHealth technologies in collaboration with industry and public sector are part of the project, although these issues will mainly be addressed during the final year of the project (2016).

The main objective of the 3 year *Health in Hand* project is to establish long-term Indo-Swedish R&D collaboration around leading-edge applied health technology, with a focus on mobile health services. *´mHealth technologies*' in this context refers to mobile services which inform, motivate and enable individuals to manage their own health information and knowledge sharing, as well as support communication and community building among both patient and caregiver communities. Another important objective is to contribute to method and tool development for measuring impact of mHealth technologies on health outcome and for supporting continual formative evaluation and adaptation and design in use of mHealth technologies for enhanced usability and usefulness.

COLLABORATING ACROSS BOUNDARIES

The *Health in Hand* project aims to work across disciplinary as well as cultural boundaries, in and between Sweden and India. The involved researchers share an interest in socio-technical prototyping (Gonsalves *et al.*, 2011) which aims at taking context into account in leveraging useful and sustainable ICT solutions that are accessible for socially and culturally challenged groups in all countries.

On the Swedish side, the *Health in Hand* project is one of the first multi-disciplinary projects at BTH where health sciences, computing and engineering sciences are all jointly involved and have shared interests. The methodological challenges we are facing in our research project concern not only bridging of cultural differences between Sweden and India, but also bridging of different research cultures and practices between different disciplines, in both Sweden and India. Thus, we expect the cross-disciplinary collaboration in the research teams in both countries to offer new and richer insights concerning established research practices within the various involved disciplines, their strengths and limitations. One of the aims of the project is to develop research methods and practices that can be applied and shared across disciplinary boundaries, for enhancing collaboration around the complex systems which are the base for innovative mobile technologies in healthcare. These systems include software-intensive communication networks as well as hardware, people, their lifestyle habits and health issues, healthcare organizations and their established work practices and cultures. New and rapidly evolving markets focusing on support for healthy lifestyles, healthcare provision, health services and health technologies are also part of the broader context within which the cross-disciplinary research collaboration is taking place (SICAHT).

Working across cultural boundaries in the *Health in Hand* project includes coping with considerable cultural differences between India and Sweden in our research collaboration. We have addressed this above all by keeping coordination mechanisms between the Indian and Swedish case studies on a level of low resolution. Indo-Swedish research collaboration in the project will mainly take place in the form of recurring shared fieldwork and research collaboration in the roles of guest researchers and guest Ph D students visiting each other and taking part during shorter or longer periods in each other's case studies. As visiting guests with shared over-all goals in a joint project, we will be participating in development within the local project framework developed and applied in Sweden and India respectively, thus crossing Indo-Swedish cultural boundaries under knowledgeable and experienced local leadership.

However, there are also cultural boundaries to be addressed and worked across within the project frameworks in India and Sweden. In both countries, not only academic partners but also healthcare providers and ICT service providers are participating in the *Health in Hand* project. Participation in development with the ambition of transforming healthcare delivery through mHealth means taking on the challenge of addressing and engaging with current cultures not only within academic disciplines, but also in professional healthcare provision and health service provision in Sweden and India respectively. Examples of what this might imply will be given in the following sections about the on-going Swedish and Indian case studies in the project.

ON-GOING CASE STUDIES IN SWEDEN AND INDIA

As the project started in January 2014, we are still in the initial stages of the first case studies in India and Sweden. Due to unforeseen delay in the funding process on the Indian side, the Indian partners were not able to start their part of the project until the end of March 2014. Thus, in the following, we are mainly presenting results so far from the first Swedish case study and framework for the initiatives on the Indian side.

First, we provide an overview of what we have planned for the near future concerning the case studies. The overall work plan for the project has been set up based on positive experience from previous multi-disciplinary R&D collaboration between BTH and IIT-M in a *Swedish Research Links Asia* project 2007-2009 funded by the Swedish Research Council and SIDA with a focus on Participatory Design of e-government services and methods for measuring User Experience of e-services (Eriksén and Ekelin, 2008; Fiedler *et al*., 2011; Gonsalves *et al*., 2012).

The comprehensive shared project work plan is characterized by low resolution. Detailed planning is shared only regarding exchange visits and shared workshops. Milestones and deliverables are coordinated through the iterative design and development cycles that are part of each use case during the 3 year project. These are set up so that the prototypes of mobile health services that are developed in the different use cases can be tested and evaluated through at least one full cycle per year. One type of deliverable is thus a prototype from each case study, evolving from a first to a second and finally a third version during the 3 year project. The ambition is to develop the second or third version of prototypes to a stage where they can actually function in daily healthcare delivery practice, and can thus provide a base for focusing, during the last year of the project (2016), more specifically on participatory design of methods and tools for measurement of impact and support for continual formative evaluation for informing continuing local design and adaptation in use of the mHealth technologies.

The two use cases in India and the two use cases in Sweden have been specifically chosen because they are part of the on-going health initiatives in each location where target groups and goals are to some extent similar or overlapping between the Swedish and Indian cases. The challenges of transforming healthcare delivery with mobile health services are in many ways vastly different in India and in Sweden, but there are also interesting parallels and similarities. From past experience, we know that participating in, exploring and comparing developments in local R&D projects between globally distant sites in this way can be extremely inspiring. It can help both partners to "see things differently" in ways that are conductive to innovative thinking around designing and developing innovative mobile health services and transforming healthcare delivery, in India, in Sweden, and, not the least, in Indo-Swedish collaboration in the rapidly evolving area of applied health technology. The use cases provide the touchstone and shared arena for the Indo-Swedish R&D collaboration during the 3 year project.

Research activities on both sides will be coordinated by the schedule and timeline for the cooperative project. This in turn will follow a yearly prototyping cycle where shared milestones and deliverables for the 4 different use cases provide the base for comparisons between use cases and planning of visits in both directions. This allows for flexibility of content of deliverables between the use cases, which means contingencies in the different use cases can be managed without upsetting the overall time plan. In fact, contingencies and how they are managed are part of the challenge of transforming healthcare delivery with mHealth technologies for health promotion and better health outcome in both Sweden and India, and thus part of the object of study in this R&D collaboration.

Central elements of cooperation will be discussions and negotiations around shared milestones and deliverables in the project, the development of shared ethical guidelines, shared mentorship and supervision of the younger researchers and PhD students participating in the project, sharing of innovative ideas and practices around design, development, implementation and commercialization of mHealth technologies, insights into existing and emerging health-related ecosystems and business models in this area in Sweden and India respectively, as well as jointly developing methods for measuring, mapping, evaluating and validating the health outcomes of using the mHealth solutions in the 4 use cases (during 2016).

Validation of the use of the mHealth technologies, to which degree they meet expectations in terms of functionality and quality, and to which degree they become (and remain!) integrated in people's daily lives and struggle for health are important issues in the *Health Hand* project, and will be in focus during the final year of the project. When the second or third versions of the developed prototypes are sufficiently mature to be used in daily healthcare delivery practice, even if only to a limited extent, this type of validation can be done per site, and cross-site, the later in order to include different angles of view.

Swedish Case Study 1: mHealth in a Hospital Context

In the first Swedish case study, our field studies so far have already raised issues about how to integrate mHealth applications into an organizational context where current technologies in use are poorly integrated and in many cases managed through numerous work-around practices. The Swedish county hospital we are collaborating with in the project 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 in no way a unique situation in Swedish healthcare environments today, even though Swedish healthcare is in many ways considered to be at the forefront in using technology to enhance healthcare delivery.

In the first Swedish case study, we are mapping out current information and communication flows and work practices within the involved hospital ward and between the hospital and their patients. The case study is focused on supporting patients with type 2 diabetes in living a healthy life. 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.

During the spring of 2014 we have initiated a pilot study within the framework of the Swedish case study 1. In the pilot study we are taking a closer look at current use contexts into which we plan to introduce the future mHealth service for supporting diabetes patients and their healthcare teams. Using ethnographic field-study methods (individual and group interviews, observations, shadowing), we are mapping current work practice and communication flows from the healthcare provider's perspective within the medical clinic at the Blekinge county hospital in Karlskrona, in parallel with doing field-studies of everyday life for patients (who have volunteered to participate in the study) with type 2 diabetes.

What we have discovered so far from our field-studies 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. So, for example, search strings are written down on bits of paper beside the workstation and repeatedly fed into different systems due to insufficient integration of information and incompatibility of different systems which are constantly in use in parallel. The same information is entered into different systems by hand, when this should easily be able to be automated. 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, but the security regulations within the county hospital do not allow this. Instead, patients are required to use a website which requires a digital ID and 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.

It quickly became clear to us that if we simply brought in yet another stand-alone application, in this case a mobile prototype of a service supporting communication with patients with type 2 diabetes, we would be adding to the frustration of the healthcare professionals rather than supporting their work. Thus, we have decided to use PD methods to map the current obstacles and challenges to transformation of healthcare delivery with mHealth technologies and aim to discuss possible solutions to at least some of the current problems before introducing our prototype in the medical clinic. As one of our industry partners in the Health in Hand project provides several of the information systems (IS) currently in use in the County hospital, we believe there may be possibilities of improvement of the current situation through giving voice to some of the usability issues experienced in everyday work life by the healthcare professionals. Our ambition is to carry out Participatory Design workshops with patients and healthcare professionals in the autumn of 2014, with a focus on designing the first prototype of an mHealth solution.

INITIATIVES ON THE INDIA-SIDE

RTBI along with IIT Madras, have long looked at Information and Communication Technologies (ICT) enabled interventions to improve the health status in the general population and in recent times drew its focus to improving maternal and child health, a National Priority purview that is a crucial indicator of the health status in a country. ICT, in particular, the mobile phone technology, holds great promise to the women and children of India, particularly those disconnected from physical healthcare infrastructure. Through our Indo-Swedish collaborative efforts, we have come up with two initiatives that could facilitate in addressing the existing gaps in maternal and child healthcare delivery.

India Initiative 1: Intelligent Cross-Platform Support for Enhanced Accessibility to Healthcare Services

RTBI along with IIT Madras has conceptualized an exciting model and will be working alongside a healthcare start-up in the area of health information systems, which will involve an intelligent cross platform support for the end-users. This model will be developed and tested in a PD process together with representatives of future user groups. The aim is that it will address the need for finding quality healthcare services. This is envisioned to be a large, intelligent and comprehensive electronic hospital/ doctor repository enabling instant access of information and provision for instant feedback by user on healthcare facilities and doctors. This platform is expected to contribute to creating a demand for quality maternal and child healthcare services.

India Initiative 2: Improving Maternal and Child Healthcare outcome using innovative ICT solution, customized to the targeted beneficiaries

In continuation to our efforts on enhancing maternal and child health through innovations, we have recently undertaken a collaborative initiative called Antenatal and Infant Monitoring (AIM), along with partners; a premier health institute Christian Medical College (CMC) Vellore and our Incubated Company as our technology partner; Uniphore Software Systems and Solutions Pvt. Ltd. This initiative will harness the multi-facets of mobile phone technology and web, as a platform to reach out to pregnant mothers, new mothers and also to the healthcare workforce enabling them to provide better healthcare services. The intervention will include robust, dynamic and intelligent applications using both mobile phone and web that will build rapport with the end-beneficiaries and deliver customized services to the beneficiaries, specific to their stage of pregnancy and post-delivery child immunization requirement.

Using Interactive Voice Response (IVR) in any context needs a thorough understanding on how the end-user will perceive and make use of such a system. For instance, in this maternal and child health initiative, the initial work consisted of working alongside the participants to understand their usage of words/connotations in their likely responses. This user interface design is the backbone of service delivery as we need to keep in mind

what is said/what is heard/what is understood as this will vary in different contexts and regions.

Through these initiatives, we are attempting to create a sustainable model, which can then be replicated with add on customizations and scaled to suit the needs across a range of users and geographies. These two initiatives can be looked at as trailblazers for increasing access to healthcare; facilitating efficient functioning of the healthcare system; enhancing timely delivery of services and improving the quality of care; and making healthcare delivery a better experience both for the provider as well as the recipient.

SURFACING ISSUES OF INTEREST FOR PARTICIPATORY DESIGN FOR DEVELOPMENT

Usability and User Experience as Strategic Assets in Transforming Healthcare Delivery

In the case studies in both India and Sweden, usability and user experience issues have surfaced as central challenges to transforming healthcare delivery with mobile technologies. At the same time, these surfacing issues and obstacles strengthen the argument for using an overall PD4D approach in our project, both in Sweden and in India.

In our first Swedish case study, when we took a closer look at how we might smoothly integrate mHealth applications into a highly institutionalized organizational context in the healthcare sector, we found that there were a number of serious usability issues with already implemented technologies in this sector that might threaten the effective implementation of mHealth solutions. Here, the institutionalized context in itself becomes a challenge for participatory design for development, especially as we are aiming to design mHealth that crosses institutional boundaries and supports communication, collaboration and community building for both patients and their families and for healthcare professionals. In this situation, 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 organization itself. The American Health Information Management Systems Society (H*i*mss) has recently presented an adapted Usability Maturity Model (UMM) (Staggers, 2014) for leveraging user experience to be a strategic asset in health organizations. As one of our PhD students has been collaborating with researchers who have been central in developing the UMM for health organizations, we decided to test this model with our Swedish project steering committee as a shared model for moving ahead in the Swedish case study 1. 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 in innovative mHealth technologies. The UMM is basically a tool for upper-level management of Health Information Systems (HIS) in the health sector. We are now exploring if it can be combined with a bottom-up PD4D approach for promoting change in connection with the introduction of innovative mHealth technologies in the highly institutionalized context of a Swedish county hospital.

In the Indian case studies, where the focus is on healthcare delivery for pregnant women/mothers and their infant children, usability and user experience are as central as strategic assets for healthcare delivery as they are in Sweden, although the UMM model may not be as applicable or useful a lever as it appears to be in a Swedish, highly structured healthcare delivery context. This, however, remains to be explored, as does the issue of how to combine participatory design for development with management oriented tools and techniques such as UMM in a transformative process in healthcare delivery.

CONCLUSIONS

Transforming healthcare delivery with innovative mobile technologies involves multiple stakeholders, including users of existing ICT in healthcare delivery organizations and multiple potential users of future mHealth solutions. Patients and their families are important stakeholders and users/future users in this context. Participatory design for development is, we argue, as relevant and important in a Swedish as in an Indian healthcare delivery context. We are facing multiple stakeholders and heterogeneous user groups in both Sweden and India. In fact, we are only at the very beginning of learning to understand who the future users are, and what their actual needs are, as the case studies now begin to unfold. (Dittrich, Eriksén and Wessels, 2014) The very specifics of the respective case studies are forcing us to realize that there are challenges to mHealth we had hardly even considered when we wrote the project funding application in 2013, such as the huge gap between how information and communication tools are being used in clinical settings and in non-clinical settings of everyday life in Sweden today. Although we are currently too early on in the *Health in Hand* project to provide any well-grounded conclusions based on research results, our aim is to make use of the Indo-Swedish research collaboration in the project to reconsider established assumptions, concepts and habits that were previous taken for granted in the disciplines and cultures involved. (Ekelin and Eriksén, 2014) Innovative mHealth technologies as well as design methods, techniques and tools need to be evaluated in the local context, while the trans-national Indo-Swedish collaboration, hopefully, can help us question the way we do things and see new, more inclusive and sustainable design potentials beyond the "as-is".

Concerning the scientific communities and discourses involved in the area of "D for development", whether the perspective applied is labelled ICT4D, HCI4D or SE4D, or even PD4D, they are not home ground for the authors of this workshop paper. We challenge the dichotomy between developed and developing environments which we perceive to be a foundational part of the "D for Development" approach. We hope the workshop will contribute to a richer understanding of how PD can be applied for local development in a global context.

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