

# Infrastructures for Healthcare: Global Healthcare

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# INFRASTRUCTURES FOR HEALTHCARE 2011

GLOBAL HEALTHCARE

**Proceedings from Infrastructures for Healthcare 2011**

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## PREFACE: CALL FOR PARTICIPATION

The workshop follows the two previous workshops organized at the Technical University of Denmark in June 2006, and at Copenhagen University in June 2009. What is special with the IHC workshop is that it attracts researchers, health care professionals, IT professionals, administrators, IT companies, and others engaged in the development of infrastructures and new, integrated applications and services for improving the quality of health care services.

The purpose of this third international workshop is to continue this forum for discussing current issues and trends related to the integration and coordination of health care practices across institutional, organizational, professional, and global boundaries.

Healthcare has increasingly become a global phenomenon. Even the work within the smallest clinic is inevitably affected by global aspects such as research network of treatment practices and support network of patient groups. The global infrastructures thus affect the local infrastructures and vice versa. Global phenomena such as the increase in patients with chronic diseases also pushes the boundaries for healthcare creating a network of technologies, people, and social arrangement as treatment of one patient involves different professions spread over several institutions and organizational boundaries spanning across various distributed networks. Shortage of local national resources such as workforce, labs, and medical instruments also increases the need to discuss new opportunities to re-think healthcare in a global economy. Finally, global healthcare re-introduces telemedicine and e-health, since new technological opportunities enables complex medical practices, where the patient and the healthcare professional are geographically distributed. In a globalized world policy makers, health care professionals, IT professionals, and researchers share an increasingly pressing interest in understanding, designing, and creating innovative systems of care, which improve communication, coordination, and collaboration among patients and healthcare professionals.

We wish to bring international researcher, healthcare professionals, IT professionals, administrators, and IT companies together to re-think and discuss new opportunities for healthcare technologies, medical practices, and global infrastructures. We wish to highlight how new global infrastructures – socio-technical assemblages – simultaneously connect existing practices, influence and change these practices, and create entirely new practices in health care work (e.g. related to the maintenance of the global infrastructure itself). What characterizes infrastructures in health care? What role do they play in transforming and reorganizing health care and in creating new actors in health care? How are infrastructures established and maintained? What is the impact on work practices, organizational structures, cost effectiveness, quality of care, and continuity of care?

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# Any role for interpretive research in the design of healthcare infrastructures?

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**Abstract.** Currently, most of the design of large-scale information infrastructure in healthcare is conducted by vendors. For interpretive researchers in the healthcare field, this implies that some sort of collaboration with these vendors is necessary. In this paper, I reflect on my own experiences with largest EPR vendor in Norway.

## Introduction

During the last decades, health-based information infrastructures have gradually been established in Norwegian healthcare. At the core of this infrastructure is the Electronic Patient Record (EPR), which in different forms is running in every Norwegian hospital. The first initiative to design EPRs for hospitals was initiated in the late 1980s when the NORA project emerged at the National Institute of Public Health, which at that time represented a strong research-based medical informatics environment (Ellingsen and Monteiro, 2003). Later, in the beginning of the 1990s the DIPS EPR project emerged at a local hospital in Norway. And finally, around 1992, a consortium of Norwegian university hospitals promoted the Medina project. The first two projects resulted in the systems DocuLive EPR and DIPS EPR, which today cover the lion's share of the Norwegian market for hospital-based EPRs.

A key characteristic of these projects was that local forces were leading the way in the initiatives. It was a mode of environment, which allowed, and encouraged a lot of experimentation with new information systems. Practitioners



and researchers with technical insight worked side by side with the common goal of establishing running EPRs.

However, the challenges facing IS researchers in the healthcare field today is very different. Currently, there is no way a researcher can mess around with large integrated “live” systems. Any modification of the software must be carried out by dedicated personnel and through standardized procedures to ensure that the patient’s data isn’t corrupted. It is extremely hard to have an overview of the total infrastructural portfolio, how the different components are integrated and how these are depending on each other.

Accordingly, the time for experimentation and small-scale ad-hoc initiatives is over. Changes to the software have to be made by the vendors involved. This implies that researcher-initiated changes and contributions of existing large-scale IS portfolios have to be carried out through some sort of collaboration with these vendors. For researchers in this field this begs the question of what role researchers should play in the design of large-scale health-based information infrastructures. Accordingly I pursue the following research question: What is the nature of the researcher/vendor collaboration? What counts as a design contribution and what are the consequences of such collaboration?

I am particularly interested in the researcher’s role from an interpretive perspective (Klein and Myers, 1999; Walsham, 1995), where researchers traditionally don’t intervene technically, but rather base the core of the research on analyzing different stakeholder’s perspectives. The data is typically collected by ethnographically inspired methods (Atkinson et al., 2003) such as interviews, participant observation, informal discussions and document analysis.

The case presented is a reflection on my many years of collaboration with the largest EPR vendor in Norway. The vendor has partly funded several of the PhD projects I have been supervising.

## “Putting the facts right”

Doing interpretive research implies to deal with different perspectives and interpretations and you have to prepare being challenged on your viewpoints. This indicates that *facts* are not given, but performed (Latour, 1987), and the findings are outcome of several levels of interpretations as the researcher interprets the informants’ own interpretations (Walsham, 1995).

In my first meeting with the vendor (prior to any research collaboration) my findings was strongly challenged. During 2004 I had conducted an evaluation of the implementation of the vendor’s EPR at the University Hospital North Norway and had presented the result for the top management at the hospital and for the top management at another university hospital in the middle part of Norway who had been interested in my results. The management of the latter put my PowerPoint presentation on the web whereupon the vendor found them by chance. In my

presentation I had provided quotes from users and project participants who expressed somewhat critical viewpoints both related to the implementation process as well as to the functionality of the EPR. The vendor disagreed on several points and I got an email from the vendor's CEO where I was invited to come to the vendor's head quarter and "to put the facts rights" as the CEO put it in his email. An illustration was the CEO disagreed with a statement from a super user at an existing EPR installation at one local hospital, which claimed that that the software needed "50-60 upgrades a year", thus causing an unstable use environment. In doing so, the CEO asked me about who had said this and when, and argued that "this number is far beyond any reality". In this situation I was left to defend both my own interpretations of the data as well as of those interpretations provided by my informants. A lesson learned from this was to build a more robust argument by lending support of additional information sources as, in my opinion, the super user's original claim was a valid one and thus had to be taken seriously.

## Product- versus process focus in design

Interpretive studies of the use of information systems, typically geared toward in situ descriptions of work practices and user perceptions, are potentially a rich resource for determining the requirements for system design. However, the exact nature of what design has been hugely debated (see, for instance, Dourish, 2006). In practical terms this can also be seen in research collaborations with vendors. While the users in the work practices were much concerned about the work process and how they used (and chose to use) the EPR, the vendor was concerned about the actual product and was clearly interested in that our design suggestions where down-to-the-point product improvements. For one thing, this points to the value of an interpretive perspective: the researcher may analyze the vendor's focus on the product and the users' focus on the process, and to try to bridge the two perspectives in the design as the users put it:

"We are so happy that you have contact with the vendor because then you can tell them how we really work".

However, we experienced that the vendor primarily found the product specific design suggestions valuable and any deviation of the pre-scribed use patterns among the users typically would make the vendor consultants challenge the deviated use by stating:

"Why are they doing it like that? (...) that is not proper use. They should have been trained more to do it correctly".

As a result, working closely with the vendor made it conform to see things basically from the vendor's product perspective, thus failing to conveying the users' perspective to the vendor. A danger with this is that it is a tendency for interpretative studies in general and ethnographic studies in particular to be

reduced to a mere “toolbox of methods for extracting data from settings,” so “aligned with the requirements-gathering phase of a traditional development model” (Dourish, 2006: 543).

## Looking forward through a retrospective perspective

It is difficult to “sell” an interpretive perspective, because initially you have very little concrete, just some diffuse claims about the results of an implementation may be of a different character than initial expectations and that surprises may occur. Furthermore, suggesting that different perspectives may translate into controversies among the project participants don’t seem particularly convincing as from the outset of a project everybody agrees on the overall goal (Ellingsen and Obstfelder, 2007). A consequence of this is that the interpretive researcher frequently has to face comments questioning the foundation of your research:

“Can you be more precise on what you can do and how you can contribute?” (Vendor analyst in a workshop)

A lack of a satisfactory response may easily imply that the vendor suggests an alternative research focus for you:

“We really want you to find out what kind of *effects* the system has on the organisation ... maybe you can do a survey?”

Here you may easily imagine a snapshot survey or the like before and after implementation. This was something I wasn’t interested in doing of course. Luckily this changed during the course of the collaboration. As one of the projects matured, it became obvious that the deployment of one of the EPR modules faced serious challenges, which was a result of quite complex organizational problems in one of the involved hospitals. I was then approached by one of the vendor’s managers whereupon he asked about the reason for all the delays and confessed he couldn’t really understand what has happened. “Please explain to us”, he said. This was something that I did quite happily do of course, hence lending on the recognized values of ethnographic inspired research – namely achieving detailed insight of a complex work practice (Klein and Myers, 1999; Walsham, 1995; Forsythe, 1999), hence rescuing me, at least for a while, from more simplistic research approaches.

## How political issues count, as well as delimit action

An opportunity for a broader political angle for our research emerged during 2009. The Norwegian Nursing Association recommended replacing the standardized terminology NANDA (North American Nursing Diagnosis Association) and NIC (Nursing Intervention Classification) with ICNP (International Classification on Nursing Practice) as a Norwegian standard in the

nursing care plans. This was both a blow to the vendor, which had developed the nursing care plans as well as for the 25 000 thousands nurses who were trained in, and used NANDA and NIC in their daily work. Both the vendor and many users questioned the rationale for this decision. The vendor also wanted to know why neither someone from their organization nor any of the users had been included in the process. On a commission for the vendor, we explored these issues more thoroughly. By talking to the different stakeholders, the Nursing Association, the Directorate, users, the vendor and other key players, we recognized a strongly politicized process where the stakeholders had contrasting interests (Latour, 1987). We pinpointed how the Norwegian Nursing Association's envisioned neutral process became inherently political. Through our increased knowledge on this issue, we took part in debates at meetings and workshops, and consequently we increasingly became part of the process ourselves assessing pro and cons for the different strategies. However, in this process, we sometimes found it difficult to inform the vendor about everything the informants told us even if we did this on a commission from the vendor. This was particularly related to highly political positions and strategies, such as reasons for keeping the vendor and the current users out of the process as compared to ordinary user requirements, which the users really wanted us to convey to the vendor. One reason for our self-imposed restrictions was that we wanted our research to be taken seriously by all of the involved stakeholders (Atkinson et al., 2003).

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# Personal Health Records in the US and Denmark: From visions to versions?

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## Introduction

One finds many organizational visions for the introduction of health information infrastructures (HIT) and the vision for personal health records (PHR) exemplifying this has gained prominence over the past decade. PHR has been defined as internet-based, lifelong health records that are controlled by the individual and are meant to promote the individual's engagement in his or her healthcare as well as to make critical patient data available across healthcare delivery sites. Nonetheless, PHR as an organizational innovation remains a vague and contested vision, characterized as being "in its infancy" (Gearson, 2007). Moreover, competing ideas and technological views on PHR have taken shape (Tang & Lee, 2009), adding to confusion and uncertainty about the possible trajectories and likely outcomes of this health information technologies (HIT) innovation. Parallel to this fluid debate one finds a number of stakeholders actively engaged in the development and testing of prototypes and experimental systems. This raise the question: how do these PHR organizing visions translate into actual working systems? What elements of the PHR visions get amplified, disappear from view and what new components are added in the translation from vision to physical system?

We explore these questions by taking our point of departure in US-based PHR organizing visions (Davidson, Østerlund, & Flaherty, Under Review). Swanson and Ramiller (1997) (p. 460) define an *organizing vision* as “a focal community idea of the application of information technology in organizations ... a vision for organizing in a way that embeds and utilizes information technology in organizational structures and processes.” To address these questions we review two PHR prototypes: HealthTransitions developed in the US and myRecord developed in Denmark.

## PHR Organizing Visions

Based on extensive discourse analysis Davidson et al (In Review) distinguish one general PHR vision and five variations on this vision. Here we focus on the overall PHR vision and the fifth variation: PHR as applications, as the two prototypes we analyze fall closest to this version of the PHR vision. We argue that these visions diverge in terms of 1) the innovative community participating in the promotion of the vision, 2) the core technologies and organizational practices related to the health data management, and 3) the institutional arrangements which will support each version of the vision.

## Two Prototypes and their Visions

Both prototypes are relatively small endeavors compared to large-scale systems by for instance Kaiser Permanente, Google, and Microsoft. They develop out of *innovation communities* dominated by health professionals from teaching hospitals and university based information system scholars. They are supported by government funding and have sought collaborations with HIT vendors only after prototypes were developed. Neither have close collaborations with healthcare foundations or provider professional organizations beyond the teaching hospitals involved in the collaborations. The innovation community associated with myRecord includes researchers in Cardiology, Health Informatics, Computer Science, and Sociology (see [Http://cith.dk](http://cith.dk)), where HealthTransition involved researchers and practitioners in pediatrics, family medicine, social workers and service coordinators, information management and information science (see [Http://healthyTransitionsNY.org](http://healthyTransitionsNY.org)). Both projects have engaged patients and significant others, and in the latter case, also parents.

The *core technologies and organizational practices* of HealthTransitions and myRecord follow at the outset the general vision by striving to support the aggregation of data from multiple sources on a web-based platform where patients are able to enter personal health information.

At the same time they fall closest to the PHR as application vision by focusing on particular diseases and life-state application. HealthTransitions supports adolescents and young adults (ages 14-25 years) with developmental disabilities as they transition from pediatric to adult health care. It targets youths, family caregivers, service coordinators and health care providers. The site strives to support a number of activities including: keeping a health summary, setting health goals, managing medications, finding community resources, speaking up at the doctor's office, scheduling appointments, facilitating service coordination, getting healthcare insurance, deciding about guardianship, and understanding the patient's disability. myRecord is designed to support patients with implantable cardioverter-defibrillators (ICDs) living at home and their providers (Andersen, Bjørn, Kensing, & Moll, In Press). It allows patients and providers to jointly monitor the ICD and access an overview of the patient's condition. It support activities like: maintain overviews of consultations and medication, keep a diary, communicate symptoms and raise questions, manage health contacts, support document sharing.

When it comes to *institutional arrangements* the two prototypes build on the general vision of obtaining higher quality service through increased accountability of patients by empowering them to manage (some of) their personal health data. Equally important the prototypes strive to integrate an otherwise fractured health information system by facilitating the collaboration and communication among a distributed and heterogeneous group of patients, significant others, and healthcare professionals.

## Discussion and Conclusion: Visions to Versions

The *innovation community* associated with both projects has been changing since their inceptions, with patient groups being enrolled as participants early on and HIT vendors joining later in the process. However, the core innovation community remains the research-based participants. For instance, HealthyTransitions started out as collaboration between a few physicians at a teaching hospital and information management researchers at an adjacent university. As the project progressed more participants joined the community. First, the researchers engaged patients and parents to learn about their information needs and some of these became active participant in the project. Social workers and family physician also joined the effort as those subgroups deemed particular important for the information needs of the patients and their parents. A small IT company joined the effort to assist in the building of the prototype. myRecord emerged around its core research project, CITH and the prototype developed has only recently been handed to a HIT vendor in the hope of developing a more stable and scalable system which can be used in a clinical trial. How the vendor will execute the system is too early to judge.

One also finds changes in the *core technologies and health data management* from the broader vision to the prototypes. Where both projects envisioned connectivity via mobile devices neither have yet to realize the idea. Similarly the research oriented communities initiating the projects started out with the vision of joining information resources and coordinating data management in a heterogeneous community. However, in both projects the prototypes have to date ended up paying significant attention to patient education and facilitating the doctor-patient encounter by assisting the patients to prepare for consultations with their care providers. This includes educating the patients about their health status and how to actively participate during consultations. HealthTransitions, for instance, strives to help patients set health goals, manage medications, finding community resources and speaking up at the doctor's office. Likewise, myRecord helps patients to prepare for their consultations by prompting them to answer questions defined by the cardiologist, update their medication list and raise questions to be addressed at the consultation.

Finally, when it comes to *institutional arrangements* we find that through their development the prototypes have maintained their commitment to empower the particular patient groups by promoting patient-entered data in their focus. However, to avoid too much complexity both have shied away from the original vision of integrating data in a fractured health care system. For instance, HealthTransitions has spent significant time simply gaining permission from hospital IT management to develop a web-based prototype containing patient entered data and facilitating provider-patient communication. Integrating EHR or other provider generated data into the prototype would require substantial financial and political capital. These early prototypes also show that empowerment comes with a cost, and not all patients are ready to engage actively with their disease, especially at times when they feel well. Healthcare professionals found patient generated data valuable but they also raised concern that the final systems should not increase the time used on each patient.

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# Perspectives on Infrastructural Challenges in Persuasive Personal Monitoring Systems

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**Abstract.** An increasing number of persuasive personal healthcare monitoring systems are being researched, designed and tested, many of them being based on Smartphone technology. However, many of these systems are designed as isolated islands focusing primarily on supporting the needs of the patient and to a less extend designed to exist and run in an ecology of existing treatment procedures, clinical practices, and computer systems – in short; the existing infrastructure of healthcare. This abstract contains perspectives from patients and clinicians on the challenges of situating a persuasive system for bipolar disorder in the existing infrastructure around the treatment of this illness. The paper derives it empirical founding in the design and development process in the MONARCA project; MONitoring, treAtment and pRediCtion of bipolAr Disorder Episodes.

## Introduction

Persuasive personal monitoring systems have been suggested for the management of a wide range of health-related issues. These types of systems help users by enabling them to monitor and visualize their behaviors, keeping them informed about their physical states, reminding them to perform behaviors or tasks, providing feedback on the effectiveness of their behaviors, and recommending healthier behaviors or actions. In addition to numerous studies on general behavior change (Oinas-Kukkonen, 2010), research has also targeted health-related behavior change such as physical activity (Lin et al., 2006; Consolvo et al., 2008), healthy

eating habits (Pollak et al., 2010), cardiac rehabilitation (Maitland and Chalmers, 2010; Korotitsch and Nelson-Gray, 1999), and the management of chronic illnesses like diabetes (Mamykina et al., 2006; Smith et al., 2007), chronic kidney disease (Siek et al., 2006), and asthma (Lee et al., 2010).

Persuasive monitoring systems also have the potential to help with the management of mental illnesses such as depression, bipolar disorder, and schizophrenia. These systems can monitor data on mood, behaviors, and activities, providing timely feedback to patients in order to help them adjust their behavior. Review of data by both patients and clinicians can support illness management in a multitude of ways. For example, patients and their clinicians can use the data to determine the effectiveness of medications, find illness patterns and identify warning signs, or test potentially beneficial behavior changes. Data collected could be used to predict and prevent the relapse of critical episodes. Through persuasion, systems can help patients implement preventative long-term habits and effective short-term responses to warning signs.

However, most of these systems have – for very understandable reasons – primarily been designed from a patient’s perspective, trying to answer the question of how the system should work in order to help the patient adopt healthy behavior, which in the end would help management and treatment of the illness. Less attention has been paid to the ecology of these systems – i.e., how these persuasive healthcare systems are to be situated in the overall ecology of existing treatment structures, clinical practices, and technologies.

In this paper we want to highlight some core questions related to considering the “situated” nature of such patient-focused persuasive systems in a greater infrastructure of established clinical treatment, practices, and technologies. The paper builds on experience from the MONRACA project<sup>1</sup>, aiming at designing a persuasive system based on Smartphone technology for treatment of bipolar disorder. The MONARCA project is a cross-institution effort to develop and validate solutions for multi-parametric, long term monitoring of behavioral and physiological information relevant to bipolar disorder. The focus of this paper is the user-centered design process for the development of the mobile phone application within the project.

## Perspectives in Design

We have found that one way of dealing with the tension between the patient-focused system design and its situated existence in a clinical infrastructure, is to talk about perspectives in design. There are several perspectives to consider, but for the simplicity of this paper, we will focus on the “patient perspective” and the “clinical perspective”, and the inherent questions and tradeoffs between these. The patient and clinical perspectives represent the two broad groups of users of a

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<sup>1</sup> See <http://www.monarca-project.eu/>

persuasive system. These perspectives and their associated questions are illustrated in Table 1. The table consists of a range of questions to be addressed and considered in the design process of a persuasive healthcare system.

<b>Patients,</b> relatives, communities of patients	Adoption	What do patients gain from using the system? What will motivate them to use the system? What can patients learn about themselves, and what can they and others do with this knowledge? Does the perceived value of using the system outweigh the burden and sacrifices?
	Acceptance	Will the system fit into the daily lives of patients, including aspects that are, and aren't, related to their illness? How will the system handle fluctuations in the health and stability of patients? Is the system perceived as trustworthy by the patient and others? Who gets access to the data?
	Sustained use	Do the type of data collected and the method of collection make the patient feel comfortable enough to divulge frequent and honest personal information? Is data collection nonintrusive and convenient enough that regular use of the system can be sustained?
<b>Clinicians,</b> doctors, nurses, GPs, therapists, nursing home staff	Adoption	Does the system use evidence-based treatment strategies? Does the system adhere to clinical practices? Can it be incorporated into typical interventions and treatment? Do the clinicians and their organization have the resources to run the system? Do they have the skills?
	Acceptance	Does the system present a liability for clinicians? Is the system going to impose an additional workload on the clinicians? Does the system encourage patients to make decisions without consulting a clinician – whether explicitly or implicitly? Or does the system assume increased communication between the patient and clinician? Will the system bypass normal patient-clinician communication channels?
	Sustained use	Are the data collected relevant, applicable, and customizable for a variety of cases? Is the data presented to clinicians in a useful and convenient way for analysis to support decision-making? Does the solution scale over many patients over long time? How can the system provide evidence for continuous improvement in clinical care and treatment?
	Infrastructure	Is the system integrated with existing systems in the clinic, like electronic medical records? Will data flow into the back-end biomedical infrastructure of the clinic? Will data from the clinical systems flow into the system, like medicine prescriptions? Are sufficient resources and technical infrastructures in place for hosting, running, and maintaining the system? What are the consequences for the incentive and reimbursement infrastructure in the healthcare organization?

**Table 1. The two perspectives in design, identifying different, sometimes conflicting, concerns and questions to consider in the design of persuasive monitoring healthcare systems.**

## Patient Perspective

The patient perspective attempts to capture the perspective and motivations of the patient's realm, including the patient him- or herself, his relatives, friends, community of other patients, and other stakeholders that are present in this part of the system. From the patients' perspective, important questions to address in the design of persuasive technology are related to adoption, acceptance, and sustained use. For example, in order to foster patients' and relatives' to adoption of the

technology, it is important to consider questions like: What do patients and others gain from using the system? What will motivate them to use the system? And; what can patients learn about themselves, and what can they and others do with this knowledge? Similarly, for patients and others to accept the technology as a part of their lives and routines, the following issues should be addressed: Will the system fit into the daily lives of patients, including both aspects that are and aren't related to their illness? How will the system handle fluctuations in the health and stability of patients? Are sufficient levels of privacy and confidentiality established? Finally, for use of the technology to be sustained over time, we should consider the following issues: Do the type of data collected and the method of collection make the patient feel comfortable enough to divulge frequent and honest personal information? Is data collection nonintrusive and convenient enough that regular use of the system can be sustained?

## Clinical Perspective

The clinical perspective is attempting to capture the perspective and motivations in the clinical realm, including nurses, doctors, residents, interns, nursing home staff, therapists, and other stakeholders in the more institutionalized part of a healthcare organization. Similar to the patients' perspective, important questions to address from the clinicians' perspective, in the design of persuasive technologies are also related to the issues of adoption, acceptance, and sustained use. For example, in order for clinicians to adopt a persuasive healthcare system, it is crucial that it can provide evidence for improved patient treatment and care, and it must adhere to established clinical practices while being incorporated into the daily clinical practice in the clinic that is going to host the system. Similarly, concerns about acceptance by clinicians are related to whether they are able to document their care and treatment when using the system, and whether the system would bypass normal patient-clinician communication channels and potentially impose additional work on the clinicians' part. And in order to ensure sustained use by clinicians, important issues are related to providing evidence for long-term improvements in care and treatment, and long-term usability issues like the scalability of the system in terms of handling many patient over longer periods of time. The latter often implies support for access to concise patient overviews and notification mechanisms.

In addition to the concerns about adoption, acceptance, and sustained use, concerns for embedding the system into the technical and organizational infrastructure of the clinic is crucial to the success of a persuasive healthcare system. It is important to consider how the system integrates and works with the existing clinical systems infrastructure. For example, how will the data from the persuasive system be moved to the electronic medical record (EMR) and vice-versa, how will relevant data like medicine prescriptions be synchronized from the EMR to the persuasive healthcare system? Moreover, the over-all organizational socio-

economic context of the clinical system setup needs to be scrutinized. For instance, will the clinic be reimbursed for their service to patients using the system? In Denmark, for example, clinics only get reimbursed when a physical consultation between the patient and a doctor takes place.

## Asking the Right Questions at the Right Time

The questions can be asked both in the design of a new persuasive technology – which is the case in the MONARCA project – as well as in the organization and clinical implementation and use of an existing system. Therefore, when we in the following use the term “design”, we mean both technical systems design as well as organizational design of usage and work practices involving the system.

The questions are to be asked and used within a user-centered, participatory design process. Hence, the three groups of stakeholders (patients, clinicians, and designers - PCD) should work together in various workshop sessions like future workshops, prototyping workshops, organizational prototyping workshops and evaluation workshops. In this user-centered design process, the questions are constantly addressed and gradually answered. The aim is not to ensure that the system has a positive answer to all of them; the aim is merely that the different questions are addressed and a conscious and shared consent on the item is reached. For example, there might be an inherent conflict between the need of patient to constantly contact the clinic, and the clinicians need for shielding themselves from a massive telephone storm from anxious patients – a tradeoff existing between the patients’ concerns in achieving sustained use versus the clinicians’ concerns of acceptance (see Table 1). This conflict may not be solvable, or a decision may be taken to allow for patient to call their doctor directly – as we did in the design of the MONARCA system. As such, the systems will shortcut normal patient-clinician relationships, but in this case this decision has been deliberately taken. And we know that this decision and system feature will introduce problems if the system is going to be deployed in a large-scale setup. Handling and dealing with tradeoffs in the PCD framework is discussed in the next section.

When asking the questions, we argue that it is important to always consider both stakeholder dimensions. Even though some persuasive healthcare technologies are entirely targeted towards the patient’s perspective, and leaves out the clinical perspective, we argue that it is still important to consider the clinical perspective for several reasons. First, if the system cannot provide clinical evidence, then the success of the system may be hard to obtain, at least in the long run. Moreover, any personal healthcare appliance or system seldom exists in vacuum; often these systems and the data they provide are brought to the clinic or the GP’s office. Hence, even though the clinical use of a system may seem limited, it still needs to be designed with its role in a clinical context in mind.

## Summary

We have presented perspectives on the challenges in developing persuasive monitoring healthcare systems for treatment of patients. The aim was to illustrate the tradeoffs and questions that need to be asked when such systems are to exist and work in an overall clinical infrastructure. We will be able to present further designs and results from our design and development process during the workshop presentation.

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# Open and flexible Infrastructures: Scaling across diverse settings through open software, open standards, and open architecture.

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**Abstract.** Many poor countries developing health information systems face huge challenges of uneven infrastructural development. This relates both to the physical infrastructure such as internet, and even electricity, but also of skilled people and organizational maturity. While cities can offer the latest in technology, there can easily be a wide range of different context in other parts of the same country. In this paper, we argue that free/open source software, open standards, and an open-ended architecture are appropriate for such a setting. We use the case of Sierra Leone to illustrate this.

## The challenge of integration and uneven development

The design and implementation of sustainable, functional, scalable and comprehensive health information systems (HIS) based on Information and Communication Technology (ICT) is difficult. Particularly so in many developing country contexts where technical infrastructure, power, connectivity and skills may be unevenly distributed across urban and rural areas (Braa et al, 2007). In this paper we present an architectural perspective which has evolved in part from lessons learned translating Health Metrics Network's (HMN) health

information system framework guidelines (Health Metrics Network, 2008) into a practical implementation in Sierra Leone.

Growing consensus on the vital role of information and good information systems in the provision of health services lead to the launch of the HMN, a partnership hosted by the World Health Organization (WHO), in 2005. The HMN provided global leadership as well as a consensus-based overall strategy for the development of national HIS – conceived as interoperable sub-systems within a national framework where aggregated data from the subsystems are integrated and made available in a national data repository. However, when the HMN Technical Framework advises countries to implement a central data repository receiving data electronically from sub-systems and the peripheral levels, it presupposes uniform access to a wide area network like the Internet. Furthermore, when many of the data sources are paper-based, as is the dominant tendency in Africa, new ICT solutions need to be established and interoperability created based on the available infrastructure, which ranges from a complete lack of power and connectivity through portable data systems, such as USB memory sticks all the way to mobile networks and the Internet.

Our case study, Sierra Leone, presents a typical example of fragmented health information systems and uneven development. Various health programs, such as malaria, mother and child health, extended programme on immunization, HIV/AIDS, etc, maintained separate information streams. This resulted in both a certain degree of overlap, for example the mother and child health programme also collecting data on malaria and HIV (for pregnant women, infants, and children), and also incompatible electronic platforms where such existed. The results are a higher burden of data collection, typically leading to lower quality, and at the same time the unavailability of relevant data for decision making. Even though more data than necessary was collected, much less was available to any single person. At the same time, these structures were reinforced by global partners, who are typically themselves organized in a fragmented manner (for example; UNAIDS for HIV, UNICEF for childrens health, various departments of WHO, etc).

Sierra Leone also presents extreme differences in infrastructure. While never a given, electricity is more stable in the capital, Freetown, and the Ministry of Health had reliable internet connection. But in the districts, even those district offices which had generators had very variable supply of fuel, and everything became even more unpredictable during the rainy season.

To solve the challenge of creating a central data repository in such a setting, we argue that an open and flexible architecture which can take root and thrive on sub-optimal infrastructure was necessary. This architecture is dependent on a) a technology-neutral scaling model, i.e. able to function across paper, stand-alone computers, and cable and wireless connection, and b) an open standard for



statistical data transmission, allowing various sub-systems to integrate through the data repository.

## Defining the architecture:

The problem of fragmented data flows and reporting systems is addressed by an overall enterprise architecture approach where aggregate data from the various data sources are integrated in a shared data warehouse. This is the framework within which we apply our proposed open architecture. Further, we distinguish 3 levels; organisational, application and data interoperability.

At the organisational level the primary task was to achieve consensus and a common vision between health program management teams. This level of integration is an essential enabler for the harmonisation of data elements, redesign of routine paper forms and development of a national health information dataset. It is the single most important factor in reducing the burden of redundant data collection, reducing duplication and increasing data quality. The relationship between organisational integration and practical implementation is nevertheless complex. The practical implementation and use of appropriate solutions at the application level in turn plays a role in mediating negotiation at the organisational level.

At the application layer the plethora of existing data management tools (mostly spreadsheets) is progressively replaced by a purpose-designed health information system software (DHIS2 <http://www.dhis2.org>) which is sufficiently flexible to meet the requirements of the health districts as well as a national data warehouse. Data from chiefdoms and facilities is entered from the paper forms at each of the 12 districts and monthly aggregate reports are fed up to the national level, taking advantage of whatever transport is available – typically this is email using a dial-up wireless internet connection. Feedback resulting from aggregation and analysis is returned through the same channels. Whereas DHIS2 provides the backbone of the information system, it needs also to be able to source aggregate data from other systems – in particular the patient record system used for ART management in Connaught Hospital and the anticipated human resource planning and logistics systems of the Ministry of Health and Sanitation.

Data interoperability with these systems has been tested using a WHO-driven open standard for exchange of statistical health domain data and metadata (SDMX-HD). The use of an open standard was preferred over the ad-hoc XML format which is native to the DHIS2 software. The WHO mediated open process around the standard provides a managed terrain for vendors, developers and end users to reach agreement on the fundamental interoperability requirements.

## Conclusions and lessons

The ICT infrastructure in Sierra Leone continues to pose challenges. District users cannot directly access the national server via the web. Software is deployed on commodity hardware and maintenance of the district sites demands more dispersed and comprehensive skills than would typically be required in more developed settings. The DHIS2 software is deployed on a linux platform and workstations are running Microsoft Windows. The workstations suffer regular virus problems and are frequently reinstalled by local IT companies in the districts. The linux servers have proved more robust, but when there are problems (usually related to power outages and network equipment failure) they are not easily solved locally at the district. Despite this fragility, the health information architecture has survived and continues to provide a rendezvous point for useful health management information. As the system continues to provide increasing value in terms of health management information it acts as a driver and advocacy focus for improvement of infrastructure and better governance.

Human and technical infrastructures and connectivity are unevenly developed and distributed in most poor countries. Scaling strategies and the involved solutions need therefore to be flexible. A country will need a wide range of systems; systems for management and statistical data, medical records, birth and death registration, human resource systems, lab systems, pharmacy and logistics tracking systems etc. Uneven infrastructure means that these different components will be introduced and scaled according to maturity and infrastructure. The use of open source and open standards has enabled the growth of a regional community of practice across West Africa. The landing of ever more cables around the coast of Africa offers a further possibility to circumvent many infrastructure problems by hosting systems in “the cloud” using IAAS or SAAS models. This is a strategy currently being pursued in the implementation of HIS in Kenya. We hope to be able to compare these experiences in a later paper.

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# Towards a Software Ecosystem of Health-care Services

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## 1 Introduction

Telemedicine<sup>1</sup> has a long and reasonably successful history in sparsely populated countries like Australia, Canada and Norway (Wootton, 2001; Smith et al., 2010). However, in densely populated countries and areas, uptake has been slow and the economic benefits small or non-existent (Medcom, 2010). In Denmark for example, telemedicine seems to be caught between national standardization initiatives and local experiments. Thus, on the one hand, new standard infrastructures are developed and deployed while, on the other hand, new, local experiments, e.g., supporting patients with a chronic disease, are developed without connection to this infrastructure.

Currently, a number of initiatives are being formed in order to address this situation. On an international level, the US and the European Union are entering an agreement on interoperability and minimum data sets for electronic patient records (Mosquera, 2010). At the same time large national initiatives are being carried out in, e.g., England and Denmark to deploy national and regional electronic healthcare records as well as selected national healthcare services, e.g., the “common medicine card” (FMK)<sup>2</sup>. These initiatives so far do not include concerns for international interoperability nor effective means for supporting accelerated deployment of telemedicine. Thus numerous, uncoordinated local experiments are still being initiated; and in the light of the quite dramatic development in demographics and the continuing development in technology one may expect creation of new local experiments to continue.

In this paper we suggest that instead of trying to improve uptake, efficiency, quality etc. through more emphasis on the existing strategies like standards and interoperability one should take a different approach based on the concept of software ecosystems. In this way we expect to be able to point to new possibilities for creating more viable healthcare services and accelerate uptake. A ‘software ecosystem’ may be defined as “the set of software solutions that enable, support and automate the activities and transactions by the actors in the associated social or business ecosystem and the organizations that provide these solutions” (Bosch, 2009) where a social/business ecosystem “consists of actors, the connections between the actors, the activities by these actors and the transactions along these connections concerning physical or non-physical factors” (Bosch, 2009; Bosch and Bosch-Sijtsema, 2010). See also (Moore, 1993) and (den Hartigh and van Asseldonk, 2004) for

<sup>1</sup> In this paper we use the term ‘telemedicine’ to denote ICT-supported healthcare services where some of the people participating in service delivery are not co-located with the receiver of the service

<sup>2</sup> <http://www.nsi.dk/Projekter/FMK.aspx>

applications of the ecosystem concept to business. Examples of software ecosystems include Apple's iOS platforms, Google's Android, and Microsoft's Office platform.

While software ecosystems share such goals as cost reduction and reduced time-to-market with software reuse (and software product line) approaches, it differs organizationally in terms of a focus on contexts of use and technically in terms of building on a common platform. Many issues with generic software component reuse have been resolved in software product lines through reuse of assets other than software (Bass et al., 2003). Software ecosystems build on this approach.

## 2 The Current Healthcare Services Ecosystem

Figure 1a) illustrates central aspects of current Danish (telemedical) healthcare services using the SEM notation of Boucharas et al. (2009). The figure shows the telemedicine application RRS (Remote Rehabilitation Support<sup>3</sup>) that among others provides postoperative support for patients that have had total hip replacement. While RRS uses the services of the telecommunication provider TDC that owns the fixed-line copper network, it does not use the services of MedCom<sup>4</sup> including the national health data network or FMK. And the FMK illustrates some of the difficulties in the current set-up: It is a national initiative which should have been fully deployed in 2010. However, current plans state that a first launch is expected in 2011. And this first version will not include the general practitioners, a group which is vital for many telemedicine applications. National Health IT (NSI) provides national management of Danish healthcare IT and are responsible for FMK and others. In essence, each of the telemedical applications form an isolated ecosystem with FMK, NSI, and MedCom forming another.

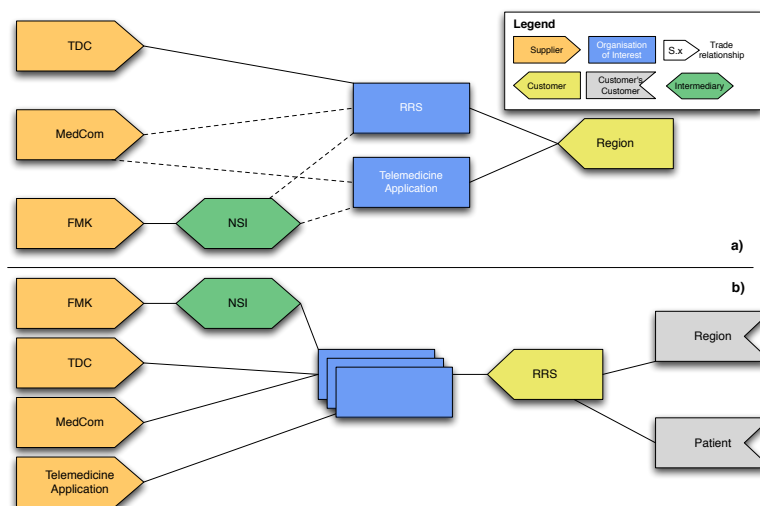


Figure 1. a) Software Supply Network (SSN) diagram for current healthcare services; the value flow is not shown. Dashed lines show connections that would be valuable, but that do not exist. b) SSN diagram for possible future services.

<sup>3</sup> <http://www.caretechinnovation.dk/en/projects/index.htm#RRS>

<sup>4</sup> MedCom is responsible for the Danish national health data network (SDN) and for certifying conformance to MedCom defined standards. <http://www.medcom.dk/wm109991>

## 3 A Connected Healthcare Services Ecosystem

Rather than supporting separate systems of healthcare services (cf. Section 2), a model for a possible common ecosystem is shown in Figure 1b. The figure illustrates that national and locally developed services (e.g., provided by the “Telemedicine Application”) are made available through a number of organizations (cf. Section 3.2) from which RRS purchases/consumes services. The strategies pursued by the actors in an ecosystem provide a high-level characterization of an ecosystem. However, we are interested in promoting the formation of a new ecosystem for telemedicine. In order to ensure that such an ecosystem is ultimately both viable and beneficial to its members, we must consider the incentives that are in place for each actor to perform in accordance with the vision for the ecosystem as a whole.

### 3.1 Make standards *and* implementations

The national standardization initiatives are in the current system disconnected from the local one-of-a-kind systems aimed at needs of particular niche domains. The developer of a local pioneering solution for a specific domain has two primary goals: First, ensuring appropriateness of the solution for the niche domain, and, secondly, getting a functional prototype or product ready quickly and efficiently. Conformance to and development of national standards is at best a distant third priority. Reuse of existing and free software components is a means to achieve the second goal. If standards-compliant core components such as for example communication and integration were freely available, this would thus help developers. More importantly, it would provide a way to leverage the experience of developers of local niche solutions in the standardization process.

First, if these components are available under open-source licenses, the developers could, if needed, modify them to ensure their solution is appropriate for the niche domain. If such components are modified, then knowing what modifications are made for a particular domain would be valuable input to the standardization process. Secondly, if the developers use such components, even in a modified form, their solutions would be much closer to conforming to standards compared to similar examples in existence now.

### 3.2 Ensure access to trusted components

Even the most useful third party components and solutions are only beneficial to consumers if available and of sufficient quality. We envision that an entity akin to, but more general than, Apple’s “App Store” would be beneficial to the ecosystem. First, it would provide a way for developers to locate third party components for re-use. Secondly, it would provide a mechanism to help market their products. Thirdly, it could be integrated with a certification authority that would gauge the quality of components. Several aspects of quality could be considered, including reliability and performance, user satisfaction, and compliance with legal requirements.

In summary, we envision the formation of one or more organizations responsible for: 1) Standardization of data models, protocols etc., 2) implementation of open source components, 3) certification of components, and 4) managing a market place for services and reusable components.

The organizations responsible for these areas must consider, e.g., the licenses of software available in the ecosystem, how solutions are funded and consequently which business models will be supported, and which platforms that can be used in the ecosystem.

## 4 Future Work

We find it reasonable to expect that the suggested approach will lead to improved ICT support for healthcare services, mainly through better interactions between national and local ICT initiatives. However, in order to drastically speed up uptake, the economic benefits for the involved companies and public authorities have to be improved beyond what can be achieved through better ICT support only. To achieve this, and combine such improved economics with better quality and availability of healthcare services, ICT support has to be co-developed together with the organization of service delivery. To the best of our knowledge, no commonly accepted, validated models for this exist. Furthermore, it is not clear how the (software) architecture of such a software ecosystem should be designed. Thus the best way forward seems to be to combine research on international best practices with a small number of practical experiments on co-development where the ecosystem approach is extended to cover both ICT support and organization of service delivery.

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# A Formal Approach to Distributed Coordination of Healthcare Workflows

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**Abstract.** We exemplify and discuss a recently developed technique for distributing workflows described formally in the declarative Dynamic Condition Response Graphs model on an oncology workflow obtained from a field study at Danish hospitals.

## 1 Introduction

Healthcare workflows involve coordination of a heterogeneous set of professionals, patients, organizations and sectors, and must be able to adapt to inevitable changes of treatment processes and organization of the work (John Fox (1998); Terenziani et al. (2004)).

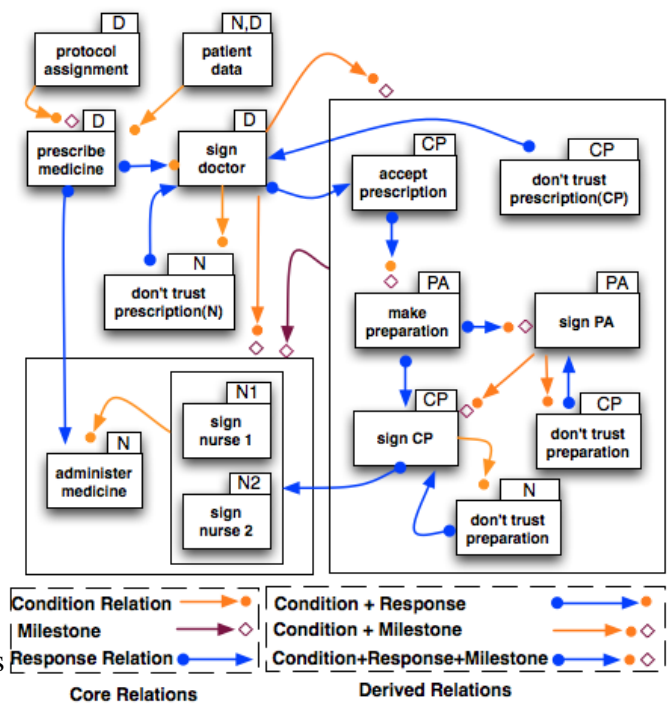
The overall goal of the Trustworthy Pervasive Healthcare Services (TrustCare) project funded by the danish research agency for strategic research is to address this challenge in a strategic and interdisciplinary research effort in collaboration with the industrial partner Resultmaker, a small danish provider of workflow and e-government services.

As part of the project we have developed a formal declarative workflow language called Dynamic Condition Response Graphs (Hildebrandt and Mukkamala (2010); Hildebrandt et al. (2011)), which generalizes the Process Matrix model developed by Resultmaker as a flexible declarative process model. A number of researchers have advocated the use of declarative process models to represent requirements of process-aware information systems used by knowledge workers, as it is the case in the healthcare domain (Chesani et al. (2008); van der Aalst et al.

(2009); Mulyar et al. (2008); Chesani et al. (2007, 2006)). One argument is that declarative process models are closer to the way requirements are usually specified than the typical imperative process models, such as BPMN or Petri Net, based on flow graphs that specify particular ways to implement the requirements, and thus only indirectly represent the requirements. Even worse, this typically leads to over constraining the workflows, in turn leading to rigid and inflexible systems (Mulyar et al. (2008); van der Aalst et al. (2009)).

In this paper we show how an oncology workflow obtained from a field study carried out at Danish hospitals (Lyng et al. (2008)) can be represented as Dynamic Condition Response Graphs (DCR Graphs) and demonstrate a recently developed technique for deriving a distributed version of the workflow. The distributed workflow consist of a set of DCR Graphs, one for each actor, equipped with the necessary interface events that are the results of tasks carried out by actors at other locations.

DCR Graphs have five basic relations between activities, namely: *condition*, *response*, *milestone*, *include* and *exclude*. The last two relations are used for dynamically including and excluding the activities in a workflow. In this paper, we will limit our discussion to the first three relations only. The chemotherapy treatment workflow modeled as a DCR Graph is shown in Fig. 1.



Activities in DCR Graphs are represented as rectangles with the role markings on the top right corner. Sometimes, the activities can also be represented as nested sub-graphs, such as *medicine preparation* as shown in Fig. 1 as a rectangular box around some child activities. In case of nested sub-graphs, the relations pointing from/to them are applicable to all the child activities. For example, the milestone relation from the *medicine preparation* nested sub-graph to the *administer medicine* nested sub-graph results in milestone relations from all the child activities of *administer medicine* to all the child activities of *medicine preparation*. Furthermore, a derived relation is a short handed notation for representing more than one relation between activities.

The condition relation imposes precedence between the activities in a workflow, whereas the response relation imposes a follow-up relation between the activities.



For example, the condition relation between *patient data* and *prescribe medicine* states that *patient data* must have been done at least once before *prescribe medicine* can happen. Dually the response relation from *prescribe medicine* to *give medicine* means that whenever *prescribe medicine* happens, *give medicine* must happen at a later point in time as a response. Similar to the condition relation, the milestone relation is also a blocking relation, but it will only block if its preceding activity has a pending response. The milestone relation (as part of condition+milestone) between *sign doctor* and the nested sub-graph *medicine preparation* indicates that, in order to do any of the child activities of *medicine preparation*, the *sign doctor* activity should not carry any pending responses on it.

## 2 Distribution

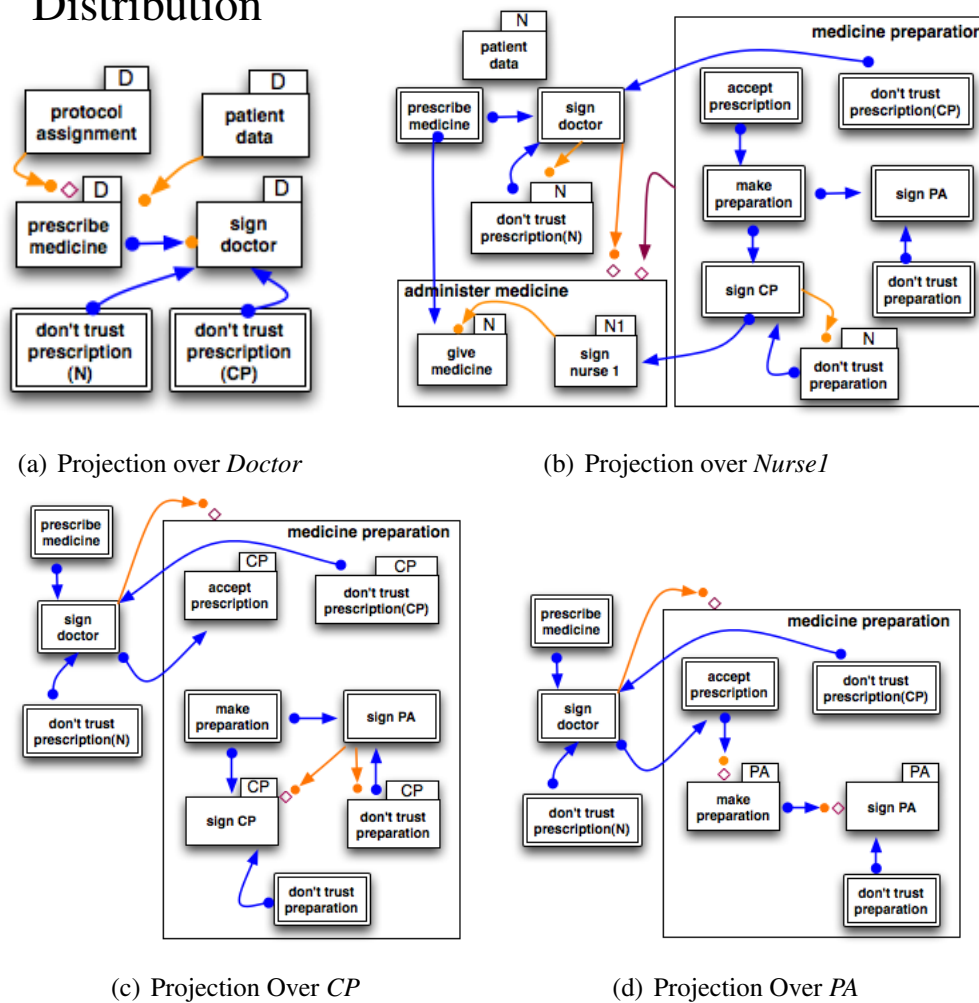


Figure 2. Projecting Workflow Over Different Roles.

A dynamic condition response graph can be projected according to a projection parameter, which consists of a set of actors, a set of roles and a set of activities, to a projected graph which represents a subset of the functionality described by the full graph. In most cases the parameter will be chosen so that the projected graph shows the full responsibilities of a specific role or actor. A set of DCR Graphs can

be executed in a distributed fashion, meaning that there is a separate implementation for every graph and that the execution of shared activities is communicated between them. The original graph can be seen as a *choreography*, describing how the system as a whole should function, from which we project multiple end-points for individual roles or actors that can be implemented independently.

Fig. 2(a) shows the projection for the role *Doctor*. When projecting to this role, we start by selecting the *internal activities*, i.e. activities that have the role *Doctor* assigned to them. We also include all relations between these activities. We then select all activities with other roles that have a relation pointing to an event with role *Doctor*; these are *external activities* that can directly influence the internal activities and we need to include them (but without role assignment) in the graph so that we know when internal activities are allowed to be executed or when they are required as responses to external activities. In the example these are the two *don't trust prescription* activities, because they place a pending response on *sign doctor* when executed. We include these activities and relations from them to internal activities. They indicate that the workflow of the doctor should subscribe to events from the workflows for role (N) and role (CP) signaling the execution of their *don't trust prescription* activities. Similarly, the projection for the role (CP) has *sign doctor* as external activity, since it is a condition and milestone for the entire set of *medicine preparation* activities and requires *accept prescription* as a response. However, to know if *sign doctor* is required as a response and consequently by the milestone relation will block all *medicine preparation* activities, we also need to include the two activities *prescribe medicine* and *don't trust prescription (N)*, even though they are not directly related to any activities carried out by the CP.

A distribution is *safe* if the set of distributed executions corresponds to the set of executions of the original "choreography" DCR Graph. Not all distributions obtained from projections are necessarily safe, and in particular the distribution shown in Fig. 2 is not safe: If for instance the CP signs the preparation but subsequently changes her mind and decides that she doesn't trust the preparation made by the pharmacist assistant (PA) then PA in the global choreography graph shown in Fig. 1 would immediately be required to sign again as a response, which would immediately block the nurses from signing and administering the medicine because of the milestone relation between administer medicine and medicine preparation. However, this is not the case in the distributed graph, since the event that CP did not trust the preparation may not arrive to the nurse before he decides to sign and give the medicine. We have provided a formal characterization of when such race conditions can arise for a given distribution. The unsafe distribution in the example above can be solved in a number of ways which we currently investigate: First of all, one could ask the workflow designer to redesign the choreography graph in Fig. 1 such that no such race conditions can arise. Secondly, one could try to derive an algorithm to derive a safe redesign, essentially by adding activities that implement a pessimistic concurrency control mechanism, e.g. by locking activities. Finally, one could simply warn the users about unsafe activities and leave the option to coordinate between themselves how the situation should be handled.

## Acknowledgments

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# Evaluation of National Strategies – an Analysis of Status Reports

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**Abstract.** This paper deals with national strategies and status reports for e-health in Denmark. Four strategies have since 1995 been launched each with a different focus. In the middle of the period for the latest strategy we have seen a large number of status reports being published from different public institutions. These reports are analyzed and discussed. It is stated that the large number of ambiguous reports makes it obvious that there is no rational planning process in this highly complex area. But it would be natural to have a greater coherence with other related areas such as quality management, chronic diseases health plans and cancer programs.

## Introduction

According to Rossi et al (1999) the former governor of New York, Mario Cuomo described his mother's rules for success as (a) figure out what you want to do and (b) do it. These are pretty much the same rules that national strategies for developing and implementing health IT systems must follow. Strategy decision makers must identify the needs, and conceptualize a strategy capable of alleviating that need, and then implement it. Health IT and the electronic health record in particular is, however, a very complicated infrastructure, which is, according to one of the pioneers in health informatics Morris Collen "a more complex task than putting a man on the moon," (Collen, 1995). Add to this an infrastructure that constantly evolve and change its objective. From CPOE systems to home tele moni-

toring via comprehensive interdisciplinary clinical workstations and collection of health data for secondary use. Detailed studies of e-health and the programs reveal more asymmetry than symmetry, mainly due to the local practice and appropriation of the technologies. Various health care professions with individual work practice are using e-health systems (multi purpose). The systems change over time (eg. versions 0.1 to 2.0) and different clinical specialties calls for local appropriation.

Therefore, the complex task of developing and implementing integrated health information systems in the entire health care sector is hardly achieved within the lifespan of a single strategy. A rational approach for improvement between strategies would be to evaluate the progress achieved by each strategy and acknowledge the achievements and insufficiency. In this case study we examine to which extent this has been an issue by analyzing a number of e-health status reports published in Denmark in 2010. These status reports tempt to evaluate strategy plans and their implementation.

National strategies have been launched in Denmark in 1995, 2000, 2003, and 2008. The four strategies have been analyzed by Bruun-Rasmussen M., et.al. (2008), and assessed to what degree the strategy focus on five factors:

1. Business support: Support of health care process.
2. Technical infrastructure: The use of computer power, network with high bandwidth, wireless solutions etc.
3. Clinical infrastructure: How the IT systems can support the clinical work eg. Evidence based medicine, bioinformatics, genomics, drug reactions etc.
4. Governance: coordination and management; policies and requirements for the use of standards, terminology and the structure of data.
5. Stakeholder involvement: Involvement of parties who affect or can be affected by the strategy.

The differing focus in the four strategies was plotted in a radar diagram as in figure 1.

The first strategies from 1995 through 2003 had a clear focus on the technical infrastructure and the clinical infrastructure. During this decade the hospitals had implemented a great number of different stand-alone proprietary systems (between 200 and 400 systems in each region), and the public debate exhibited serious discontent with the bothersome work practice caused by non-integrated systems and extra cost arising from parallel development of systems. The strategy released in 2007 was presumably a response to this trend.

## Methods and material

The progress following each strategy has not been systematically evaluated. Preceding each new strategy there is, however a number of status/evaluation/progress reports analyzing a number of issues. There has been no systematic survey of all

these reports, but we have plunged down on year 2010 to investigate the reports from this year. A search on the web sites of the main actors in health informatics in Denmark revealed 6 different reports. They were all public accessible, characterized by a national approach, and had a health informatics infrastructure focus.

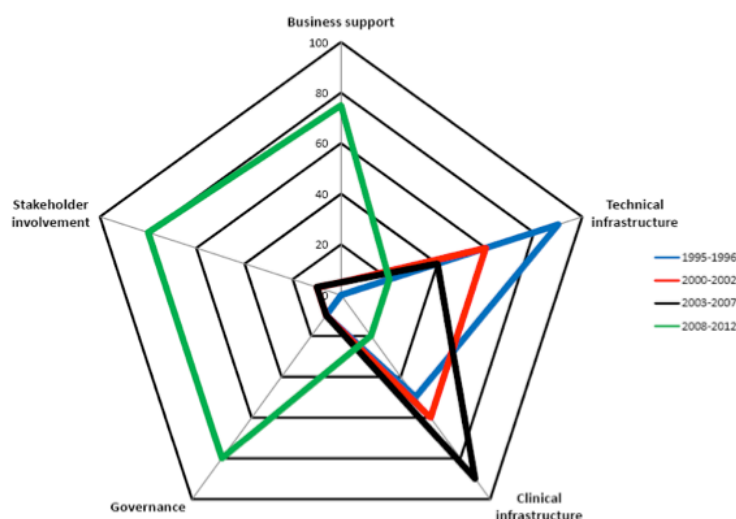


Fig.1. The different focus of the four health IT strategies.

The reports were examined to determine who commissioned the report, what was the terms of reference, who was the investigator, what methods were applied, what was the main focus and the main results.

In addition the magazine “Dagens Medicin” has asked the five regions to answer a number of standardized questions about the status of their EHR implementation. The reports examined here are published and can be accessed via the Internet (Finansministeriet 2010, Rigsrevisionen 2010, MedCom 2010, Next Puzzle 2010, Teknologirådet 2010, Digital Sundhed 2010)

## Results

The results of the survey are shown in table I. All reports are written in Danish language and the titles have been translated. The majority of the reports are made from the initiative of public authorities and commissioned to private consultants. A few of the reports are self-initiated. Interviews and questionnaires are the dominant methods applied. All the reports are not status reports in a traditional meaning with summaries of actions and statements about resources spent, but some also include new perspectives, new ideas and point at areas that should be included in the future.

Title	Commissioner	Terms of reference	Investigator	Methods	Main Focus	Main Results
Investigation of the health IT efforts in the Regions	Danish Regions, Ministry of Health, Mins-SDSD, Ministry of Finances	Not stated in the report	McKinsey & Company	Interview, questionnaire	Governance, financing	<ul style="list-style-type: none"> <li>• Insufficient insight in expenditure</li> <li>• Insufficient general view of technical matters</li> <li>• Insufficient background for IT investment</li> <li>• High degree of decentralization and fragmentation</li> <li>• Limited co-operation among the regions</li> <li>• Insufficient use of best practice</li> <li>• Insufficient coordination between the regions</li> <li>• No common goal on the national level</li> <li>• The Ministry of Health has launched three standardization councils to ensure communication standards are used</li> <li>• The Regions have consolidated their infrastructure</li> </ul>
A memo on IT support of the hospitals tasks	Audit of the state accounts	Not stated in the report	Audit of the state accounts	Meetings, correspondence	Governance, Accomplishments	<ul style="list-style-type: none"> <li>• Main application areas:</li> <li>• Videoconferencing, Exchange of medical images, Home monitoring</li> </ul> <p>Barriers:</p> <ul style="list-style-type: none"> <li>• Economy, Jurisdiction, Clinical evidence, Cultural issues, Local differences</li> </ul>
Statement about tele-medicine	Ministry of Finances	Not stated in the report	MEDCOM	Not stated	Identify solutions, experience, and issues	<ul style="list-style-type: none"> <li>• From EHR to clinical workstation</li> <li>• Access to patient data (e-record for provider and patients)</li> <li>• Moving target according to demands and technological development</li> </ul>
Development in the Regional EHR-Landscapes	Region's Health IT Organisation (RSI)	Not stated in the report	Next Puzzle (Consultants)	Interviews, questionnaire	Dissemination, Consolidation	<ul style="list-style-type: none"> <li>• The seminar facilitated the exchange of ideas between different actors in the health care system and provided the participants and the audience with a mutual understanding of the current situation and future needs.</li> </ul>
Coherence in health care. Can IT make a difference	The Danish Board of Technology	Self-initiated	The Danish Board of Technology	Seminar	IT and Coherence in health-care	<ul style="list-style-type: none"> <li>• Description of initiatives to share data by:</li> <li>1) Expanding the common infrastructure</li> <li>2) Establishing common services</li> <li>3) Digitization at the individual actor</li> </ul>
Status on the result of the strategy	Digital Health	Self-initiated	Digital Health	Not stated	Description of accomplishments. Status of finances spent.	

Table I: Results of the analysis of six status reports on e-health in Denmark 2010



## Discussion

National strategies are important subjects in public planning of the health sector, and a good planning strategy has often been characterized as a comprehensive analytical process, where the decision makers have clear goals and full knowledge about alternatives and their consequences. These conditions are, however, hardly ever present because the problems faced are very complex and adequate solutions equivalently tough to find. Furthermore the specific organizational issues and the state of the technology capacity set the agenda for the planning of e-health – two issues that are constantly changing. With this in mind it is not surprising, although remarkable that so many reports have been published within a very short period from January to June 2010. The organizational framework for the public health sector has undergone major changes during the period for the current health IT strategy 2008-2012 - 12 counties have merged to five regions, and 375 municipalities have merged to 99. Furthermore all hospitals are now Wi-Fi covered, and the basic EHR modules have been implemented in more than 50% of the hospital wards.

A different noteworthy aspect of the health planning situation is that in addition to all the status reports in the e-health area a number of other domain specific strategies for infrastructure and health management have been launched, i.e. chronic illnesses, cancer, quality management, DRG reimbursement etc. and the public debate about these domains have not incorporated any e-health aspects, although it is quite obvious that there is a close relation between e.g. quality management and electronic health records.

These issues will be further discussed at the workshop.

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# The Thinking House: configurings of an infrastructure of care

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**Abstract.** We discuss some figurations (figures) that have emerged out of the resent reconfigurations of health care, which are rooted in the so-called tide-wave of elderly. We take a closer look at the phenomenon *smart house* for elderly to understand the *home* when it, at the same time, becomes an in-baked infrastructure of *public* care services. Such in-baked infrastructure supports senior citizens and disabled people in their daily life, but, simultaneously, we argue, in such infrastructure technology and care becomes intertwined and difficult to separate. We subject the topic through readings concerned with care and care technologies.

## Introduction - coining the paper

Health care and care services are currently re-organized and re-distributed by moving a larger proportion of such services from hospitals and district health care centers to private residences. With this move policy makers aim at enable senior citizens to stay longer in their own homes and herby sustain their autonomy. In the Scandinavian countries, as in many others, the population is growing older while at the same time the working population is decreasing. This move in demography poses socio-economic challenges when maintaining the welfare state offering health and social care to citizens. In overcoming such challenges policy makers aim to increase development and implementation of new technologies and digital services (e.g. Jansson et al. 2007, Roberts & Mort 2009). One of the turns the Norwegian government has chosen to take is to increase ICT-based nursing

homes and care flats, aka smart houses for elderly. The concept of the smart house is not new; but it hasn't, until recently, appeared in public discussions as a means to defeat a number of challenges associated with the tide-wave of elderly (e.g. Sosial- og helsedirektoratet 2004, Bartolomeu et al. 2008). The first smart homes were designed in the 1970-80:ies with the intent of fully automating one-family houses (Berg 1994; Aldrich 2003). There seems, though, to be a difference between the fully automated one-family house and the home for elderly, which offers autonomy, trust, and security through a digital infrastructure of care. That is, in changing the context from fully automated houses to autonomous elderly, technology turns invisible in the sense that it becomes difficult to separate from care. Thus, what we find interesting here and want to take a closer look at, is how, in the smart house for elderly, technology and care becomes intertwined. Politics on care, ethics, and normativity are just a few examples of what is inscribed in the technologies and part of making the new *home* for elderly. With such view at the fore we take a closer look at *home* and its assembly of participants (humans-nonhumans) that are intertwined in its very maintenance (Latour 2005).

## Theoretical orientation

Our research builds on a relational ontology in which people and technology come into existence in intra-actions in material-discursive practices (Barad 1996). Within such view neither the smart house nor the elderly are pre-given; rather, they emerge out of ongoing activities and doings. Barad's agential realism builds on an ontology, which is "not a fixed ontology that is independent of human practices but is continually reconstituted through our material-discursive intra-actions" (Barad 1998:7). In following Barad we learn that '*what*' is included in intra-actions depends on how the boundaries are drawn. In the smart house both humans (elderly, care staff, relatives, alarm providers) and nonhumans (alarms, sensors, etc.) are intertwined. This also goes for more intangible entities such as e.g. policies, technological push, gender division of labor, governance regimes (new public management). Yet, entities that are in- or excluded in iterative intra-activities are not innocent "they are necessary for making meaning" and "have real material-consequences" (Barad 1996:187). That is, with Hekman's words: "Drawing different boundaries has different ontological implications" (2010:73).

Municipalities purchase smart house solutions according to their requirements specifications with positive prospects in mind. Design processes, however, don't stop when a system or service is implemented, they continue in ongoing day-to-day practices (Bjerknes, Bratetteig & Epseth 1991). With our focus on iterative intra-activities we're able to examine (re)configurations of smart houses, homes, care *and* how they come into existence in day-to-day practices or in intra-actions with a range of actors. Thus, we take such theoretical orientation to be important for gaining understandings of how the assembly of participants is part in forming what care and care technologies is and *becomes* (Latour 2005; Barad 2007).

## From notions of Smart Houses to an analysis of infrastructures of care

In the smart house for elderly, the *public* is invisibly at work as a guard that keeps an eye out and assists with care – it is baked into walls, beds, lofts and floors to create at home-like feeling. Thygesen (2009:93) makes a similar observation in her study on dementia and smart homes in a Norwegian setting. She states that the invisible alarms simultaneously enacts privacy and a lack of it, and further that “it is important to note that the very fact that the smart home alarms are invisible contribute to the home-like and private atmosphere of the care flat.” In addition to Thygesen’s analysis we could say that the issue on alarms also raises questions about how the residents’ and their activities are entangled in sociomaterial relations. Specifically, while the technologies open up a range of possibilities that enable elderly to live at home with all the benefits that can follow from being and feeling at home (Randall 2007), it also prompts us to take a closer look at the infrastructure of the smart house and the different participants that are entangled in the maintenance these homes for elderly (Latour 2005).

The alarms and other technologies installed in the smart houses are often prerequisites for the elderly to feel safe and to be able to remain in their homes. But it is not only safety and autonomy that is constituted in the smart houses - control and surveillance of the residents are other constituents, which are equally important to look at. The alarms, e.g., are programmed to receive and send specific information and act in accordance with such specificities (Bjørneby et al. 1996). In the infrastructure of care information is input that turns into output. Similarly, lack of information is input that turns into output. I.e., even if a resident continues her/his daily routines in the usual way s/he risks triggering an alarm if s/he does not act in accordance with the programmed environment. Leaving a bed at night, e.g., and not returning within a specific duration of time becomes lack of information (input), which triggers the alarm (output). This is a very different situation from that of a person who doesn’t live in a smart house and doesn’t trigger an alarm if she/he doesn’t return to bed within a specific duration of time. The question, then, is whether the resident of a smart house behaves normally or abnormally or whether s/he ought to behave in a more disciplined way in order to not trigger any alarm? In this example on alarms the drawings of boundaries of in- and exclusion of information come to have very specific ontological implications for the person living at *home* within the *public* care-infrastructure of the smart house. Thus, with the introduction of care technologies the situation (*home*) changes: it is a different network of humans and non-humans that have specific effects on how we go about with each other in the world of care: “all the actors we are going to deploy might be associated in such a way that they make others do things.” (Latour 2005:107).

## Conclusion

We have looked at in- and exclusions in accounts on *home*, which, via digital infrastructures, becomes intertwined with the *public* through its care services. The

intermingling of *home* and *public*, here, becomes a crossroad of technology and care difficult to separate in that politics and normativity inscribed in the technology is part of making the new *home* for elderly. That is, the in-baked infrastructure of the smart house supports senior citizen; but, simultaneously, it draws new boundaries that brings about new figures, such as *home*, who don't just act, but are acted on as well (Pols & Moser 2009).

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# Building a Trauma Registry for Low and Middle Income Countries: Globalization and the Challenges of Achieving Infrastructures in Healthcare

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**Abstract.** An overview of issues related to globalization which emerged in relation to development of a trauma registry for low and middle income countries is provided. Reflecting on observationally based fieldwork undertaken in relation to a pilot project in a public health hospital in South Africa over a 3 year period, three aspects of globalization are identified which came to bear on the development of health infrastructures.

## Background: Trauma Registries for LMICs

Low and middle income countries (LMICs) suffer a disproportionate share of the global burden of injury. More than 90% : of total worldwide deaths due to injury occur in LMICs. The largest gains in injury prevention are likely to be made in LMICs, but success in reducing the burden of injury in these countries has lagged far behind more developed countries (Segui-Gomez and Miller 2008). Although injury data collection and analysis is presently possible both these activities are very resource intensive. As a result, there has been little sustained injury monitoring in LMICs. The availability of high quality data is essential to public health decision making. Data are required to assess health burdens and health status, and to evaluate the efficacy of interventions aimed at improving health outcomes. An absence of data in low and middle income countries (LMICs) has

been identified as a constraint to health management and monitoring of health status. Although health information systems are frequently identified as a possible means through which the collection of health data can be improved, numerous challenges associated with the collection of health information in LMICs have been identified, along with challenges associated with building computer based tools to support collection and analysis of data in LMICs. Insights gained about the influences of globalization on system development which emerged in relation to a project aimed at supporting the development of a trauma registry for low and middle income countries are outlined. The project is a partnership between academic and health sector partners in Canada and South Africa.<sup>1</sup>

## Globalization as an Infrastructural Issue

There are at least three ways in which globalization has come to bear on infrastructure in our study site. First, global flows of labour led to our interest in the hospital which has become our study site. Second, globalization, and the desire for cross-national comparisons of injury rates has come to bear on the development of data collection infrastructures in our project. Third, the dynamics of providing aid to low and middle income countries has important implications for infrastructural development. Each of these issues is addressed briefly below.

### Overview of Our Capetown Study Site and Project: The Influence of a Global Workforce on Project Development

Working with partners in public health and acute care in Capetown, South Africa our team developed a means of data collection for injury data which we hope will become the basis for collection of injury data suitable for use throughout low and middle income countries (LMICs). As a result of completing a one month surgical rotation at what has now become our Capetown study site, one of our team members, now a trauma surgeon in Canada, developed a long term interest in improving collection of injury data in our study site. This led to a partnership with the medical director of the trauma unit which has become our study site, and a researcher funded by the South African Medical Research Council who is affiliated with the University of Capetown. Over time, a partnership of South African and Canadian clinician-researchers and academics obtained research funding to conduct several linked pilot projects designed to yield local benefits (in the form of a trauma registry), and at the same time contribute to the advancement of scientific knowledge related to injury prevention, epidemiology

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<sup>1</sup> In light of the length limitations of the extended abstract format, we have elected to focus on identification of ways in which globalization has come to bear of development of the registry, rather than present detailed empirical case examples. In the event we are invited to submit a full paper, we will provide extensive empirical detail.



and data integration and analysis. Our team hopes our South Africa work will contribute to the development of a trauma and injury registry suitable for use in varied LMICs.

Our study site emerged from an environment in which doctors from developing countries frequently travel to Capetown to obtain trauma training, precisely because the rates of traumatic injury in Capetown are so high. Hence the international flow of labour and dynamics of the traumatic burden of injury in Capetown set the stage for this infrastructural development project, in which Canadian clinicians and researchers assisted South African clinicians and researchers in developing and implementing infrastructures to be used for data collection. Global dynamics of labour mobility which provide physicians from developed countries with opportunities to gain experience unavailable in their home countries plays a role in subsequent infrastructural development.

### Comparing the Burden of Disease Internationally and the Challenges of Localization

Work with our project participants consisted of iteratively developing a paper based tool for collection of data about the mechanisms of traumatic injury which brought patients to the trauma service in our study site, and testing and modifying the paper based data collection instrument, which will, eventually, be implemented in a computer based format. In light of the fact that the project had as one of its goals development of an injury scoring system which could be used to compare the burden of injury across national contexts in LMICs, at the same time we developed the categories which would be used in our paper based tool in Capetown, we also were aware that data we collected through our tool should also allow us to compare data cross-nationally. We immediately faced a problem which has been well articulated in literature concerned with the sociology of infrastructures (e.g., Bowker and Star, 1999). In the context of our study site, a means of transportation called a *backe*, a term not used elsewhere in the world, and an unlicensed drinking establishment called a *shebeen*, also unique to South Africa, are important sites of injury, and our team wanted to document frequency of injury in relation to *backs* and *shebeens*. We were aware, however, that these terms were not in common use elsewhere in the world, and our use of these terms—well known to those living in Capetown, and a source of epidemiological interest—would introduce a new level of complexity to our data set, in relation to comparing our data cross-nationally to sites and mechanisms of injury in other LMICs. On the one hand, using the terms *backe* and *shebeen* on the form reflected local practices, and would help document the magnitude of traumatic injury which occurred in relation to these local phenomenon. On the other hand, these terms were unknown outside of our study context, and use of these terms on our data collection form will require that we translate our local terminology to

accommodate cross-national comparisons (e.g., *backe* would become *vehicle*, and *shebeen* would become *drinking establishment*). Movement of our data collection instrument to a computer environment should include a mechanism to translate between such local terminology, and terminology in more common use.

## Globalization and Aid: Navigating Funder's Information Systems

Like most LMICs, South Africa receives aid from numerous organizations around the globe (such as the Bill Gates Foundation). It is quite common for organizations providing aid to require aid recipients to use a computing platform provided by the aid organization, and/ or to report data in a particular format to satisfy accountability needs of the aid organization. One of the potential consequences of this situation is that it contributes to an environment in which computer based health information systems abound, with little coordination between aid projects, and, as a consequence, system and data interoperability in the health sector. Further, the “fly in, fly out” nature of partnerships with LMICs can make it difficult for well intentioned individuals and organizations providing assistance to LMICs in developing health informatics systems to identify local efforts underway to support health information data collection, leading to further fragmentation of efforts to develop health informatics infrastructure.

## Concluding Thoughts

Three ways in which globalization comes to bear on health information infrastructures have been identified and briefly discussed. First, the dynamics of “first world/ third world” labour (the need for doctors in LMICs and the need for “first world” doctors to obtain trauma training) laid the foundation for subsequent development of infrastructure aimed at improving trauma data and prevention strategies. Second, the desire to generate data that on the one hand was locally relevant and on the other hand could contribute to cross-national comparisons raised issues about development of classification systems which are both locally relevant and yet could contribute to cross national comparisons. Finally, the dynamics of global aid—and specifically requirements imposed by international funders to use specific health informatics systems- are contributing to a fragmented health informatics landscape in LMICs.

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# Cyborg at Heart: ICD Patients and the Apparatus of Bodily Production

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**Abstract.** This paper explores Donna Haraway's cyborg configuration as an analytical lens for making sense of ICD patients.

## 1. Introduction

ICD (Implantable Cardioverter Defibrillator) patients are literally cyborgs, relying on a 'command, control and communication' mechanism inserted in their organism: A small battery-powered electrical impulse generator, programmed to detect cardiac arrhythmia and correct it by delivering a jolt of electricity is implanted under their skin. The device appeared in the US in 1980, and in Denmark in 1989. More and more people are under treatment, both people surviving severe heart problems, heart stops and the like, and the device is increasingly used for prophylactic reasons.

The condition of ICD patients and their treatment call for an exploration of Donna Haraway's cyborg figuration. Donna Haraway takes as point of departure the blurring of the distinctions human versus machine, organic versus inorganic, natural versus artificial which contemporary scientific approaches in biology as well as communication sciences have brought about. These sciences differ radically from sciences operating on essential categories of the human, the organism, the machine, the body etc. They challenge distinctions between what belongs to nature and what belongs to culture. Those distinctions 'implode' when sciences work by translating the world into a problem of coding and information

processing, depending on command, control and communication mechanisms that connect humans and machines; “mind, body and tool are on very intimate terms” (Haraway1991: 165).

But the cyborg figuration is not only an attempt to accurately describe new scientific circumstances and their effects. In addition it invites us to explore political and ethical implications. In the words of the feminist philosopher Rosi Braidotti, the cyborg is a “connection-making entity, a figure of interrelationality, receptivity and global communication”. It aims at rethinking the unity of human beings and suggests an enlarged sense of community (Braidotti 2006:200).

In what follows we want to explore those ideas: How is the world translated into a problem of coding in the case of ICD patients? How are we to understand interrelationality and subjectivity when we pay attention to the heterogeneous networks and complex infrastructures involved in surviving as an ICD patient and as cyborgs?

## 2. The Empirical Case

The study presented here is part of a larger research project, Co-constructing IT and Healthcare (CITH). It took place at the Heart Center (HC) at Copenhagen University Hospital, where ICD patients from the east part of Denmark as well as Greenland and the Faeroe Islands are in treatment. Implantation and device follow-ups are conducted in Copenhagen at the same time as the medical examinations of patients from Greenland and the Faroe Islands take place closer to their homes. The project demonstrates very well the idea that health informatics involves information processing, coding and design on a global scale, and just as importantly, the idea that those processes can be studied from various pragmatic perspectives. The CITH project focuses on collaborative practices among heterogeneous actors involved in managing ICD patients, with “the aim of designing, developing, and evaluating IT applications and services supporting the work of both healthcare professionals and patients”. While much empirical work have been conducted (see Andersen, Bjørn, Kensing, & Moll, 2010) including ethnographic encounters and design activities, the focus in this paper is mainly theoretical and analytical in order to explore the cyborg figuration.

## 3. The Apparatus of Bodily Production

In Donna Haraway’s approach scientific representations act as interventions in a dynamic reality, and do not mirror nor control a passive reality. Alluding to Simone de Beauvoir’s famous statement, ‘one is not born a woman’, Haraway argues that the same is true for organisms. She offers the term “the apparatus of bodily production” as an analytic device to capture the generation of bodies and

other scientific objects in scientific knowledge production (Haraway 1984: 200). The apparatus depends on what Haraway terms material-semiotic actors or nodes, which boundaries are drawn by mapping practices. The idea resembles the notion of infrastructural inversion coined by Geof Bowker and Leigh Star (Bowker, Star 199:34). An ICD patient may appear just as a person, an individual with an implant; the inversion points to the array of interdependent non neutral technical networks and standards as well as the politics and knowledge production without which neither person nor device would survive.

The apparatus of bodily production of ICD patients comprises a network connecting practices, technologies, bodies, and people, global in scope. We have for instance the connections between the flesh and muscles and the wires measuring and monitoring the heart inside the body of the human being. Muscles vibrations refigure as ICD data, a coding that makes particular mappings and measurements possible, and reconfigures the heart in specific ways. There is a wireless connection between the device in the body and a telemonitoring system, located at the device manufacturer as well as at the Heart Center. Besides providing the actual device and assisting the surgery procedure of inserting the device in the body, the medical device manufacture companies provide geographical distributed global monitoring of the device & heart. When an ICD is inserted into a body, and a patient has returned home to e.g. Greenland, the ICD data are sent through the technical networks, and stored on servers in Europe in order to communicate updates to the Heart Center. Thus the connection is established and maintained by the telecommunication companies, but in fact handled by the patients and their families in relation to the device manufacture company. These various entities act invisibly and regularly in order for this particular cyborg configuration to survive.

In addition, the telemonitoring system is a strong material semiotic actor. It automatically assesses the ICD data that the patients regularly send to the heart center. The assessment can be tricky and is therefore further controlled by other important actors, the health care professionals. They browse through the information they receive on the screen and investigate curves and graphs in order to examine the values of the data — are they stable or not? Sorting out which data deserve to be discussed with an additional source of information, namely the patient present in ‘flesh and blood’ is a crucial node in the mapping of patients and the reconfiguration of their further treatment.

This particular ‘version of the patient’ is not addressed primarily as a rational actor accountable of her or his intentional behavior. On the contrary, we observed situations where patients are encouraged to recall bodily affects such as nightmares and dreams in order to localize things in the past that the data show have triggered jolts of electricity, things that might have left other material semiotic traces, such as dreams. Indeed, “mind, body and tool are on very intimate terms” in monitoring the survival of the patient and keeping her or him alive. The

infrastructure does not work as a neutral substrate on which human interactions and interpretations take place; it co-constructs and takes actively part in forming the apparatus of bodily production of the ICD patient.

## 4. Cyborg at heart

ICD patients are unique cyborgs in the way they are tightly and intimately living in a sometimes quite violent apparatus of bodily production. Donna Haraway claims however, people living in contemporary society influenced by techno sciences are cyborgs. From a political and ethical point of view it urges us to pay attention to the often surprisingly material and not just semiotic interconnections and interdependencies we are involved in, as patients, but even more in most settings. We should take note of the range of material semiotic actors involved in our lives, and of what tends to figure as not us, but 'the other'. We discovered for instance that many patients imagined that a doctor is overviewing all the data that their ICD are constantly producing without noticing the role of the telemonitoring system. Braidotti is even more explicit than Haraway in wanting to think of life without the human at the centre and define an ethics of sustainability based on the subject as an ecological entity – a cyborg at heart?

### Acknowledgments

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# When Work becomes Opaque. Nurses at the Junctions of Medical Infrastructures

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## Introduction

The introduction of Electronic Patient Records (EPR) in medical practice relies on the conviction that a seamless web of communications improves the quality of care, reduces errors and wastage, and generates greater overall efficiency. Nevertheless, the reality of infrastructuring processes often presents scenarios in which paper-based and electronic systems coexist but the latter are poorly interconnected, resist customization, and are unable to deliver information efficiently (Hyssalo 2010).

Many suggest that the adoption of standards and protocols and the use of participatory design techniques could avoid the need for specific work by healthcare personnel in connecting all the systems in use together. This paper, instead, reflects on the difficulty of eliminating such work. Moreover, it argues that the adoption of forms of participatory design may paradoxically increase the amount of such interconnection work (here 'junction work') and push into the background parts of the work that they are supposed to support. The case analysed here concerns nursing work in a hospital oncology department. It enables reflection on the increasing opacity of certain work tasks and the technical-organizational implications of the concentration of these duties at the junctions among healthcare infrastructures that are not fully interoperable.

## Invisible work, background work, junction work.

In CSCW, the need to devise forms of support for activities undertaken in workplaces has clashed with the difficulties of observing, analysing, and representing them in all their complexity. Such difficulties concern those non-formalized activities – or ones deemed of minor importance – that are denoted with various labels: ‘invisible work’ (Star and Strauss 1999, Suchman 1995), ‘articulation work’ (Strauss 1985), ‘coordination work’ (Ellingsen 2003). In this paper we propose the concept of junction work to indicate the work of facilitating the exchange of data among different information systems (both electronic and paper-based) and which especially characterizes technologically dense environments. By ‘junction work’ we mean activities involving direct and explicit action to overcome barriers impeding data exchange among two information systems. These activities are the transcription or digitization of data, their transfer from one system to another with memory devices (e.g. USB keys, hard drives) or manual uploads, change of format, and so on. Junction work, in other words, is performed when communication does not occur in a seamless web. It is not in itself visible or invisible, and it can be both formalized and performed through workarounds and tricks of the trade that avoid standard procedures. Although the need for explicit (and non-automatic) intervention to have the systems communicate is not negative in itself, it often results from the delegation to human actors of what has not been possible, or has been deemed not necessary, to realize through infrastructuring (Piras and Zanutto, under review).

## Setting and methodology

The research was conducted in an oncology department of a hospital in North Italy which for more than ten years has used an EPR constructed with the collaboration of a medical informatics research group. Working in the department was a team of ten doctors and eleven nurses who treated (mainly with chemotherapy) 35-40 patients daily. Semi-structured interviews, personal conversations, and participant observation were carried out. Interviews (five in total) and conversations were used to reconstruct the birth and evolution of the EPR through the narratives of the members of the development team, the doctors, and the nurses. The observation consisted of a series of weekly shadowing sessions conducted on doctors and nurses for a period of 8 weeks across six months. In light of analysis of the data collected in the first two weeks, the subsequent observations were focused on nursing work, and in particular on how the various information systems used in the department were linked together.



## The EPR (and how is it fed with data)

Analysis of practices in department started from the observation that the oncologists did most of their work using the EPR, while the nurses and secretaries more frequently used other computerized and paper-based systems. The reason for this difference was identified by reconstructing the history of the system.

The project which originally gave rise to the system had proposed the electronic networking – via a synchronous teleconsultancy tool – of 27 departments of 9 hospitals in a small Italian region. From the outset, however, the realization that it was necessary to have a system of shared data management induced a shift of the project towards the creation of an EPR. In that period, a new chief had been appointed to run the oncology department of the largest hospital. S/he saw an EPR as the tool with which to steer the doctors' work practices towards greater collaboration and sharing, in particular by changing from a care system in which each doctor had his or her "own" patient to one in which the patient could be managed by any doctor in the department. The design of the system interwove with redesign of care delivery by the doctors. Collaboration between the medical personnel and the design team was close and prolonged (it still continues), and it led to frequent meetings during which the system's requirements were identified and a prototype was produced and trialled. This prototype initially enabled only the management of strictly clinical data, but the weekly briefings between doctors and designers gave rise to requests for new functionalities able to manage the workflow (e.g. appointment books), accounting (e.g. consumption of medicines), communication with other departments (e.g. to book examinations), or analysis of the department's performances (e.g. waiting times). These were studied and implemented during the two years of the project.

The analysis of the interviews showed that, during that period of time, mutual shaping took place between the system and work practices, so that the EPR became the pivot of doctors' work, who wanted it to be used for management of all their activities. The observations verified that this desire was substantially fulfilled, and that large part of the doctors' activities were supported by the EPR. Nevertheless, the same observations showed that this was because a portion of the work was transferred to the nurses. The doctors, in fact, needed data contained in other information systems not fully interoperable with the EPR (those of other departments, outlying hospitals, analysis laboratories) and which arrived in the oncology department via different media (e.g. fax, paper documents). The data necessary for the completeness of the oncological EPR were acquired through the compilation of templates by the nurses (e.g. the results of a blood test made in a private lab). The nurses also undertook the reverse work of transferring information to other systems. For instance, if a doctor requested a TAC and put it on the calendar in the EPR's appointment book, it was the nurses who managed the information flow with the laboratory via phone calls, faxes and paper

documents so that the appointment became effective. This also applied to a series of other actions (e.g. booking of blood tests, providing car park permits to patients) whose accomplishment depended on the nurses' work in creating junctions between systems. Moreover, this work frequently interrupted the nursing workflow, as faxes, telephone calls and paper documents arrived without warning and without the EPR transfer of the data required for an examination.

## Discussion. Building the junctions

The shadowing of the nurses made it possible to observe the mundane and material practices of the junction work performed by nurses and how it affected their workflow. As seen, (i) the nurses' junction work was what made the EPR files complete and usable by the physicians; (ii) this work required the use of various artifacts (e.g. fax, telephone, paper); (iii) the junction work interrupted the nursing workflow. A further finding is that the junction work observed consisted of a chain of micro-actions (e.g. receiving a fax, making a brief telephone call) that sometimes concretized the transfer of information from one system to another over a time-span of some weeks. This made both these actions and the overall process difficult to represent in formal terms, with the consequence that they were undervalued by the doctors. The history of the development of the system and the analysis of a specific functionality introduced during the observation period suggest that the scant visibility of this work was one of the factors which, over time, turned the system into a tool for the redefinition of work tasks and their substantial delegation to the nurses. Paradoxically, this happened because the close collaboration between clinicians and designers came about through mechanisms of participatory design. In contexts such as this, in fact, the difficulty of representing and appraising the amount of work required to connect systems together leads to the devising of functionalities useful for the doctors without full awareness of their effects on nursing work.

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# Experiences with Voice Based Data Entry System over Mobile Phone in Rural India

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**Abstract.** Under the Integrated Child Development Scheme of Govt. of India it was required to monitor the attendance and distribution of supplementary nutrition packets provided to rural women who visited the Anganwadi Centers. However, in Madhya Pradesh where the scheme was implemented, their current system of data collection using paper-based process has its challenges; unmanageable amounts of paper data, too much time consumed in generation and aggregation of reports, inefficiency in flow of information and tampering of data. A voice based system has been developed to support voice biometric<sup>1</sup> and voice based data entry. When this system is substituted for the current paper based data collection processes, it will play a pivotal role in enabling real-time data collection from remote areas thereby reducing discrepancy in data which is most commonly observed in the data collection phase. The innovative use of Modern Voice recognition technologies indicates effective data storage and immediate access of the same. This paper aims to share experiences and the credibility of using the voice biometric system over the mobile phone to capture and monitor Maternal and Child Health data on a real-time basis.

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<sup>1</sup> <http://www.bytelabs.org/pub/papers/biometrics04.pdf>

## Introduction

The Government of India has employed several health schemes to combat malnutrition and improve Maternal and Child health status. Integrated Child Development Scheme (ICDS), one of the world's largest and most unique programme for pregnant women and early childhood development. ICDS aims to provide pre-school education to children and to break the vicious cycle of malnutrition, morbidity, reduced learning capacity and mortality. These objectives are achieved through a package of services comprising of supplementary nutrition, immunization, health check-up, referral services, pre-school non-formal education and nutrition & health education. Supplementary Nutrition includes supplementary feeding and growth monitoring. For providing supplementary nutrition, all families in the community are surveyed to identify children below the age of six and pregnant & nursing mothers. They are provided with supplementary feeding support for 300 days in a year. This scheme attempts to bridge the caloric gap between the national recommended and average intake of children and women in the low income and disadvantaged communities. For growth monitoring, children below the age of three years of age are weighed once a month and children between 3-6 years of age are weighed quarterly. This helps to detect growth faltering and helps in assessing nutritional status. However, the success of these schemes and programs are hampered due to enormous amount of data generated and distortion in government records. This paper- based system of reporting; is very slow, ineffective, the incidence of falsifying data is high, outdated and the data generated is enormous. Timely interpretation and analysis of the gathered data is unattainable and hence it defeats the very purpose of documenting.

In the recent past, a relatively new, affordable and efficient communication technology using mobile phone has enabled connectivity in rural India. It has been estimated that rural tele-density has increased more than eleven times from 1.57% to 18.37% from March 2004 to August 2010.<sup>2</sup> Data collection via mobile phones has been explored for the past couple of years, but the concept of voice based data entry system with authentication is fairly new and perceived to be far more effective than the previous types of data collection carried out through mobile phones. This paper aims to share the finding of experiences with voice based remote data collection over mobile phone in rural India.

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<sup>2</sup> [http://www.indembassy.co.il/Additional%20files/India\\_Information.pdf](http://www.indembassy.co.il/Additional%20files/India_Information.pdf)

## Methods and materials: The Technology

Voice Net is a Personalized Voice based Information Retrieval and Transaction System (PVIT) jointly developed by IITM's Rural Technology and Business Incubator and Uniphore Software Systems<sup>3</sup>. This technology enables remote voice based data collection and viewing of real time data on a web portal. Unlike other voice based tools that leverage speech recognition, this system does not require training of the speech engine. It supports multiple languages and dialects. Voice Net enables remote data gathering at low cost using mobile phones and state-of-the-art speech recognition and intelligent analytics tools at the backend. Already Voice Net has its footprints with applications in Punjabi, Marathi, Tamil, Hindi and other regional languages of India and these applications are being accessed by farmers, job seekers, and skilled workers across Rural India. The basic architecture of VoiceNet enables the services to scale easily across states and geographies without significant increase in investment and is independent of service provider.

## Project Location

Madhya Pradesh is a state which has long been side-lined out of India's robust economic picture. The incidence of malnutrition-related mortality in Madhya Pradesh is higher than sub-Saharan African countries and has reached epidemic heights<sup>4</sup>.

Maternal and child health status among rural and tribal population is an area of growing concern. According to the NFHS-III, 60 percent of the children in the 0-3 year's category in Madhya Pradesh are malnourished, with 82.6 percent children in the same age group being anemic<sup>5</sup>. The reasons postulated by experts point to poor health care reforms, lack of transparency, low health literacy and most importantly slow reporting system. For this pilot study, Dhar, a tribal dominant district situated in south-western corner of Madhya Pradesh in Central India was chosen. The majority of the population in Dhar District belongs to the Scheduled Tribes who live below the poverty line.

## Maternal and Child Health Project

Voice based biometric system was introduced in the Anganwadi centers (rural healthcare outreach centers) in two districts namely Gunawat and Dhar of Madhya Pradesh to register and monitor the rural or tribal mothers and children who were the beneficiaries of the ICDS. The mothers were enrolled in the system using their voice and the children were registered under mother's ID. The reason

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<sup>3</sup> <http://uniphore.com/>

<sup>4</sup> <http://www.thehindu.com/health/article56048.ece>

<sup>5</sup> <http://beta.thehindu.com/news/states/article109702.ece>

for registering the child under mother's ID is because a child's voice has a tendency to change as they grow. After enrolling, the beneficiaries (mothers) authenticate themselves every time they visited the Anganwadi centre and enter data about their activities at the Health Center and the benefits they have received. The data that was captured using the voice based data entry system included details such as

1. Registration of mother/child/guardian and supervisor
2. Authentication
3. Data Collection for monitoring the weight of mother/child

Number of nutrition packets received by mother / child ,Counseling received by mother and Infant Mortality.

## Implementation and Results

This section deals with the various options that were provided with mobile phone for registration, authentication and data collection along with the results obtained.

**Registration:** The Registration process was done for four categories of individuals- Mothers, Children, Guardians and Supervisors. The mother registers for herself and her child, for a child a unique ID is generated with the prefix of the mother's ID. The system generates a unique user ID which is a three digit number for each registered individual. About 589 mothers, 702 children, 9 Guardian and 3 supervisors have registered themselves between the months February 2010 to June 2010.

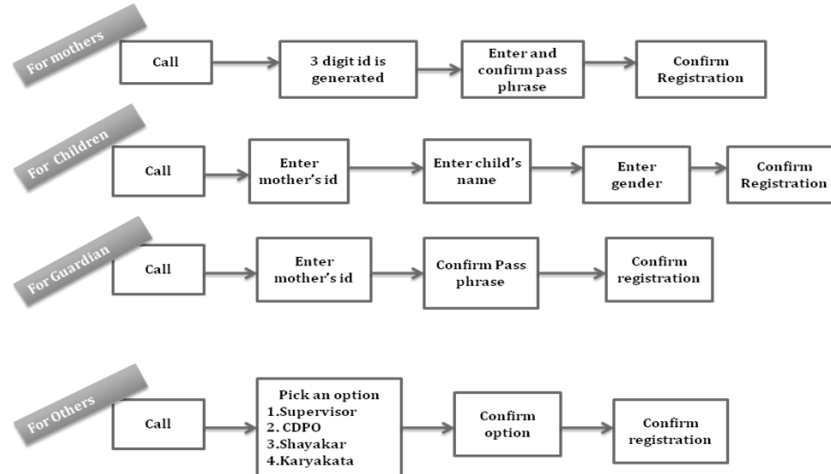


Figure: Registration Process

**Voice Authentication/Attendance:** The registered users had to authenticate themselves first before they proceed to enter data into the system by a simple three step process,

- A phone call to the system's mobile number
- Confirming the unique three digit User ID generated when registering
- Voice authentication: Repeating the "pass phrase" three times

Some participants failed to remember their individual pass phrase and made a few mistakes which resulted in the system rejecting the authorization. E.g. If a

participant registered using a pass phrase “My name is Mala” and later forgot the pass phrase and said “Mala is my name” the authentication would fail as the system would not identify the user. Occasionally there were other reasons for authentication failure such as loud background noise, faulty handset and bad network coverage

**Data Collection:** Once the voice is authenticated, the user can navigate various options given in the system using voice prompts and the data is entered. After which they can either exit the system and end the call or return to the system and enter additional data under other options given. This process was entirely carried out through a simple call from a mobile. Most of the participants were from rural background and illiterate but quickly adapted to the procedure. The supervisors would be present during the data entry but it was the participants who entered the data. Initially the data that was collected from the field would be saved in the system data base and then transferred to readable excel sheets.

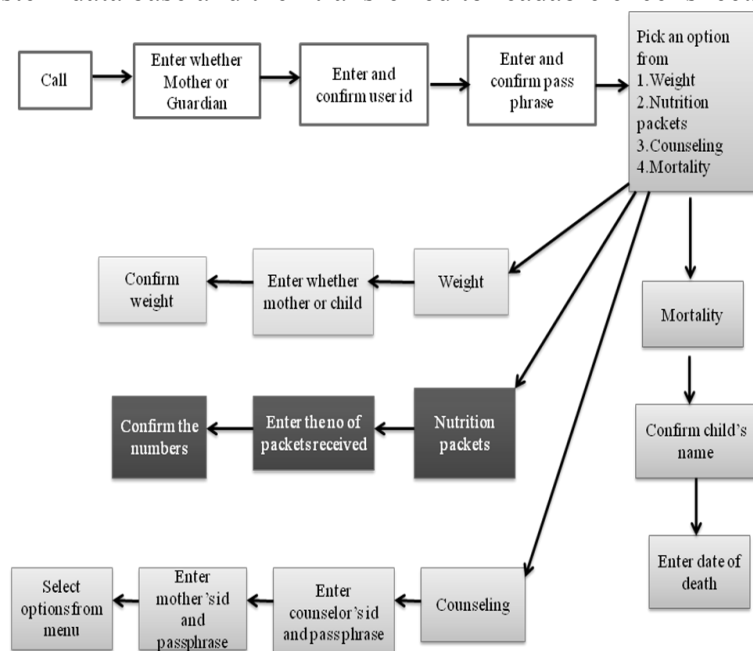


Figure: User Interface of Voice based data collection system

**Weight:** The system was configured to record height and weight indices of the beneficiaries (mother and child). Measurement of these indices enabled to calculate the total number of supplementary nutrition packets to be given. Although the setting for this feature was available, it was only tested and not rolled out for implementation. Meanwhile, the number of nutrition packets to be given was calculated manually.

**Supplementary Nutrition Packets (SNP):** The beneficiary (mother) had to call up the service number and enter data pertaining to SNP that she and her child received. Types of information collected under this option include the number of Supplementary Nutrition packets received by the mother and or the child, the gender of the child, the number of lunch and or breakfast packets received. About 172 breakfast packets and 674 lunch packets have been distributed to beneficiaries during the pilot period.

**Counseling:** Some of the mothers who visited the AWC were counseled by the Nurse on Diet and Nutrition and ANC follow-up. However after the counseling, confirmation of the session was to be given by the mother on receiving the counseling and the nurse to confirm if the counseling was given. This option was tested for functionality but was not implemented.

**Infant Mortality:** Infant mortality provision enables the capture of information on the death of the child including the date and reasons, this information is given by the mother along with the supervisor. However in phase 1, this option was not used by the beneficiaries, the reason postulated for which range from non availability of the mother to social reasons towards registering death of the child.

The voice based data collection process was designed such that the data that was captured on the field would be uploaded on a web portal, where the administrators could view real-time data. This web portal has information categorized by District, Block and Anganwadi center. It has all the information about registration, weight, number of Supplementary Nutrition Packets received under government scheme, it also had additional information about immunization schedules, growth charts of children and nutrition and health education and preschool education.

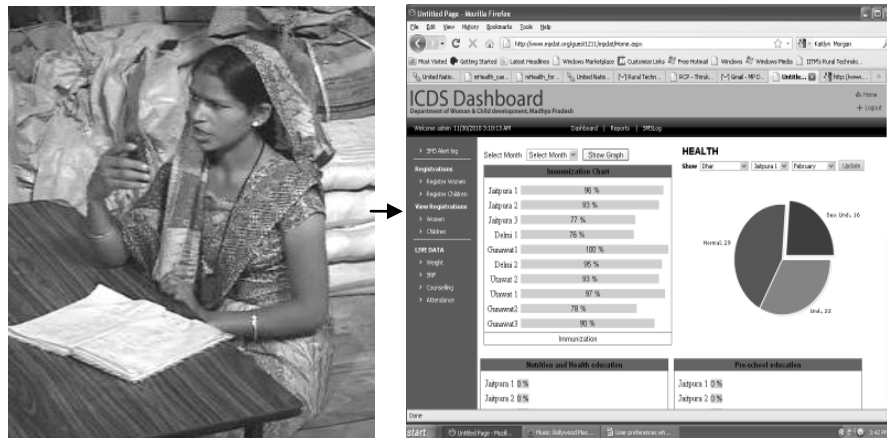


Figure (A) User entering data

(B) ICDS website where data is streamed live

Later in the phase of data collection, other options such as Antenatal Checkup date of expectant mother, Number of Iron and folic acid tablet received by mother, date of receiving Tetanus Toxoid injection was incorporated.



# User Interface

## a. Usability

All the users of this pilot belonged to one of the following categories

1. Mothers who visited AWC
2. Guardians nominated by mothers
3. Supervisors of AWC

Most of the users were Below Poverty Line (BPL) rural and tribal mothers with little or no education who visited the AWC for their antenatal check up or to collect Supplementary Nutrition Packets for themselves and their Children. Despite their illiteracy or limited literacy the users were comfortable in using the voice based system as it was in their local dialect. The supervisor would be there to guide them but the data entry and authentication was entirely done by the users and entire phone call would only take about 2 minutes.

## b. Convenience Factor

The voice based data entry system was used alongside paper based reporting system in the pilot project. However the voice based system emerged was far less time consuming and less expensive as paper based documentation is laborious and painstaking. The data collected is authentic and completely tamper proof as it is entered and validated by the user and the data can be analyzed and collated in a matter of few minutes and can also be viewed by the supervisor when the need arises.

## c. Customization

This technology can be fine-tuned to suit user-requirements and customized accordingly, the voice based system supports several languages i.e. the voice recording and voice prompts can be changed to any particular language or dialect of the chosen target audience to suit them more appropriately. The system has a unique Multi-lingual Speech recognition for data capture and speech to text conversion. For instance this voice based data collection system was hosted in *Punjabi* language to conduct a survey among rural farmers in Punjab.

## d. Other cases this Voice based data entry system has been used

- a) Survey: This voice based system was used to take a survey in Punjab among farmers in which about 800 farmers participated. It was a quantitative survey and we received about 200 complete responses, the prompts were done in *Punjabi*
- b) Resume Collections: Ejeevika a Rural HR Company had used this system to collect resume of rural candidates in rural Tamil Nadu,

about 500-600 resumes were collected over voice (*in English and Tamil*).

## Conclusion

Mobile devices have shown great promise for improving the efficiency and effectiveness of data collection in resource-poor environments. Compared to a traditional process that relies on paper-based forms with subsequent transcription to a computer system, mobile devices offer immediate digitization of the collected data at the point of survey. This allows for fast and automated data aggregation, more user-friendly and cost effective. In the context of this pilot data entry happened on both over voice and paper. And our study indicate the use of voice biometric system to collect data and enable real-time viewing of data in remote areas can facilitate monitoring activities of various Government schemes.

## Acknowledgments

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# The Augmented Binder: Supporting Cooperative Home Care Work

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**Abstract.** This paper offers an exploration of home care work and the design of computational devices in support of such work.

## Introduction

On the global stage Asia and Europe may be singled out as the two regions where a significant number of countries face severe population ageing in the near future. In these regions within twenty years many countries will face a situation where the largest population cohort will be those over 65 years of age and average age will be approaching 50. An aging population means that the health care sector becomes under increased pressure and it becomes a growing concern how to for example support elderly people in a manner that allows them to continue a quasi-independent lifestyle in their own homes, rather than moving them to some sort of institutional care. Allowing the elderly people to stay longer in their own home makes sense seen from the elderly persons point of view as well as from the point of view of the economy of the welfare state - institutional care of older adults is in general significantly more resource demanding than home care (Gesano et al. 2009).

This paper is concerned with an understanding of home care work and the design of associated technologies that may enable older adults to stay longer in their own home.

## Methods & related work

This paper is based on ethnographic fieldwork carried out in the course of five months in relation to home care work. Subsequent to the fieldwork, four participatory design workshop were held with both family members and care workers.

In relation to other ethnographic accounts of home care work this paper makes a contribution as it takes a special interest in not only the division of labour between family members and professional caregivers as they perform home care work but also the diverging values and attitudes held by the various participants. Whereas a number of previous studies have focused solely on the practices of the care workers (Petraou 2007), the interest here is as indicated to explore how

family members and care workers actively and in cooperation engage in the practicalities of taking care of older adults (an interest partly shared with e.g. Rook 1987; Spitze and Gallant 2004).

In regard to the literature focused on the design of technology to support the elderly in the home setting this paper diverges from other papers on the subject as it aims to support *articulation work* among the network of actors that support the elderly, rather than support e.g. awareness practices (Mynatt et al. 2001; Rowan and Mynatt 2005) or monitoring of the elderly (Abowd et al. 2006) or the collection of sensor data (Morris et al. 2003).

## Cooperative home care work

Many family members are far more than mere spectators to the lives of their elderly kin. More to the point, there is a *de facto* division of labour between professional caregivers and family members. Where the professionals, simply put, handle what may be dubbed ordinary tasks (e.g. personal care and food preparation, and etc) and the family members handle what is beyond the job description of the professionals (e.g. social events and light maintenance).

Notably, not only does the kind of work tasks performed respectively by care workers and family members differ their attitudes towards the work differs too.

Generally speaking family members are emotionally invested in the care of their aging relatives. They are emotionally invested in the tasks that they themselves perform as well as the tasks performed by others most notably the care workers. This state of affairs may come as no great surprise, although we could ask what sort of description we are giving when we say of someone that he or she is emotional or emotionally invested? According to Ryle (Ryle 1949), being emotional is to *react* in some vaguely describable, thought easily recognizable, ways whenever certain junctures or circumstances arise. We may say that family members are emotionally invested in the care of their elderly in the sense that they are frequently e.g. glad, distraught or flustered when faced with the various circumstances pertaining to the care of their loved ones.

In regard to the values and attitudes of the care workers it is worth mentioning that burnout stemming from emotional stress is a significant liability for workers in service industries (Ashforth and Humphrey 1993; Rafaeli and Sutton 1989), especially those employed in care giving professions (Kahn 1993). Care workers are often forced to manage their emotions when dealing with clients and family members. In this process they may adopt what could be described as a detached attitude towards their professional work in order to safeguard their own emotional health. As such their engagement with elderly persons, compared to that of family members, is of a different nature. We may say, then, that care workers attempt *not* to become as emotionally invested as family members in the care of older adults.

These differences in values and attitudes are part of what any given technology design aimed at supporting home care work must take into consideration.

At present articulation work i.e. coordination involving family members and care workers is mainly handled through the exchange of written messages placed

in a paper binder as well as the *ad hoc* use of telephones. Such a binder is for example often placed in the kitchen. The binder includes the nursing and care plan, specifications for medicine intake, food and liquid intake forms, as well as sheets of blank paper to write messages on (see also e.g. Petrakou 2007; Rook 1987). However, both care workers and family members find the binder cumbersome and ineffective in use not least because many messages written in the binder seem to fail to reach their intended recipients.

## Design concept: the Augmented Binder

The (design) challenge, then, emerging from this study is related not only to the fact that home care work is highly cooperative in nature but also to the fact that it is carried out by a work ensemble comprised of professional actors (the care workers) as well as non-professional ones (the family members). How can we with information technology support cooperative home care work while remaining sensitive to the highly diverse sensibilities, values and attitudes of the actors? The design below offers our preliminary suggestion.

The proposed design is the Augmented Binder (see figure 1), where messages are written with an Anoto pen and paper. The Anoto digital pen is a combination of ordinary ink pen and a digital camera (as well as supporting hardware) designed to digitally record everything written with the pen. The new binder is also equipped with LED light message indicators. This design allows the different actors to write, forward and address messages to each other, with a notification when the different messages have been read. We shall now turn to describe a short use scenario.



**Figure 1. The Augmented Binder employs a pen for the digital capture of messages, and provides notifications of new messages employing RFID technology.**

message has been entered or updated as this is also indicated with small led lights on the register tabs. In this manner no messages goes unnoticed (a problem with the use of the present paper binder).

Once read, Sarah can write a reply and the message may be addressed to e.g. a family member and the LED on the binder's' front cover indicating a new message

for the family members will be turned on the next time he or she (with his or her RFID tag) enters the home.

The design aims to allow family members to stay in touch while respecting the private sphere of the care workers. For example, messages (or merely an indication that they have been read) may be forwarded via the Internet. In this manner especially family member may feel that they are in touch with the situation wherever they are (and this may provide peace of mind). There is also the option *not* to receive messages remotely or when off duty - this option was suggested by the care workers and may reduce stress and contribute to upholding the division between work and personal time.

In this manner the Augmented Binder design attempts to supports collaboration between care workers and family members, extending the original binders functionality in a manner that supports the division of labour and respects the various attitudes and values held by the respective actors.

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# The challenges of seamless integration in nursing documentation

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**Abstract.** This paper present a workplace study of documentation practices within a surgical department and emphasize the interplay between heterogeneous information systems in the preoperative and postoperative care process. The aim of this study is to illustrate some of the challenges in relation to integration and emphasize integration as a process of interpretation, translation and negotiation in a socio-technical network.

## Introduction

“The right information at the right place at the right time” is a slogan in health care and expresses some of the expectations for the use of electronic patient record (EPR) as a means to obtain continuity of care across time and space. Yet, it is hardly something new that the use of EPR has not gained expected outcomes. Some of the key challenges are seamless integration (Ellingsen, et al., 2003), redundancy (Cabitza, et al., 2005) and re-use of data across sites and social scale (Ure, et al., 2009). Similar studies have focused on the implementation and use of EPR as a dynamic interaction in a complex socio-technical network and emphasizes the interaction between the technical systems and the related dynamic of the surrounding social arrangements (Hanseth, et al., 2001). Accordingly, seamless integration and re-use of data in a hospital information infrastructure is not just a technical issue, but “efforts to integrate practices across organizational divides and to link them with applications” (Pollock, et al., 2010, p. 545).

The aim of this study is to investigate how the EPR system is aligned with the care process in nursing practice. The objective is not only on the use of electronic nursing documentation per se, but on the interplay between different information sources used in nursing practice such as an electronic nursing module, medication sheet, medical chart and post-anesthesia record. Furthermore, the paper illustrates the role and condition to redundancy of information and concludes with some implication for design of integrated information system.

The empirical setting investigated is a surgical ward and a post-anesthesia care unit (PACU) at a regional health enterprise in Norway. During the last years the hospital has made major efforts to standardize the hospital infrastructure for computer technology and the last major project was the implementation of an electronic nursing module during 2008 and 2009. However, a large part of clinical information like medication sheet and medical chart is still on paper and they are no planning to digitize this information as part of the EPR.

This study was designed as a case study in the interpretive research tradition in information system (Walsham, 1995) and the empirical data was primary collected through interviews and participant observation. During summer and fall 2010, it was carried out 140 hours of observation of work practice of nurses in a surgical and post anesthesia care unit (PACU). In addition, it was carried out 5 semi-structured interviews to gain further insight into information work at the ward.

## Interplay between the care process and documentation

The main goal of the pre- and postoperative phase is to prepare the patient physically and mentally for the surgery, prevent complications and support patients' needs in recovering after surgery. Since the implementation of the electronic nursing module in 2008, the care plan has become a key player in the coordination and performance of nursing care at the gastroenterological ward and is an integrated part of the EPR system. The nursing module contains two separate parts, the report section and the care plan. At the core of the care plan are the international classification systems of North American Nursing Diagnosis Association (NANDA) and Nursing intervention Classification (NIC). These classifications are supported by research, and facilitate continuity of care across settings and have been translated into Norwegian. The term nursing diagnosis has become an internationally used concept for identifying the specific nursing needs of the individual patient. These are needs that provide a focus for the planning and implementation of nursing care. For example, it is common to use NANDA diagnosis "Deficient knowledge" and then add "related to stoma" to specify to the current situation. The same procedure is used to create an intervention where the NIC classifications are available in the system. Actual intervention may be "Teaching" and then specify to particular actions like "Inform about having a



stoma". In this way, the care plan is established and serves as a support in the care process during patients' trajectory before and after surgery. Since the plan is attached on all new nursing document, they do not need to repeat information in the plan, but only report on the status and deviation to the plan. In line with changes in the clinical care process, nursing diagnosis and interventions are completed and new ones are composed. Although the care plan has become a key player in the planning and performance of nursing, they are also dependent on other information sources such as medication sheet and medical chart. Medication sheet is a multidisciplinary working tool used by doctors to prescribe drugs and by nurses to sign for a given medication. However, the care plan may also include drug information, but for a different purpose. For example, it may be prescribed antiemetic medication on the medication sheet. If the patient gets nausea, it is created a nursing diagnosis and interventions in the care plan, such as "Nausea". Nursing intervention like "Nausea management" may be further specified to an activity such as to observe and evaluate the efficacy of prescribed drug therapy. Similar, if the patient needs intravenous drug treatment it has to be prescribed in the medication sheet. This prescription may lead to two different nursing diagnoses and/or intervention in the care plan. For example, it may be appropriate to compose an intervention in relation to observing the effect of the medication and then nursing intervention in relation to venous catheter. In addition, insertion of venous catheter and fluid is also documented in the medical chart. This is a multidisciplinary document that is used to document measurements (blood pressure, pulse, temperature), observation/treatment, fluid balance, and so on. The medical chart used at the department is a day-to-day graphical and tabular presentation and overview of clinical data. Moreover, during surgery and at the PACU, another type of medical chart is in use. In contrast to the paper-based medical chart used by the surgical department, the anesthesia and PACU have since 2002 used a specially designed electronic record. In this environment the nursing care plan are not used and the work is more focused on situation actions to stabilize vital function after surgery and anesthesia. The electronic post anesthesia record has become a key player during this process and are an integrated part of the monitoring system used to continuously collect and store vital signs like ECG, blood pressure and so on. In addition to real-time information from the monitor equipment's, the system provides information about, for example, medications, fluid balance, clinical assessments and free text documentation. Data is stored in a local network, but is not integrated with the EPR system at the hospital. Consequently, data from the post anesthesia information system have to be manually transferred to the paper-based medical chart and the electronic nursing module when patients are back at the surgical department.

## Discussion and conclusion

The paper illustrates how different artifacts are used to share the same or similar information in a local practice as well as across different contexts. Redundancy of data is considered as an obstacle for integration and seamless care and are also entangled with redundancy of effort in producing and consuming redundant data (Cabitza, et al, 2005). There are two different types of redundancy that is interesting in this case, duplicated and supplementary information. When identical information is reported in different artifacts we speak of duplicated data (Ellingsen, et al, 2003). As shown in the case, identical information is manually transferred from the electronic record used at the PACU to the paper-based medical chart used in the surgical ward. This is an example of non-integrated information, but even if the information had been transferred between two electronic applications, it would have still been a challenge. Information stored in the post anesthesia record is comprehensive and specifically designed for close monitoring after surgery. Transmission of this information requires interpretation and sorting in relation to what is relevant for further postoperative care. The second type of redundancy is supplementary information where related information is represented in different information system (Ellingsen, et al, 2003). In this case, similar information is used in different contexts. For example, medications are signed for in the medication sheet while similar information in the care plan is used to observe the effect of treatment and care. To summarize, I have argued that integration is not just a technical issue, but also an integration of work processes and information in a socio-technical network. Moreover, I emphasize that this is a process of interpretation, translation, and negotiation and is a challenge for further design and development of an electronic medical curve.

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# Design for health promotion: going beyond traditional interface issues to core-values

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**Abstract.** This paper focuses on health promotion principles as a logic choice for framing the development of developing sustainable web based health communication infrastructures using Participatory Action Research approach. Development of sustainable “health promoting communication” infrastructures demands genuine participation of users and integrating of formative evaluation throughout the design process. The main contribution of this paper is to discuss how health promotion values and principles can guide the design process of ICT supported “health promoting communication” infrastructures using examples from a case study based on Primary Health Care in Blekinge region, in the South-East of Sweden.

*“With today’s information age translating into a wild and wired world, promoting health can become a greater challenge in this new, global, un-centralized information world”* Scott C. Ratzan

## Introduction

Increasing lifestyle related ill health, escalating health care costs and ever expanding health inequalities within and between nations are challenges facing countries throughout the world (Ahern, 2007, Nutbeam, 2000, Parker et al., 2003). Governments, especially in industrialized countries like Sweden, are investing in health promotion and communication, particularly in Information and Communication Technology (ICT) supported health communication, as a way to raise health literacy among the citizens (Nutbeam, 2000, Ratzan, 2001, Kickbusch and Ratzan, 2001). ICT has the ability to enhance active learning, increase motivation, self efficacy and provide an environment for shared decision making; making it an attractive strategy for improving health literacy. Health literacy as a

concept encompasses more than transmitting information and developing skills, it entails improving people's access to health information and capacity to use it effectively. Improving health literacy is critical to empowerment (Nutbeam, 2000). These exciting opportunities also pose challenges as design of technology mediated information systems (ISs) is usually in the hands of professional system designers with limited understanding, or at times misunderstand the social context of work practice. This often results in discrepancy between functionality of the system and its ease of use (Wessels et al., 2008a, Baskerville, 1999). Health care providers on the other hand face the challenge of offering health communication services that are adaptable to complex health care settings and the people they serve, but lack the technical knowledge to realize their goals (Kreps et al., 2003, Skinner et al., 2006, Norman and Skinner, 2006, Eysenbach and Jadad, 2001).

Ethnography and Participatory Design (PD) are two methods and approaches used in IS research to develop systems that adapt to the social context. Even though these methods/approaches have been successful in developing accessible systems, same success has not been achieved in developing health communication infrastructures for the health promotion. Studies show that health communication is dominated by the bio-medical, so called "pathogenic" paradigm where health is generated by eliminating risks for diseases instead of focusing on resources and processes that promote health (Ratzan, 2001, Eriksson and Lindström, 2008). The antithesis is salutogenic paradigm; a perspective takes into consideration the social, cultural, economical and spiritual factors that determine health. Salutogenic perspective is the foundation on which the socio-ecological model of health promotion is built (Tones and Green, 2004). Unfortunately, ICT mediated health communication within health care services has also adopted the pathogenic paradigm even in the design of infrastructures that are meant to promote health (Wessels et al., 2008a, Ratzan, 2001, Pilemalm and Timpka, 2008). We argue that conducting a PD or ethnographic research in this case is insufficient; it may lead to usable infrastructures but not necessarily facilitating health promotion or health literacy. We have to go back to basics and ask important questions such as "who is the system being designed for?" For what purpose? and in which context/contexts? (Pilemalm and Timpka, 2008, Wessels et al., 2008a) and that's where values come in.

## **Health Promotion values and principles**

Health promotion is the process of enabling people to increase control over the determinants of health and thereby improving their health (WHO, 1986). Ottawa Charter emphasized a holistic approach that focuses on structural factors and the need for intersectoral collaboration, creation of healthy public policy focused on everyday living (Nutbeam, 2000). The Ottawa Charter further identified five main action areas: building healthy public policy, creation of supportive environment, strengthening of community actions, developing of personal skills and reorienting health services. To address the underlying values in the health promotion concept, Rootman (Rootman, 2001) pointed out guiding principles focused on *empowerment*, *participation*, *holistic* and *intersectoral* approach, *equity*, *sustainability* and *multi-strategy* to guide health promotion policies and activities. Values and principles that advocate a strong bottom up approach (Tones and Green, 2004). Using health promotion principles as foundation for the design process of ICT mediated health

promotion infrastructures will not only take into consideration the socio-technical factors of workplaces but also engage different stakeholders in a dialogue resulting in a better system based on shared values, and sense of ownership based on mutual interest for all parties (Lintonen et al., 2008, Baskerville, 1999, Kreps and Neuhauser, 2010, Ratzan, 2010, Henwood et al., 2011, Kock and Lau, 2001).

This paper proposes using health promotion values and principles as the foundation for design process as a way of developing ICT mediated systems for health promotion, going beyond interface design issues to “shared values” based systems. There is a need to explore and map underlying principles and methodologies in the fields of IS, health promotion and health communication to give of developing web based health communication for the purpose of promoting health. Infrastructure that is capable of promoting health and in the long term, enhancing health literacy. We illustrate how this can be done by drawing examples from an ongoing project entitled “Virtual Hälsotorg” (VHT). First a short description of VHT project will be given, followed by description of the development of VHT and how health promotion values and principles informed the design process and finally end up with some concluding remarks. A big challenge facing designers is that these values are not integrated in PHC contexts (Mahmud et al., 2010, Frankish et al., 2006).

## **VHT project and PAR**

VHT is an internet based interactive health channel that connects primary health care services (PHC) and the local citizens in their jurisdiction. The VHT research and development project, is part of a larger EU sponsored research and development project entitled “*Syster Gudrun Fulskalelab (SGF) inom vård och omsorg*” (Sister Gudrun's full-scale lab within care and welfare services). The VHT project main objective was to create a sustainable, relevant, accessible interactive health information channel and support to the citizens in making healthier choices using Participatory Action Research (PAR) approach (Jama-Mahmud et al, 2008).

### **Designing VHT using health promotion principles**

VHT project was carried out in collaboration with the County Council of Blekinge, Ronneby Municipality and local community representatives from Ronneby. PHC staffs, municipality personnel and local citizens, were involved throughout the design process; from concept design to evaluation of the final product. They were all regarded as users and active co-designers. Using PAR approach, will contribute to increased health literacy among the project participants and the populations at large, ownership and thereby usability (Whyte, 1991, Baskerville, 1999), and contribute to making PHC a more health promoting health care service as stipulated in the Swedish national public health goals (Socialdepartementet, 2008). An iterative model entitled Spiral Technology Action Research (STAR) which combines health promotion and social theories, PAR approach, critical pedagogy and ICT systems design (Skinner et al., 2006) was used as a tool to guide the design process. By involving the health care staff and creating contact with the local people, we have put in place structures that will enable VHT to grow and adapt to future organizational demands (Wessels et al., 2008b). A “work group” consisting of PHC personnel, local citizens, researchers and an interactions designer together designed a VHT channel prototype from concept to end product; deciding on the content and interface design through dialogue and rapid

prototyping (Skinner et al., 2006). The final prototype was then tested and re-tested in several steps with different groups of “users; ranging from health care workers, migrant groups and senior citizens. The results were then the work group integrated the changes, modifying the prototype after reaching a consensus. The five health promotion principles formed the backbone of the design process.

#### *Participation and empowerment*

Participation and empowerment were the locus of VHT project. As in any health promotion intervention/action, participation of and empowerment of problem owners, was the ultimate goal (Nutbeam, 2008). Empowerment in health promotion is “a process through which people gain greater control over decisions and actions affecting their health, a process through which individuals and social groups are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and achieve political, social and cultural action to meet those needs (Nutbeam, 1998). A lot of work was put in into creating conducive environment for participation such as rules of collaboration; all participants were regarded as “experts” in their respective area, including “laymen. In this way, the collaborative process in the development of VHT, created a learning environment whereby end users and system owners obtained insight in design process and thereby capacity to maintain and adapt it to the needs that might arise in the future (Wessels et al., 2008b). Participation fosters capacity building and empowerment, which are core principals of health promotion interventions (Hirschheim, 1983, Pilemalm and Timpka, 2008). According to Freire, learning process’ main function is to “raise consciousness” of the involved stakeholders in order for them to take action. Creating supportive environment caters for the need for praxis, which is a process of reflection and action (Freire, 1972). This circle of reflection and action reflects the design on which the design of VHT is built upon. Two levels of empowerment were identified; individual and community. At the individual level; members of the working group gained skills and competencies they would never have thought possible prior to taking part in the project. At the community level, different groups such as pensioners, immigrant groups and high school students were consulted to broaden the user perspectives. This action was taken as a result of workgroups own suggestions. This process upset the power balance, as weeks went by, local citizens in the work group became major contributors doing own research and coming in with innovative suggestions to improve the quality of VHT.

#### *Holistic and Intersectoral approach*

Health promotion involves the population as a whole in the context of their everyday life, rather than focusing on people at risk from specific diseases (WHO, 1986). When it comes to health promotion, there is a need to work over organizational borders. In Sweden for example, Municipalities are charged with the responsibilities of promoting health at the local level while the county council are more involved in “prevention” and curative services of health. During the development of VHT, workers from these two organizations together with the local citizens, negotiated on how this health channel would best serve each of them in the best way possible without compromising the existing practices. This translated into a health channel that, they could all ascribed to and identify with,

not a system that was shoved onto them from above. This resulted in linking the municipality's health promotion activities to the VHT health channel, despite the county council being "the owner" of the system.

#### *Equity and sustainability*

Equity in health means that people's needs guide the distribution of opportunities for well-being. This implies that all people have an equal opportunity to develop and maintain their health, through fair and just access to resources for health" (Nutbeam, 1998). Seeking inclusion by recruiting a working group from the local community and consciously seeking minority groups and senior citizens was a way in which the issue of equity was addressed in the design process of VHT and to make the health channel relevant to all. Sustainable development within health promotion refers to the use of resources, orientation of technological development, and institutional development in ways that wouldn't compromise the *health* and well-being of future generations (Nutbeam, 1998) or cause friction within or between organizations. In the case of VHT, involving key actors of health promotion agents i.e. PHC and municipal workers, local community members, researchers and interaction designer in the design process increases the likelihood of developing a health channel that is relevant to the organization and the local people who are the end users. It also contributes to the sense of ownership among the local people and thereby increasing accessibility and usability (Whyte, 1991, Baskerville, 1999).

### **Concluding remarks**

The research fields of ISs, health communication and health promotion stress on understanding the context of communication, matching information content and delivery with the design in order to improve usability. Applying health promotion values and principles in the design process of VHT, has resulted in innovative ways of communicating health that is relevant to the local context. Preliminary results show that health promotion values and principles were seen to resonate well with the other design theories that advocate for a better integration of social context. Thus there is a need to explore the common values in order to improve health communication infrastructures, if we want to develop "health promoting communication". People adapt and adopt a system if they can relate to it and it is relevant to their lives and work contexts, otherwise we would end up producing systems and messages that are evidence based but not relevant to the people who will use them as Ratzan so candidly expressed "we experts have messages to send, but people have lives to live, and rarely do we bridge the gap" (Kreps and Neuhauser, 2010). The question is "how health promotion values can and principles contribute to bridging this gap?" Or is it just a utopia that is an unachievable and therefore meaningless to pursue?

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# e-Health Security Based on Professional Relations: The Case for Non-hierarchical Rolebased Access Control

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**Abstract.** Where Healthcare Teams use Nationwide Electronic Health Records systems their collaborative processes are subject to the effects of multiple interdependent services which are required to interwork while respecting security, privacy and confidentiality constraints. Often there is resistance to the introduction of technology intended to support professional services, because designers pay too little attention to professional patterns of work and to the requirements for effective team collaboration. This paper addresses these issues particularly as they affect access control, an important non-functional aspect of the IT infrastructure for health care. This infrastructure increasingly consists of large complex information systems constituted out of federated independent interworking services. It is argued that a non-hierarchical, dynamic rolebased security approach is preferable from the viewpoint of team collaboration. The development of the relevant concepts is traced. The main features of the architecture are presented, experience with this approach is reviewed, and its advantages are evaluated with respect to a case study of NPfIT, the Electronic Health Records programme for England. If access control architectures are designed to adapt naturally to professional activities and relationships, it is much more likely that systems will be accepted and trusted by patients and healthcare professionals alike.

## Background

Resistance to the introduction of technology intended to support professional activities such as those of healthcare teams often results from inadequate attention, by system designers, to professional patterns of work and to the requirements for effective team collaboration. Where Healthcare Teams use nationwide or regional Electronic Health Records systems their

collaborative processes are subject to the effects of a large number of interdependent services which are required to interwork while respecting security, privacy and confidentiality constraints. This paper addresses these issues particularly as they affect access control, an important non-functional aspect of the IT infrastructure for health care. It is argued that this infrastructure increasingly consists of large complex information systems constituted out of federated independent interworking services, and argues for the adoption of a non-hierarchical, dynamic rolebased security approach as preferable from the viewpoint of team collaboration.

Federated independent services need distributed access control to support both personalisation and organisational requirements to restrict access to certain information or the performance of certain functions to a defined, limited class of users (Li et al, 2008). OASIS, developed by the Opera group at Cambridge, addresses these requirements (Bacon et al, 2002). It extends beyond the basic RBAC models proposed in the NIST and ANSI standards (NIST, 2004) by including credentials, appointments, fast event-based credential revocation and a Horn-clause logic-based policy language. Of particular significance is its greater capacity to map security policy onto complex organizational reality.

OASIS is a distributed capability system in which roles are activated within a given user session. Policy rules determine whether a given authenticated user may acquire a role or roles and hence exercise the privileges associated with that role or roles. Different services collaborate via an event-based middleware and can remain responsible for different role prerequisites. Context-aware security is provided both via parameters to roles and via environmental predicates. Other RBAC implementations often extend the basic model with notions of delegation and hierarchy such that senior roles automatically have access to the privileges of their subordinates. OASIS, however, supports delegation through the concept of appointment, wherein an appointer will issue an appointment certificate to an appointee or group. Appointment certificates are persistent digitally-signed certificates; their creation involves a principal using privileges that create and revoke persistent credentials i.e. appointment certificates to be used as role entry prerequisites by other principals. A combination of role activation rules and authorisation rules allows a much closer modelling of organisational reality than that which is implicit in a role hierarchy.

The first comprehensive implementation of OASIS was done in collaboration with Clinical and Biomedical Computing Limited (CBCL) (Eyers, 2005). CBCL OASIS was used to successfully build an EHR demonstrator (Eyers et al, 2006) and subsequently in the RAED project (Neely et al., 2004). Further examples of the application of OASIS security are given in Pesonen (2008) and Singh (2010).

In the RAED project, which applied the OASIS architecture to a model of federated Virtual Universities, we showed how, regardless whether a record fragment is held by the same or different services, policy can determine that privileges to modify or read that fragment will vary according to roles. Lessons were learned from the RAED project relating to virtual organisation support and the OASIS architecture. Amongst the positive features of OASIS as shown in the RAED demonstrator (Neely et al, op cit) were: *System transparency* – users need not be aware of the location of different record fragments. *System flexibility* - the logic is sufficiently expressive to allow a wide variety of policies, also different local organizers can decide different policies for the same objects. *Generality, explicitness, and relative simplicity of policy expression* – most systems allow users to set permissions for groups and in general; users can to lock files or set activation dates, but the policy thereby expressed is implicit, and can only be deduced, possibly imperfectly, by examining all the objects and their access rights. OASIS by

supporting policy expression in high level terms gives a clean separation of data from policy and reduces the risk of error. *Dynamic qualities*: the privileges of a role commonly change over time and in response to events. (For example, a doctor comes on duty or goes off duty, and privileges over a care record should change accordingly). These changes over time and in response to events are naturally handled in OASIS by environmental predicates. OASIS with its parameterized roles can also readily handle exceptions. (In a health application, normal restrictions may be overridden in emergency).

## **The NHS National Programme for Information Technology and its Integrated Care Records System**

The National Programme for Information Technology in the National Health Service in England was launched in 1998 with the aim that by 2005 all patients nationwide would have a lifetime EHR and clinicians would have round-the-clock online access to these. This had still not been achieved when the new UK coalition government came to power in May 2010. The new administration announced in Sept 2010 that “a centralised, national approach is no longer required” However, elements of the programme persist, suggesting (to misquote Mark Twain) that “rumours of its death had been greatly exaggerated”.

Both users and suppliers of NpFIT were subjected to highhanded treatment (Black, 2009). There appeared to be little attempt to discover how health delivery teams actually worked in different technical specialisms or in different socioeconomic contexts, nor to learn from existing local e-Health initiatives. The new system did not provide for one consultant to have oversight of a patient throughout his or her hospital treatment and aftercare (Black, op cit) thus removing the element of personal-based trust.

The requirements document (Output-based Specification) states “Access to documents shall be controlled by role-based access and limited to authenticated users. All user access shall be recorded and have Audit Trails. Configuration management shall apply to the documents. Changes, amendments, corrections and deletions shall be recorded in the Audit Trails.” (op cit) 106.6.15 “The service shall support locally defined, role-based "views" of patient data.” It may be noted that the above statements of requirements do not address in any way the possibly relevant parameters of roles, nor the current external conditions, which have been so extensively researched in the Cambridge research programme discussed above. The system was designed with a Security Architecture and a Confidentiality Architecture. The Security Architecture comprised a Registration and Authentication service and a Role-Based Access Control Service. The Confidentiality Architecture comprises support for Patient Consent and a Legitimate Relationship Service. NPfIT adopted a general approach of taking up standards. In the case of RBAC, the relevant standards are, of course, the NIST/ANSI standards. This does not address the parameterisation of roles – as a result, it cannot express relational roles such as “X is the doctor who is treating Y”. The Legitimate Relationship Service is therefore not part of Access Control: the opportunity for RBAC to be built on professional relationships rather than bureaucratic hierarchy has been lost, as a result of the adoption of an unsuitable standard. Rather than presenting a principal with data only where the requestor had a legitimate relationship to the patient, the Legitimate Relationship Service shuts the stable door after the horse has bolted: access to a National Care Record without a defined Legitimate Relationship to the patient will trigger an alert, which will be referred to the Caldicott Guardians, an existing role within the NHS to defend patient confidentiality. (Ferrar, op. cit.).

## Conclusions

Becker (2007) and Eysers et al (2006) have argued for the importance of expressing security policy for the NPfIT in a formal security language. In Becker's view, RBAC is a traditional approach which is unsuitable for the purpose. Eysers et al have, however, illustrated through the CBCL OASIS demonstrator that a different RBAC model is appropriate and adaptable. Subsequent investigations in the RAED project have illustrated the usefulness of a dynamic, non-hierarchical approach to RBAC in its ability to model the lifecycle relationship between developing real-world situations and developing complex and compound data objects. Given that the ambition of the NPfIT was to provide each patient with a lifetime care record, a strong case can be made that the Cambridge OASIS/EDAC21 approach to RBAC could provide a more robust, realistic yet flexible approach to security for a national EHR service, than the combination of traditional hierarchical RBAC with a separate Legitimate Relationship Service.

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# The dual role of government in health care information infrastructure building

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**Abstract.** This interpretive study explores how healthcare authorities contribute to the building of information infrastructures through indirect governance and construction.

The challenges related to an expensive and growing healthcare sector are sought solved through neoliberal politics (Dean, 1999) where healthcare is governed in an indirect and distributed way containing organizational elements from the private sector. In Norway responsibility for the hospitals is delegated to four regional healthcare authorities. ICT is viewed as a strategy for governing and rationalizing public services including all levels of healthcare. The building of large scale integrated ICT systems has been one important instrument to implement these strategies. Such systems deeply embedded in different practices can be conceptualized and analyzed as Information Infrastructures (II) (Hanseth, 1998). The common view on building of II is that they evolve in an organic-like way (Star, 1995). This fits well with indirect governance approaches allowing for bottom-up development processes where healthcare units are encouraged to join with private companies to establish good innovative solutions. However in many projects for building health care II the authorities apply a direct governance approach playing a major role in the development, hence making health care II a

result of both evolution and construction. This paper describes how healthcare authorities at different levels build healthcare IIs, both through indirect and direct governance. Drawing on Governmentality theory (Dean, 1999) and II literature the dual role of governments' as facilitator and constructor and the consequences for vendors will be discussed. The study adheres to an interpretive approach. Data was collected in the period 2008-2011 and consisted of participant observation, interviews and document studies.

This case describes the building of a system for electronic laboratory orders intended for GPs ordering analyses from hospital laboratories. The process started in 2006 when a hospital and a small local vendor established a two year development project. The project was partly financed by a national initiative aiming at public sector innovation and industrial development. The system became a commercial product after the project phase. It was developed stepwise using agile methods which allowed for close collaboration between end users and developers. Software and work practices were developed and improved iteratively through continuous delivery and real life implementation. The system utilized the existing infrastructure in the national healthcare network and national standards and required tight integration with systems in the GP office and the laboratories. This integration was done with one system at a time, and extension of the system to referrals was initiated after successful implementation of laboratory orders. Also implementation was done stepwise starting with four GP offices and gradually increasing the number of users as more hospitals acquired the system. Presently it is used by nine hospitals and 60 GP offices in Northern and South-Eastern Norway, and the only such system in the Norwegian market.

Further deployment was stopped for long due to large procurement processes initiated by the regional healthcare authorities in South-Eastern and Northern Norway. The procurement processes were based in aims to increase use of electronic communication between primary care and hospitals, in particular electronic laboratory orders. The regional healthcare authorities had decided to coordinate procurements for all hospitals in their respective regions. To secure adherence to international legislation, and to make sure that they would get most out of their money they announced international competitive tenders. The tender requirements were comprehensive and detailed and included specifications of system architecture, general, technical and functional requirements, governmental demands, training of users, testing, quality assurance and plans for implementation. Making bids were resource intensive and in their offers the competing vendors had to confirm adherence to the requirements, to describe their (potential) solutions in detail, commit to delivery deadlines and specify the total cost of procurement and implementation. The specifications made by the regional healthcare authorities were quite similar to the system that was already used by some of their hospitals, but the regional healthcare authorities also changed technical solutions and included new features that they needed. Ambiguities and disagreements between

competing vendors and the regional authorities were clarified in negotiation meetings, and contracts were signed between the preferred vendors and the regional health authorities during first half of 2011. These contracts now serve as the basis for further development of systems for electronic laboratory orders.

Governments need to solve their governance challenges related to the building of healthcare II. The domain is complex and rapidly changing, and it has been difficult to coordinate actors and activities to establish stable and functional II. The common view on building II has been that it evolves gradually; however, Nielsen (2006) argues that II are built and scaled in an intertwined process of evolution and construction. We agree with Nielsen (*ibid*) and argue that healthcare authorities in their attempt to govern the complexity of ICT in healthcare play a decisive role in this building by using both direct and indirect governance strategies at the same time. The system for electronic laboratory orders is tightly integrated, depends on national standards, has reach beyond one single institution and embedded into work practices in the hospital as well as general practice. Hence the system could be conceptualized as a component of an II and the case shows how healthcare authorities at different levels contribute to the building of this II.

The project for establishing the first solution for electronic ordering of laboratory services was a result of the indirect governance approach. Central features of such an approach are decentralization, crossing of traditional borders such as public-private or state-civil society, user orientation, competition and organization inspired by the private sector. The consequences are that central authorities give up significant traditional power, authority, and control to regional and local healthcare institutions and vendors providing services and developing solutions. As with electronic laboratory orders, governments facilitates the building of II by establishing standards, financing infrastructure and by granting financing for projects where healthcare actors and ICT vendors together are allowed large freedom to find the good solutions. Implicit there is an acknowledgement of the need for creativity, leeway and unfolding, and the problem of managing or predicting the outcomes of such processes. This indirect governance approach allowed for the evolutionary building of a system for electronic laboratory orders.

The case also showed how the regional healthcare authorities partly constructed a system for electronic laboratory ordering through the tender process. Modern welfare states are depending on a well functioning market (Dean, 1999), and tenders are part of international competition regulations which governments have to adhere to. The tender specification document for acquiring ICT systems draws the boundaries and gives detailed descriptions of the system. Through the process of making these specifications the regional healthcare authorities contributed to the building of this II. However, the regional healthcare authorities also had to attend to another trend: an increased critical attitude towards public sector and attention towards fails. Hence, the proposed system design and implementation plan had to



encompass the means necessary to avoid failing (Dean, 1999) implying comprehensive and detailed specifications to allow for budget and time control. This demonstrated a belief in the possibility to foresee future needs and plan for these based on technology determinism. This presumes a predictable, stable and controllable future and that IT work logically and can be controlled through planning and design. However, we argue that healthcare authorities have to accept that building IT is faced with risks (Ciborra, 2003), that technology determinism is oversimplified and that governance through control and predictability seldom works.

The development of electronic laboratory orders showed how ideas, experience and potentials revealed in the small scale project was tuned and refined in the procurement specifications and eventually put into large scale use. Thus small self governed projects are a way to evoke the creative potential in the healthcare sector and at the same time contribute to industrial development. However, it seemed that for the regional health authorities the aim was more related to project efficiency and budgetary control which called for a plan and control approach. The authorities' dual roles and aims also implied multiple roles for vendors. In the indirect governance approach vendors are supposed to cooperate with the other actors on an equal basis exchanging knowledge and experience. However, a small vendor might not have the needed capacity to take the product further due to the resource intensive bidding processes. A common view among users is that vendors have control of the development process (Halford, 2008), however in the large scale procurement situation there is a customer-vendor relationship based on specifications in contracts giving the vendors only limited freedom in the development process.

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# Socio-Material Infrastructure in Emergency Departmental Work

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## 1. Introduction

Investigations of health information infrastructures often neglect the materiality of the information artifacts, for instance, the consequences of shifting from one media to another or combining multiple systems of various materialities. Most infrastructures for healthcare engage many information systems deploying multiple types of media. When entering a hospital one rarely finds purely electronic information systems (Østerlund, 2007). Healthcare organizations employ a large array of different information systems, some digital, others paper-based, which mean that state-of-the-art digital media coexist with decade old systems (Star & Ruhdeler, 1996). The co-existence of information systems of various materialities means that information system researchers should consider the materiality of the information artifacts as part of our analysis, if they hope to affect health IT design and implementation. The new systems developed will inevitable become parts of the infrastructure of current information systems with various materialities. In this paper we explore the question: how does the materiality multiple of health infrastructures relate to the collaborative practices in ED work?

## 2. Theoretical Framing

The general IS literature includes multiple calls for a better conceptualization of the technical and material elements of information systems and management

(King & Lyytinen, 2006; Mumford, 2006; Orlikowski & Iacono, 2001; Orlikowski & Scott, 2008). In recent years and predominantly outside the IS literature we find a proliferation of concepts struggling to articulate the material aspects of IT. These include “socio-material (Orlikowski, 2007; Suchman, 2007), actor-networks (Callon, Law, & Rip, 1986), cyborgs (Haraway, 1991), object-centered sociality (Knorr Cetina, 1997), relational materiality (Law, 2004).

The paper positions itself in this broader debate and develops a framework for examining the materiality of information artifacts. Where the notions of media or technology tend to refer to a rather narrow range of artifacts, we define the materiality of information artifacts broadly to encompass not only paper and electronic systems but also clipboards, racks, table tops, whiteboards, widescreens, tubing systems, smart cards, etc. We define a collaborative field of action as a particular configuration of participants collaborating at particular times and places around some content in a more or less predefined format. We propose that particular socio-material infrastructures may productively be studied by focusing on relations among 1) artifacts, 2) artifacts and their location, and 3) artifacts and people’s moves. Furthermore, we argue that particular socio-material infrastructures tend to be invisible, i.e., it sinks into the woodwork. Only in situations of change do these infrastructures and their role in coordinative practices become apparent. We provide examples of how healthcare professionals play with the materiality of different artifacts, and how these can impact further design practices. Transforming and designing new artifacts for healthcare require careful attention to the materiality of the healthcare infrastructures and its relations to location, other information artifacts, and people’s movements.

### 3. Method

The paper draws on extended ethnographic field studies involving several years of participant observation in two pediatric emergency departments (EDs) in Canada and US and smaller field studies in four other adult emergency departments (EDs) in Canada and US (Bjørn & Rødje, 2008; Østerlund, 2007, 2008).

The analysis focuses on information artifacts central to patient tracking and flow within the EDs. We compare the materiality across information artifacts used to handle the same type of activity across the EDs. This comparison makes it possible for us to distinguish how the differences in materiality bring particular affordances and constraints to the collaborative fields of action. The comparison involves among others the following materialities: paper; whiteboards, electronic whiteboards, clipboard, chart-racks, laminated paper, magnets, sticky notes, flags, racks, power plugs, and table-tops.

## 4. Results

Patient charts serve as one key tracking and flow management artifact in ED work. Some parts of the patient chart are electronic other parts are paper-based creating divergent affordances for the collaborative field of action. Many of these documents are permanent (e.g., triage form, SSP) to the patient chart while some are transitory (e.g., yellow note, green sheet, chart rack). In this section we compare paper-based and digital patient chart across the EDs and argue that the affordances of these artifacts can only be fully understood when analyzing the information artifact in relations to other artifacts, people’s mobility, and physical location. Each time one changes the relations of an information artifact to other artifacts, locations or people’s movements one changes its role in the infrastructure and the fluid coordination practices. The configuration of content, format, participation, timing and place shifts. Table 1 summarizes the cases used to compare paper-based and electronic charts in US and Canadian EDs.

Dimension of Materiality	Yellow note	Triage form	Analytical questions
Relation to other artifacts	Related to card card, triage form, expect sheet	Related to yellow note, clipboards, nurse chart	How is the artifact connected to the other artifact within the work place
Relation to places	Triage counter/desk, registration	Triage counter, registration desk, hanging folders, patient rooms	How is the artifact used in various location within the work place
Relation to people mobility patterns	Charge nurse monitoring walk	Guides the physicians and nurses between the rooms	How do people move around and what role does the artifact play in these mobility patterns

Table 1. Materiality and relations to other artifacts, physical locations, and people’s mobility

**Transforming Materiality:** The materiality of information artifacts tend to be ‘invisible’ in the daily routines of ED work. Not until changes occur do the affordances and constraints of particular media become apparent and a source of discussion and negotiation. The section compares the negotiations associated with changes in information artifacts in two EDs following the implementation of a flagging system and the implementation of an electronic tracking board.

## 5. Discussion, Conclusion & Implication

We argue that the role of socio-material infrastructures in ED work can only be fully comprehended if one approaches the information artifact and its materiality in relation to other information artifacts, their location and people’s movements.

Each time we change the relations, we also transform the collaborative field, including participation, time, location, content, formatting, and place. The ED staff continuously negotiates these relations at staff meetings. We argue that health IS designers and managers need to participate in those discussions on an ongoing basis and thus engage more explicitly in the relations among material information artifacts and ED work. Moreover, work practices within EDs continuously change (we saw this in all cases), thus it is essential that the computerized systems should be flexible and re-configurable, making it possible for practitioners to adjust and re-align the practices to fit the new materiality.

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# A study of the fragmentation of the medical record

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*‘In the early 20th century, the data in the medical record were beginning to burst the confines of the form’ (Reiser, 1991)*

The medical record, the collection of notes and other documents concerning a particular patient, is a time-honored and robust institutional artifact. However, with patients with chronic ailments that typically are treated and monitored by multiple clinical workers, sometimes at different institutions, the medical record is more than ‘beginning to burst’: it is beginning to fragment.

This becomes clear from our ongoing study of the coordinative practices of clinical workers dealing with patients with ‘implantable cardioverter-defibrillators’ (ICDs), i.e., pacemakers that dub as defibrillators.

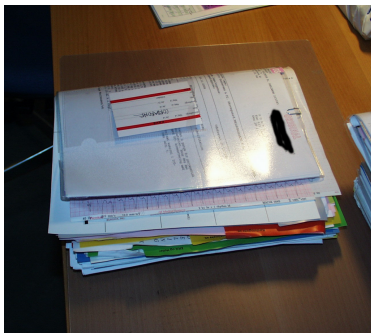
We are investigating work at the Heart Clinic of the Copenhagen University Hospital, at its outpatient clinic, and at an associate heart clinic at a regional hospital. The Heart Clinic treats patients from Eastern Denmark as well as Greenland and the Faeroe Islands. Patients with ICD implants have to be monitored on a regular basis, both in terms of ordinary cardiology and in terms of the functioning of the device. This is done by different clinical workers at different places: on one hand by the cardiologist at the heart clinic at the patient’s regional hospital and by the patients own doctor (GP), and on the other by the ‘electrical doctors’ (ICD cardiologists) at Copenhagen University Hospital and by the bio-technicians at the hospital’s out-patient clinic who download and print data from the device for specialist scrutiny. Newer ICD devices can be scanned remotely, while the patient is at home (via wireless download to a reader and subsequent transmission to the

hospital over the Internet). The data then have to be recorded, filtered, interpreted, classified, put on record, handed over, etc.

Accordingly, due to the introduction of a technology such as the modern ICD, we see the emergence of a distributed network of interdependent activities that are carried out in parallel and yet (potentially) time-critical.

The first impression of the patient folder lying there on the desk is that it is thick. Enveloped by folded transparent vinyl it holds up to about 500 sheets of paper, some loose sheets, some stapled together. The cover can barely contain the content.

Considered as a data structure, the patient folder is quite complex. Or rather, it is a motley of stuff, loosely collected in a folder. To provide some order, the first



sheet is a generic table of contents printed on a white sheet of plastic, and the content of the folder is organized into corresponding sections divided by colored separator sheets with inscribed tabs: ‘Continuations’ (grey), ‘Cardiographic tests’ (orange), ‘Paraclinical tests’ (yellow), ‘EKG and Holter’ (green), and ‘Dispatch letters’ (blue). Within each section, sheets are generally placed in inverse chronological order (with exceptions due

to haste, mistakes, etc.). The tagged separators is a recent innovation. Patient folders that were established earlier than about ten or more years ago are not organized this way, nor do they have a preprinted table of contents.

An additional technique of organization is the use of colored paper to indicate the category of information carried by the sheets. Continuations are white, administrative forms are printed on green paper, cardiographic test results are pink, references to other patients folders (in other clinics) are mauve, and so on. This coding scheme is not upheld consistently, however, as copies of test results etc., e.g., transmitted by fax or mail from other clinics, are on white paper.

When browsing the folder’s content, one is struck by the enormous heterogeneity of document types. Within the section labeled ‘Cardiological tests’ one finds, in the case of one patient, 12 different document types, altogether about 50 documents. The other sections of the folder are similarly heterogeneous. As for data types, the heterogeneity is equally remarkable: text; numerical data series; tables; prose printouts, generated by means of word processor; handwritten prose; computer printouts with handwritten annotations and comments; forms generated by means of word processor, filled in by hand; computer-generated graphs; computer-generated X-ray imagery; etc.

The ‘continuations’ consist of notes in inverse chronological order. Each entry is marked by date, sometimes by time of day, and contains a few lines describing the state, treatment plans, etc. Occasionally, notes will swell to 1-2 pages, in which case they are subdivided by headings, for instance ‘The plan is...’ or ‘Ob-

jectively: ...' in bold. Such lengthy notes recapitulate the case, for instance: '07.05.08. [9] The old medical record is now at hand.' After this follows a lengthy recapitulation of the case history as documented by records received from the hospital from which the patient was transferred.

The idea of subjecting this enormous heterogeneity of relationships, categories, and document and data-types, to one monolithic data-base scheme seems bizarre.

The patient folder is the key artifact in an institutionalized coordinative practice. It retains the character of the stack of notes, compiled as an *aide memoire* by a solitary doctor. But it is an coordinative artifact by means of which clinical actors keep each other up to date with respect to the state and treatment of a particular patient; with respect to each other's observations, plans, and occasional uncertainties, and with respect to the informational basis for clinical assessments and decisions.

The patient folder is hefty. It documents the trajectory of chronically ill patients as represented in doctors' notes, lab reports, test results, clinical imagery, and so on, and it thus gains size and weight over time. Because of the number and sheer size of patient folders, the hospital's archive of patient folders is dispersed over multiple locations. Thus, when patients are due for checkup or have an appointment for a consultancy, their folders have to be retrieved. This task is carried out by the laboratory's clerical assistant who spends about three hours daily retrieving the folders for the patients scheduled for the same day, by locating them in one of the archives and hauling them back to the laboratory on a cart. Back at the laboratory, folders are placed on the desks or shelves assigned to laboratory workers or doctors' assigned to take care of the respective patients. In addition, folders are temporarily placed on shelves in case the patient did not turn up or is expected to come in for checkup within the next week. Finally, for a variety of reasons folders also find temporary station on doctors' desks in the various sections of the Heart Clinic, outside of the laboratory. Thus, because of the nomadism of patient folders, it may require considerable effort and time to locate and fetch a particular folder.

At the Heart Clinic, the clinical record concerning a particular patient is not confined to the content of the patient folder. In fact, the clinical record is distributed over an assortment of paper-based and electronic archives and databases (Fitzpatrick, 2004). In this context, the most important 'satellite record' is what is called the 'green folders'. It is a large set of suspension folders, housed in about 40 cabinet drawers in the hallway. Each folder contains information about a particular patient's ICD unit, its configuration, and printouts from the data accumulated by the unit. The 'green folders' are maintained by the bio-technicians at the outpatient clinic and are only occasionally accessed by doctors. To ensure some coordination, a summary of the 'read-out' (number of events, etc.) is manually entered into the 'continuations' in the patient folder.



The time-honored patient-centered medical record has worked very well for centuries and has proved very flexible in its contemporary incarnation as an institutional coordinative artifact. However, our study indicates that it is now coming apart. First, the sheer size and heterogeneity of the patient folder makes it difficult for a busy clinician, in the context of a brief routine consultation, to obtain an overview of the patient's history.

Second, its robustness as a dynamic shared record of the state of the patient was predicated on its being localized: a center of documentation and coordination of a specialized local clinical practice. Thus, when it comes to supporting documentation and coordination across a network of specialists, the medical record in its current incarnation comes up short. At best, satellite records are emerging, at the cost of painstaking and error-prone manual synchronization and replication work. At worst, communication and coordination among interdependent clinical workers breaks down. The issue is not simply one of overcoming geographical distance by means of IT, nor is it one of establishing common clinical documentation standards across multiple institutions. Raw ICD data are not understandable to GPs, and as it is now, even ordinary cardiology specialists will not be able to interpret the data confidently. In the words of 'a veteran of emergency rooms, post-operative wards, and intensive-care units':

'The remarkable advances of ultramodem biotechnology have brought with them complexities of such magnitude that medicine sometimes seems in danger of being overwhelmed by forces of increasing intricacy and incomprehension. In certain situations, only the small number of superspecialists who deal in a particular aspect of diagnosis or therapy are equipped to interpret a finding or observation.' (Nuland, 2002).

Integrating novel clinical technologies in medical practice undoubtedly requires that new coordinative practices are also developed: practices of interpreting, translating, categorizing data for the benefit of other clinical practitioners.

In collaboration with 'electrical doctors' at Copenhagen University Hospital and cardiologists at the associate regional heart clinic, we are currently engaged in their (tentative) development of such practices. More specifically, in an attempt to address both of the abovementioned issues, we are developing an experimental coordinative artifact, a digital form, that supports distributed cardiologists in producing, collaboratively and ongoingly, a shared 'summary' of the state of the patient and his or her device.

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# Institutionalizing Practices as Boundary Work: the case of MyHealthRecord

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**Abstract.** This paper examines the case of the design, development and implementation of MyHealthRecord, a Norwegian web-based service platform for patient - healthcare provider communication. The focus of the paper is on the ongoing institutionalizing practices of the management team. Institutionalizing practices are those directed towards achieving a persistent infrastructural arrangement. Specifically, such practices are conceptualized as boundary work. The analysis identifies three different ongoing negotiation processes showing how MyHealthRecord gets defined as an emerging socio-technical object.

## Introduction

This paper explores the work involved in making an information infrastructure become persistent over time. Persistence over time is a critical dimension of infrastructure development (Hanseth and Lyytinen 2004) (Edwards 2003). Ribes and Finholt have analyzed “the long now” of infrastructural development by identifying three scales of infrastructure: enacting technology, organizing work and institutionalizing practices. While the first two relate to everyday use and internal project organization, the third scale is concerned with the practices of “generating sustainable goods and services linked to social or collective purposes with connotations of permanence transcending individual interests or intentions” (Ribes and Finholt, 2009, page 379). In this view, institutionalizing refers to practical activities that reveal a complex terrain of negotiations with various

actors. We are particularly interested in this third scale in relation to our case. We are studying the ongoing process of design, development and implementation of a novel technology in the Norwegian healthcare context, MyHealthRecord (MHR), a web-based platform for patient-healthcare provider communication. We thus ask: how do the projects participants work *in practice* to construct a solution that is persistent, and what are the current challenges they are facing? In this paper, we want to analyze the actual practices that constitute the institutionalization processes and that we conceptualize as *boundary work*. Rather than indicating work for intercollaboration across groups, the concept of boundary work indicates the work for defining one's own identity in relation to other actors (Gieryn 1983).

## Method and case description

The case reported in this paper is based on an ongoing (at the time of writing) study of the design, development and implementation of MHR. The focus of the case study is on the process of infrastructure shaping along social, technical and organizational dimensions. The empirical material comes from interviews with the project management, review of documents and presentations, and participation in workshops with the users. This paper is mainly based on interviews describing the practices of the management team directed towards long term use of MHR.

MHR is developed by the IT department of a major Norwegian hospital. It signifies both the prospect of giving patients access to their own medical records (which is an official patient right in Norway stipulated by the Patients' Rights Act § 5-1) and the prospect of a stronger patient role by enabling a “personalized space” from where all information related to medical conditions, treatments and drugs would be accessed, communication and cooperation with healthcare practitioners would be effected, and exchange of information and experiences with other patients would be facilitated. It is thus enforcing and requiring an active participation on the side of the patient population. Such active role is advocated in the Norwegian National Strategy for Quality Improvement in Health and Social Services (2005-2015) from where we quote: “A well-informed, participative user has a greater possibility to achieve a good result in his or her interaction with health and social services” (Sosial- og helsedirektoratet 2005).

Technically, MHR is a service oriented web-platform designed to be highly adaptable and scalable, and providing a secure, private and trusted environment for communication between patients and health professionals. MHR offers several basic functionalities such as electronic reports, secure email communication, and booking or changing of appointments. It also offers the possibility of developing ad-hoc modules based on specific requirements, for instance it is possible to create digital forms that patients can fill in on line, web shops for ordering medical supplies, or direct access to laboratory test results. MHR is not offered as solution to the general patient population, but it is selectively adopted. Clinical

units or disease specific groups in Norwegian hospitals decide independently if they want to adopt and use the solution or not, or if they have requirements for new modules. The process of tailoring MHR is then collaboratively conducted by the MHR project team in the form of workshops with users, including both health personnel and patients by way of their patients associations. At the time of writing MHR is in use or in the process of adoption by more than 20 different units in various Norwegian hospitals.

## Case analysis

As mentioned in the introduction, boundary work is the work involved in defining one's own identity in relation to external actors. In the case of MHR boundary work is enacted in various processes of negotiations. We have identified 3 such processes the MHR management team engages in.

First, an important part of the work of the participants in the MHR project is their engagement in defining the present and future role of MHR in the Norwegian healthcare context. In Norway there is an ongoing discussion stemmed from patients' right to on-line access to medical records. This discussion is partially driven by the positive experiences reported from neighboring countries, especially Denmark and its [sundhead.dk](http://sundhead.dk) patient portal. MHR is presented as a new personal communication channel between patients and their health providers. Directing it even more towards delivering a long-lasting solution, MHR is envisioned as a portal for "a life time". The same manager states:

It should adapt to different users, users' needs and ideally also throughout a life time and taking into account that a person is not sick most of his life, so when one is not sick MHR, should be about health maintenance and prevention, more that disease and treatments.

Thus in practice, MHR strategically locates itself within the health policy debate, but proposes in addition to offer a platform that will support patient's communication with the health providers stretching both in time (a life time) and in space (independently of how many providers are involved in the delivery of care). This ambition translates into presenting MHR concretely as 'record access', but also more visionary as interaction tool, which is patient-centered, supports transparency (in relation to access to data), and the continuity of care.

Second, project participants are also engaged in ongoing negotiation about the status of the MHR project within their home institution, the hospital, and their home health region that is responsible for allocating project funding. In these negotiations MHR is presented by the immediate benefits brought to the hospitals. As a manager describes: "for example for the children clinic had this functionality of changing appointments in MHR, and it has become a very popular feature and many departments are using this functionality now and different hospitals like Hospital2 has started using it". It is a solution which in short time has been able to

save costs in particular in relation with waiting list management, which is a major problem in Norwegian hospitals.

Third, negotiations are also taking place in the relation with the users from the clinical units. Here MHR is presented as an adaptable solution that can be tailored in short time to the users' needs. In addition project participants emphasize also the future opportunities stemming from long term use of MHR. For instance the secondary use of data for statistical analysis which is perceived as a critical benefit and a functionality which is not explicitly supported by any of the systems of the hospitals IT portfolio.

## Discussion and Conclusion

In this processes of negotiation, MHR's own identity gets defined more and more in and through participants' practices: the way they engage with MHR in relation with other actors shapes it. Conceptualizing such practices as boundary work helps to be explicit about MHR as a socio-technical object that is defined as it emerges from the practices.

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