# Prototyping Matters of Concern

## On Productive Relations of Participatory Design and STS in Patient-Centered Healthcare

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*Dissertation for the degree of Ph.D. (Philosophiae Doctor)*
*Faculty of Science, University of Copenhagen, Denmark, July 2012*

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*Prototyping Matters of Concern*
*2012*

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*What man actually needs is not a tensionless state*
*but rather the striving and struggling for a worthwhile goal*

Viktor E. Frankl (Holocaust survivor)
Man’s Search for Meaning

# *Acknowledgements*

To complete the journey through a doctoral project is indeed a collective effort. Without doubt, this dissertation grows out of the collaboration, friendship and support of a large number of people (and things).

Since 2008 I have had the pleasure to be part of the research project *Co-Constructing IT and Healthcare* (CITH). The work that I present here has in large parts been made possible by funding from The Danish Council for Strategic Research under grant #2106-07-0017. CITH has involved partners from the University of Copenhagen, the IT University of Copenhagen, Copenhagen Business School, the Danish Technical University, and Copenhagen University Hospital (Rigshospitalet) and Bispebjerg Hospital.

I am indebted and grateful for the valuable collaboration with health professionals and patients. A special thank you to health professionals Helen Høgh Petersen, Mie Christa Jensen Larsen, Ea Lorentzen, Jesper Hastrup Svendsen, Olav Wendelboe Nielsen and Steen Zabell Abildstrøm. To protect the anonymity of patients I will limit myself to send out a heartfelt thank you to each of you and your relatives for inviting me in and for your valuable participation in the project.

I would like to thank everybody on CITH and my colleagues within the Human-Centered Computing research group at the Department of Computer Science, University of Copenhagen. A special thank you to Erik Frøkjær for great empathy and a warm character.

Thanks to my supervisor Finn Kensing for always being encouraging and generous and for guiding and concise comments on my work – and for being there in tough times.

To Joachim Halse and Jens Pedersen for fun and encouragement along the way. You are inspiring to be around. To Jeanette Blomberg for being a warm host and making my stay at Almaden Research Center memorable. To Melissa Cefkin for inviting me along to Xerox PARC. To Leigh Star and Geoff Bowker for having me join for lunch at their beautiful home in California. To Elin Pedersen for showing me around the Googleplex in Mountain View. To Naja Holten Møller and Signe Yndigegn for great discussions and for always being cheerful. Rikke Lauth for being such a great person. To Anselm Christophersen for being an awesome developer and for putting tremendous effort into the project.

To Martin Cornelski for many good laughs and discussions. To Urs, Rudy and Roy, for opening up San Francisco and making every day brighter. Bolinas! To Emilie Møllenbach for enlightening chats and for first class support.

Some important non-human actors played crucial roles as well… my laptop, my Dropbox, my voice recorder, the little Ricoh camera, the hills of San Francisco, the French radio FIP, Tante T, and the more lustful ones, such as Bali Shag, Coca Cola, and Jack Daniel's.

A huge high-five to Balder Onarheim and Troels Mønsted for being awesome in general and for all the fun we've shared together. An extra one to Troels for just being there when needed and for our many meals on Louise's bridge. To my close friends, Bjarke and Nicki, for your encouragement through thick and thin. Mama, papa and sis for your never ending love.

Lastly, I want to thank a dear friend whose personality has been paramount in making me able to end this part of the journey in a somewhat orderly manner. Tariq Osman Andersen, you have always been there for me through good times and bad, always supportive, always helpful, always willing to figure things out and have fun along the way.

From the bottom of my heart, thank you.

Jonas

# *Abstract*

Departing on Participatory Design, the dissertation draws on Science and Technology Studies to suggest a re-conceptualisation of the relations between design and research by practicing design interventions using a performative and relational ontology.

The dissertation presents results from three years of research within the project *Co-Constructing IT and Healthcare* and combines concepts and approaches from the interdisciplinary research fields of Participatory Design, Computer Supported Cooperative Work, Design Research, and Science and Technology Studies.

The empirical foundation stems from the design and research of a patient-centric personal health record for chronic heart patients in the Copenhagen region, Denmark. The contributions are presented through four papers – two journal papers and two conference papers.

# *Overview of Dissertation*

My doctoral dissertation consists of four parts.

Part One to Three

The first part presents the research problematique that I address and the setting that my work departs from. Next, it gives a brief overview of the research and design process. I then introduce and discuss the theoretical framework that I draw on to form the argument.

Part Four

The second part presents insights and reflections from the project through four peer-reviewed conference and journal papers. The four publications are listed below and included in the dissertation in their genealogical order.

1. Andersen, T., Moll, J., and Mønsted, T. (submitted): ***Practicalities of Prototyping***. Scandinavian Journal of Information Systems, pp. 1-34.

2. Andersen, T., Halse, J., Moll, J. (2011): ***Design Interventions as Multiple Becomings of Healthcare***. Nordes '11: the 4th Nordic Design Research Conference – Making Design Matter. Helsinki, Finland, May 29 -31, 2010. pp. 11-20.

3. Andersen, T., Bjørn, P., Kensing, F., and Moll, J. (2011): ***Designing for collaborative interpretation in telemonitoring: Re-introducing patients as diagnostic agents***. International Journal of Medical Informatics 80(8), pp. 112-126.

4. Moll, J. (2010). ***The Patient as Service Co-Creator***. Participatory Design Conference 2010 – Participation :: The Challenge (PDC2010), Sydney, Australia, November 29, 2010 – December 3, 2010. pp. 163-166.

Publications not included in the dissertation

Through the years and through the different stages of my research, I have engaged in conferences, symposiums, and seminars with written material that formulated some of the central discussions we were having within the project. Below are listed four contributions to such scholarly forums. These works do not directly form the body of the dissertation, but I provide an overview here anyway to give insights into the thoughts I have worked on along the project, but which haven't fully matured yet.

5. Andersen, T. and Moll, J. (2012). ***myCareLink – A Personal Health Record for ICD Patients***. Report for EUreka Idea Submission to Medtronic, Inc. pp. 1-74.

6. Andersen, T. and Moll, J. (2010). ***Prototyping Patient 2.0***. EASST010 – Practicing science and technology, performing the social, Trento, Italy, September 2, 2010 – September 4, 2010.

7. Andersen, T., Moll, J., and Mønsted, T. (2010). ***Philosophical Issues: When design meets research***. CEPHAD 2010 Conference – The borderland between philosophy and design research. Published in 'Copenhagen Working Papers on Design' Vol. 2 2010. p. 137-139

8. Andersen, T., Moll, J., and Mønsted, T. (2010). ***Prototyping (in) Healthcare***. Participatory Design Conference 2010 – Participation :: The Challenge (PDC2010), Sydney, Australia, November 29, 2010 – December 3, 2010. [Workshop]

9. Andersen, T., Bansler, J., Bjørn, P., Havn, E., Kensing, F., Moll, J. Mønsted, T., and Schmidt, K. (2010). ***Co-constructing IT and Healthcare***. European Conference on Computer Supported Cooperative Work (ECSCW'09), Vienna, Austria, September 7 – September 11, 2009.

# Contents

# Part One

## Setting the Stage

*In order to arrive at what you do not know,*
*You must go by the way which is the way of ignorance.*
*In order to arrive at what you are not,*
*You must go through the way in which you are not.*

From the poem 'East Coker' in Four Quartets by T.S. Eliot

# Chapter 1

# Introduction

With this thesis I present (the contours of) a renewed strategy of practicing *design interventions* in Participatory Design (PD). With the renewed strategy I extend the body of knowledge on design interventions in PD in a way that integrates three important elements; (a) *the anthropological sensibility of ethnographic fieldwork*, (b) *the change-oriented and exploratory commitment of participatory design* and (c) *the critical and relational mode of inquiry from actor-network theory*.

My point of departure is the extensive history within PD on design interventions. Studies that have both explored the relations between design and research as well as shown how the two modes of understanding and intervening can be fruitfully brought together.

The analytical purchase of science and technology studies (STS), in particular actor-network theory (ANT), steadily becomes more popular within fields such as *design research* and begins to find their way into PD as well. I examine how the new approach is different from the work on design interventions in PD that I stand upon. Infused by the thinking and vocabulary of ANT I present aspects of design interventions that open new ways to query into phenomena by performing the situations that we want to study. I show how we work to study the becoming of patient 2.0 by mobilizing collective performances of this new type of patient.

With this dissertation I conceptualize elements of a hybrid and ANT-infused version of design interventions. The central argument of the dissertation is that it is fruitful to practice design interventions as situations where ethnography, design and research comes closer together to form situations of relevant futures as well as research insights.

STS invites a re-shifted emphasis on agency to focus on how human and non-human actors are connected and linked in relational performances. Informed by this thinking, I propose to work explicitly performative in design interventions in participatory design. Whereby, I propose that we deliberately perform and create the collective configurations that we are keen on exploring.

## Research Question

For the sake of simplicity, I pose the focus of the thesis in the form of a research question. The question that guides my research is:

*How can central concepts of a relational ontology be utilized as generative in participatory design to strengthen the practice of design interventions?*

# Chapter 2

# Co-Constructing IT and Healthcare

With this section I introduce the research project that I report on as well as the design and research activities that I have carried out during my participation in and running of the project from 2008-2011. This is meant to give an overall impression the research setting, show how I have worked through the project to produce the empirical material that informs my contribution(s) in this thesis. The details given will in some cases elaborate on the descriptions provided in the papers, but generally will each paper hold more empirical details in their dedicated sections with in-depth accounts of particular cases.

## Empirical Backdrop

The empirical backdrop that I report on here stems from my participation in and running of the research project '*Co-Constructing IT and Healthcare*' (CITH) through the three years from 2008-2011. CITH could be presented in a multitude of ways depending on specific aims and research interests. With CITH I have been engaged in research aimed at developing new and more patient-centered ways to improve the treatment and care for chronic heart patients.

My presentation here focuses only on my own engagement in the project and how it has framed my research. As an introductory overview, however, I will describe the setting and the project at large. For detailed descriptions of the work-settings and analyses of the collaborative practices involved, please see paper 2 and 3 (Andersen et al., 2011a; Andersen et al., 2011b), in which we unfold the telemonitoring practices in details.

CITH set out to explore the telemonitored treatment and care of chronic heart patients with particular attention on how collaboration across institutional and professional boundaries in the healthcare sector could be supported and enhanced with IT. Specifically, CITH focuses on the treatment of a certain kind of heart patient. Namely, heart patients living with an implanted advanced pacemaker (an ICD[1]) that offers remote monitoring and therapy. ICDs are one of the new technologies changing healthcare practices for patients and health professionals due to the enabling of new telemonitored paradigms for treatment and care.

An ICD can be thought of as an advanced pacemaker that is not only able to constantly monitor a patient's heart rhythm in order to ensure a stable heart rate, but which also holds the ability to deliver electric shocks to re-establish a 'healthy' heart rhythm if the heart rhythm becomes disruptive (*cardiac arrhythmia* in medical language) – e.g. if the patient experiences sudden cardiac arrest the electric shocks can restore a normal heart rhythm; thereby bringing the patient back to life (in this way the ICD functions much like a defibrillator known from the hospital emergency rooms or the walls at shopping malls).

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[1] Implantable Cardioverter-Defibrillator (ICD).

The ICD is implanted much like a pacemaker and sits to the left on the upper part of the chest. In essence, the ICD is a small battery-powered electrical impulse generator, which is implanted in patients who are at risk of sudden cardiac arrest due to ventricular fibrillation and ventricular tachycardia (critical abnormal heart beats). While monitoring the heart rhythm, the ICD continuously records data on the heart rhythm and the arrhythmic events, but also general information, which can be used as insights into the overall condition of the body, the device itself and the status of the battery. As an example, some ICDs can alert medical staff on excess fluid levels (e.g. edema) days before other medical methods would otherwise detect the indications. The purpose of collecting these ICD data is to continuously monitor the chronic condition and to support decisions about whether or not particular interventions should be initiated (e.g. change in medication or re-configuration of the ICD). (Burri & Senouf, 2009; Goldberger & Lampert, 2006; Raatikainen et al., 2008)

## Premise, Funding, Participants and Stakeholders

CITH is a joint collaboration between the *Heart Centre at the Copenhagen University Hospital*, *Bispebjerg Hospital*, the *IT University of Copenhagen*, the *Technical University of Denmark*, and the *University of Copenhagen*. The project is funded by the *Danish Council for Strategic Research* with grant #2106-07-0017 as well as by the participating universities and hospitals. More than 50 patients and relatives have participated in the project activities and around 20 health professionals.

CITH was founded on the premise of exploring and addressing the ‘lack of continuity and coordination of care’ (Pritchard & Hughes, 1995; Rubak et al., 2002), which are stated to be amongst the greatest challenges facing the (Danish) healthcare system (Kensing et al., 2007). “The problems of continuity and coordination are discussed in the international literature through terms like: lack of shared care, need for integrated care and continuity of care (Hardy et al., 1999; Hickman et al., 1994; Mur-Veeman et al., 2001). Known consequences are low patient satisfaction, high costs, medical errors, and waiting times.” (Kensing et al., 2007)

On these premises, CITH was set out to “address the problems of shared care and IT support for *communication across institutional and professional boundaries* in heterogeneous settings of healthcare professionals and patients, and will advance the conceptual and practical understanding of how to model, develop, and implement socio-technical IT solutions for communication and cooperation within heterogeneous and distributed work settings.” (Kensing et al., 2007)

## Studying Tele-Health Practices: The Patient as a Resource

Goals and projections like the ones mentioned above need to be broken down into some sort of manageable parts that can actually be explored (design researched) and improved in meaningful ways.

With this section I seek to give readers (a) an overview and feel for the research process, (b) the progression through the process, and (c) the tools and techniques used.

As I was completely new to the field of healthcare I needed to learn about the work practices that collectively make the telehealth of ICD patients a reality. This brought me to spend a lot of time and effort in the contexts where care and treatment of ICD patients is made.

I began with ethnographically-inspired and fairly open-ended field studies at central sites, through various co-design-themed workshops, and finally ending up with full-fledged IT prototypes running as part of the telehealth practice(s). Through the process we combined (mashed up) tools, techniques and methods from participatory design (Bjerknes et al., 1987; Greenbaum & Kyng, 1991) with central strategies from Computer Supported Cooperative Work and STS-informed Workplace Studies (Orlikowski, 2007; Star & Strauss, 1999), together with the inventive and explorative approaches found in design research (Gaver et al., 1999; Koskinen et al., 2008; Mattelmäki & Matthews, 2009) and design anthropology (Binder et al., 2011; Halse et al., 2010; Halse & Clark, 2008).

Working "ad-hoc and ad interim" as Geertz notes (Geertz in Becker, 1998, p. 9), with a clear acknowledgement that the process would not be "neat, logical, and unmessy" anyway (Law, 2004).

In my case the primary sites came to be the different departments at the Heart Centres at Copenhagen University Hospital and Bispebjerg Hospital as well as the many homes of patients and relatives. We have engaged in a collaborative effort with healthcare professionals at the Copenhagen University Hospital's Heart Centre, local cardiology departments and worked closely with patients. To approach the two-folded aim of CITH; On the one hand carrying out design activities to explore and experiment with IT solutions for the healthcare network. On the other hand, we focus on producing contributions to our field(s) of research by advancing methods, concepts and techniques for design of IT in healthcare.

Guided by both our reading of the literature in relevant research fields and our findings through months of fieldwork, we chose to focus on the collaborative and empowering potentials of enabling and supporting patients in becoming (even more) active participants in their telemonitored treatment and care. As we note in paper 2 (Andersen et al., 2011b), few researchers (Bardram et al., 2005; Kapland & Fitzpatrick, 1997) appreciate the collaborative engagement in telemonitoring practices and few have investigated the inevitable transformations in the cooperative work caused by new socio-technological advances, in relation to patient-centered telehealth practices. Kaplan and Fitzgerald (1997) investigate remote intensive telehealth care and provide interesting observations, but they explore the collaborative practices between dispersed healthcare practitioners and not the monitoring of patients.

Patients are essential parts of the ensemble that makes up the practice of telehealth, and it has even been argued that patients are able to act as diagnostic agents (Oudshoorn, 2008). As a diagnostic agent, essential work is redistributed from the healthcare professionals to the patient, and most often this new type of work disappears from the formal descriptions of telehealth (Oudshoorn, 2008). When patients become “absent,” their condition is separated from the context of their bodies, and the “condition” is characterized through particular forms of representation such as images and graphs (Mort et al., 2003). This means that the healthcare practitioners must rely solely on representations to create and make sense of the context, which is a huge change from the co-located practice where patients and health professionals are both present.

Previous design-oriented research on telemonitoring practices suggests different technical web-based solutions for telemonitoring technologies, where the patient and the healthcare practitioners, through one portal, can reach the clinical data collected in the patient’s home as well as the patient record (e.g. Magrabi et al., 1999; Unruh & Pratt, 2007). However, these kinds of studies are purely oriented towards the technology involved, typically deriving results from a laboratory setup, they do not take into account the organizational and hence sociotechnical practices involved.

Even though previous design-oriented telehealth research tends to focus on the technical aspects and potentials of the process, there is a trend in medical informatics (e.g. Berg, 2001; Boulus & Bjørn, 2008; Riet et al., 2001; Rouck et al., 2008) toward more patient-centered approaches and the design of computer supported cooperative healthcare systems (Koch, 2006, p. 570).

Patient empowerment has since the mid-1990s established a new paradigm in healthcare (Saltman, 1994). Patient empowerment initiatives are to increase possibilities for patients to become active participants in their own treatment and care and to become important healthcare decision-makers. Optimal outcomes are achieved when patients actively engage in the healthcare process (Street Jr et al., 2005). For this to happen, it is necessary to make relevant and adequate information available for patients in a format that is manageable for both patients but indeed also for the network of health professionals. This would require that patients are able to share experiences and ask questions in non-obtrusive ways. Valuable patient empowerment is therefore achieved when patients have easy access to relevant (and patient-centered) healthcare information and when bi-directional contact is established between patients and health professionals and in-between patients.

Recent technological innovations and Internet developments have made patient empowerment a feasible reality. Telehealth platforms and Web 2.0 health applications make it possible to connect patients to a network of remote clinicians and other patients, where they can collaborate and share experiences. New concepts are coined to embrace these opportunities. Participatory medicine, for example, a movement from the early 2000s in which "networked patients shift from being mere passengers to responsible drivers of their health" (Sands, 2012). Here, emphasis is on a cooperative model of health care that encourages and expects active involvement by all connected parties (patients, caregivers, healthcare professionals, etc.) as integral to the continuum of care.

Informed by these and similar works promoting what is termed 'Personal Health Records' (PHR) (Bates & Bitton, 2010; Pagliari et al., 2007; Tang et al., 2006a) together with research on patient 2.0 (Bos et al., 2008), I chose to guide my design research by asking; '*how to empower, enable and equip patients to become active participants in their own treatment and care, while at the same time become resources for the health professionals?*'[2]

In regard to my research this has meant that I have explored how to (re)design healthcare IT to make the patient an active participant in the treatment and care programs, in ways that shape or actualize the patient as a resource in his/her own treatment – as well as for the health professionals.

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[2] As a guiding design principle and not a research question per se.

## myRecord: Prototyping a Personal Health Record for Patient 2.0

With this section I will give an overview of how we have worked with empowering patients through the realization of the patient-centered healthcare concept promoted by personal health records. Some passages builds on work from Andersen et al. (2011b).

A study from at the Heart Centre at the University Hospital of Copenhagen show that 95% of ICD patients are very content with remote monitoring and that it makes clinical monitoring work much more effective and replaces the majority of in-clinic visits (Petersen et al., 2012). Telemonitoring introduces a solution to the problem of a growing number of ICD patients per clinic, while giving patients more freedom and maintaining possibilities for proactive patient care. Nonetheless, the study found that 84% of the ICD patients wish for more detailed feedback, 21% wish for a faster reply and 25% make unscheduled transmissions as a way to question their health condition (Petersen et al., 2012). These problems all relate to the shortcomings of telemonitoring – namely that patients have become absent from the clinical work in ways that eliminate situated collaboration between health care professionals and patients. This hinders individualized care and disempowers patients, because they are not able to actively participate (Andersen et al., 2011a).

Socio-technical solutions that integrate the philosophy of patient empowerment with the current healthcare practice into a collaborative process are often discussed under the term *Personal Health Record* or in short, PHR. In contrast to the professionals' electronic medical records, the general idea of the PHR is to enable patients to contribute with contextual health information and grant patients access to their medical data (medicine profile, lab results, data from devices etc.) and a wide range of health information sources. As an idea and concept, PHRs have existed since the late 1970s but as an organizational innovation the PHR remains a vague and contested vision being "in its infancy" (Gearon, 2007; Tang et al., 2006b). Early commercialized versions that introduce just some of the interesting possibilities of PHRs are patientslikeme.com, Microsoft's HealthVault, and in a Danish context, sundhed.dk.

### Patient 2.0

Another concept of this new healthcare paradigm defines the personalization of healthcare, remote collaboration and the promotion of health education by making use of collective intelligence and newer web- and mobile technologies (Hughes et al., 2008). A similar, but even more patient-centric definition is the ePatient or Patient 2.0 (Bos et al., 2008). This new kind of patient is defined as *empowered* to actively *engage* in their own care by means of technology; patients who are *equipped* to manage their own condition and *enabled* to make choices about self-care. In short, patients who are equipped, engaged, empowered, and enabled (Nelson, 2012).

Furthermore, studies show that optimal outcomes are achieved when patients actively engage in the healthcare process (Street Jr et al., 2005) and that the demand for technologies to empower patients increases (see e.g. Campos, January 30, 2012; Nelson, 2012). Solutions that integrate these healthcare philosophies are PHRs.

I have design-researched, developed, and tested a prototype of a PHR, myRecord, as part of my research. The focus has been to explore how to enable heart patients with an ICD to become active participants in their own treatment and care. By prototyping we have iteratively refined myRecord through 6 major versions, adding new and redesigning existing features based on insights from co-design workshops and design interventions in healthcare practices. All versions of myRecord have been fully working web-applications and have been used by both patients and health professionals at hospitals in the Copenhagen Region, Denmark[3] in various real-life situations in the period 2008-2011.

Below are visual impressions of the design and research of our PHR, myRecord.

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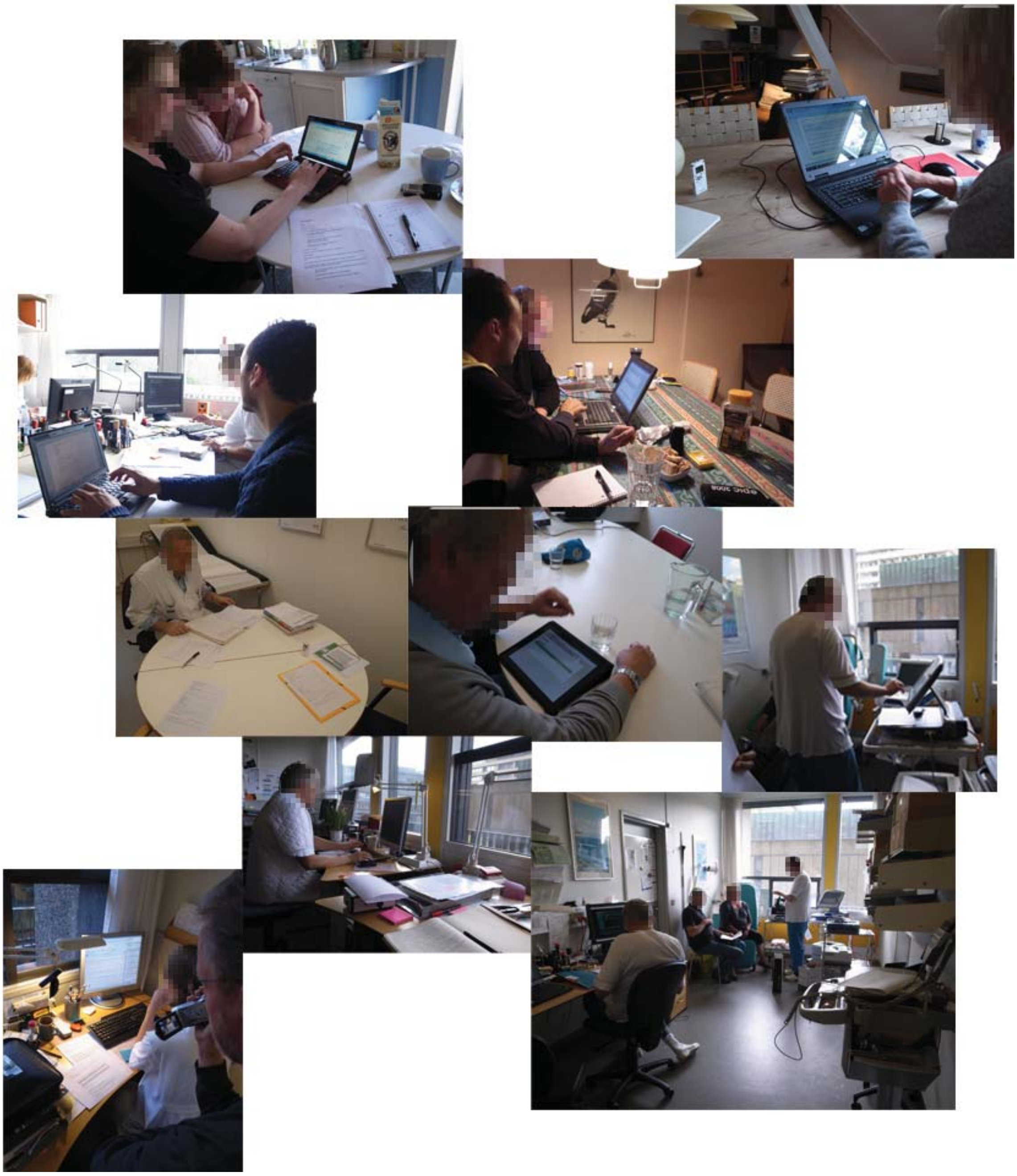
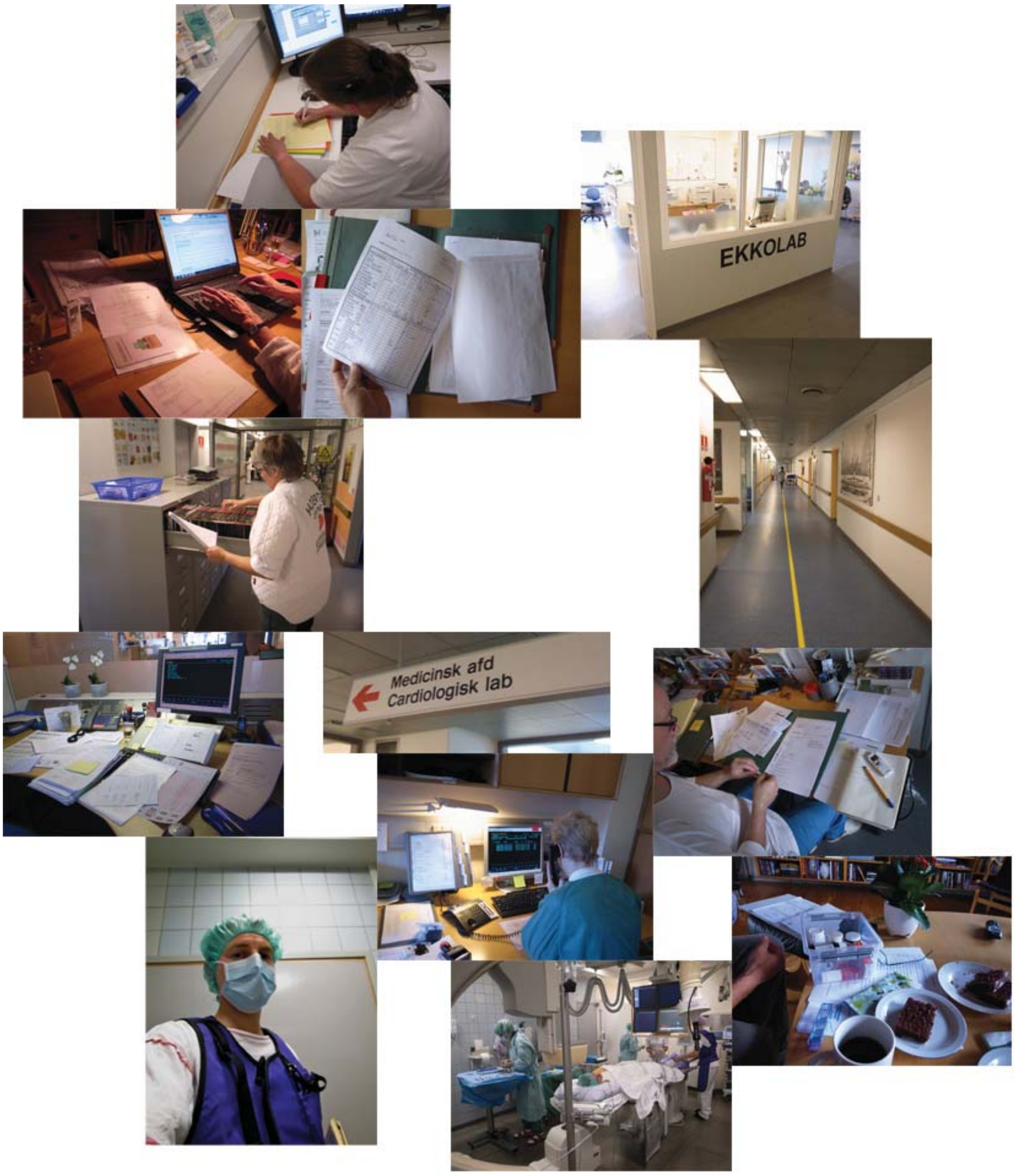
[3] The Heart Centre at Copenhagen University Hospital (Rigshospitalet) and local hospitals: Bispebjerg Hospital, Hvidovre Hospital, Frederiksberg Hospital and Roskilde Hospital in Denmark.

Co-Designing with patients and health professionals



Design Interventions



Observing work at home with patients and at hospitals

Sketching and prototyping

# Part Two

## Design(ing) Interventions

*The point is to make a difference in the world,*
*to cast our lot for some ways of life and not others.*
*To do that, one must be in the action, be finite and dirty,*
*not transcendent and clean.*

(Haraway, 1997, p. 36)

## Introduction to Part Two

With this part I will position my research by introducing the fields of research that I draw on to form the basis for the argument(s) in this dissertation. It would, however, be an eternal task to give each field a comprehensive write-up, so I present each field with focus on how it informs my work. Our work through the project has been highly interdisciplinary, but there are of course fields that I have closer relations to than others and which my work in particular departs on. Before I introduce the fields of research, I will for convenience reasons list the fields here. They are, ***Participatory Design*** *(included herein is the heritage from* ***Computer Supported Cooperative Work*** *and* ***Workplace Studies****), and* ***Design Research***.

Participatory Design (PD) is the primary research community that I attempt a dialogue with and which the contributions of my doctoral work are geared towards. In particular, I add to the body of knowledge on the *research and practice of design interventions* within PD. Based on reflections on my own work within the CITH project as well as informed by the research stemming from the other fields mentioned, specifically central notions from science and technology studies (STS).

A different way to frame how the contribution that I write up in this dissertation has come into being is to think of the process as a journey. Rooted in the traditions of PD, Workplace Studies and CSCW, I originally sat out to research (and design new) patient-centered healthcare practices through the design of new information technology. But, as I will lay out in the coming chapters, we found the ‘classic’ PD-ways of creating IT-driven change difficult to actually produce relevant change from. This was mostly due to the way we understood and were able to grasp what it meant to do ‘research’ and ‘design’. Only by making a difficult and at times very confusing and disturbing journey through the woods into the fields of design research and STS, were we able to internalize a new language and ontology, which opened the black boxes of research and design in ways that set us free to practice a new hybrid version of design interventions. A version that we found to be both productive in making actual, relevant and sustained changes to the practices we engaged with and at the same time let us produce our empirically-based insights from it.

In short, I find the metaphor productive because it shows how my core argument comes into being by utilizing central notions of posthuman ontology inform the work on design interventions in PD.

## Chapter 3

# Making Representations (of) Work

I find myself deeply rooted in the tradition of ‘socio-technical and work-oriented design of IT’ (Blomberg et al., 1995; Bødker et al., 2004; Ehn, 1988), with PD being the primary design and research community. PD is, however, an interdisciplinary and fragmented field in itself, so with this section I will strive to provide enough background and genealogy to enable readers to understand which parts of earlier works that in particular inform my (design) research.

## Understanding Work as Resource for Design: On CSCW

As CSCW and (hence) Workplace Studies play a prominent role in PD I will lay out the central contributions from those two fields in regard to PD. A secondary reason for this write-up is to lay the foundation for my later critique of how both CSCW and PD are still challenged in moving from the modes of 'understanding' (work practice) to the modes of design (of relevant IT) informed by ethnographically produced insights[4]. This chapter also underpins my discussion in relation to paper 3 (Andersen et al., 2011a) in the next chapter, where I show how we encountered problems when subscribing to a 'classic' CSCW-informed ethnographic approach organized as an *Action Research* study (Checkland & Holwell, 1998) and how it hindered us in our process of researching and designing patient 2.0. Workplace Studies, CSCW and PD are today highly intermingled and overlap in many areas, as e.g. witnessed by the many scholars who publish across these fields (Ehn, 2008; Kensing & Blomberg, 1998; Suchman, 1994; Suchman et al., 2002). With this in mind, this write-up also serves the role as a positioning of the fields and their specialties. I am aware that e.g. CSCW is a fragmented field (Bannon & Schmidt, 1989) and that my introduction here does not pay tribute to the studies within CSCW and Workplace Studies that has no intention of informing design processes based on their findings and see themselves as a purely research-driven field (Bannon et al., 2011).

With the introduction of information technology into the workplace in the early 80s, particularly personal computers, there was a growing interest in gaining a deeper understanding of the ways people work together, "with an eye to understanding how technology could support them" (Grudin, 1994). Initially, research was carried out to reach *system requirements* for building single-user systems within an 'Office Automation' realm. But problems arose with the introduction of networked and distributed computer systems. There was a need to learn more about exactly how people collaborated in groups and organizations, and what the role of technology as a transformational device in collaboration was. Put shortly, CSCW was founded on the dissatisfaction with the earlier 'Office Automation' approach, which had proven insufficient in producing satisfactory 'system requirements' that could serve as reliable resources for the later engineering of collaborative systems. As Grudin (1994) notes, the key problem in this approach was 'how to understand system requirements' – what were the precise requirements for collaborative systems? As we know now, this endeavour has proven to be even more troublesome than first anticipated (Bowker et al., 1997; Simonsen & Kensing, 2005).

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[4] Valuable changes need not be driven by or constructed with IT, but as 'design of IT' is the craft I am skilled in, this is a prerequisite, whether we submit to it or not.

Although CSCW and workplace studies are separate fields, with distinct research programs, they are as mentioned deeply intermingled. Workplace studies are primarily a sociological research tradition uncovering various sociotechnical aspects of work practices (Luff et al., 2000; Strauss et al., 1997). Primarily, by conveying the importance of the sociality of work through studies that show how work is comprised of complicated actions and interactions. A central element to the epistemology of ethnographically oriented workplace studies is, that every work environment is unique and work practices are highly situated (Plowman et al., 1995; Suchman et al., 1998). A beautiful example of how an ethnographically rich and strong account of mundane 'service work' can open our understandings of skilled routine work is Julian Orr's account that shows the sociality involved in tinkering (Orr, 1996).

The ethnographic techniques used to study work practices and the subscription to the situatedness of practices, which together emphasize thorough and in-depth ethnographic understandings of work as the basis for technology design, are central elements of what informs CSCW.

But as Pedersen notes, "workplace studies does not articulate the issue of use and design of information technology [...] as a design problem or a political problem" (Pedersen, 2007, p. 28). The epistemological challenges that lies herein is exactly what many later pointed to as the fallacy of the field. Namely, that workplace studies fail to show how the solid knowledge of the work practices can become resources for design of technology and in specific ways impact the changes of future arrangements. As Plowman et al. (1995) states, "how to present design recommendations in a way that is practically useful is a central concern." Studies are generally described as *informing* system design in the sense of 'imparting knowledge to' rather than 'giving form to.'

Through influential and ethnomethodological studies of work and collaboration, workplace studies has had immense influence on the shaping of CSCW. Unfolded in e.g. (Schmidt & Bannon, 1992) and in the anthology *Workplace studies*, who all treat this theme in rich ways (Luff et al., 2000).

## Understand to Design

On these grounds, CSCW set out to establish a field of research where the main concern would be to produce pragmatic and relevant design insights from in-depth understandings of collaborative work practices.

In their programmatic call, two of the leading figures, Kjeld Schmidt and Liam Bannon (Schmidt & Bannon, 1992), conceptualize CSCW as a research field that is concerned with developing conceptual frameworks to act as *support requirements of cooperative work arrangements*. As a central component, CSCW should be committed to understanding the "nature and characteristics of cooperative work with the objective of designing adequate computer-based technologies" (Schmidt & Bannon, 1992, p. 9). Schmidt and Bannon end their write-up with a defining statement that has since served as conceptualizing the focus and unit of analysis for the field. Namely, they suggest CSCW as "an endeavour to understand the nature and requirements of cooperative work with the objective of designing computer-based technologies for cooperative work arrangements." (ibid.)

Both working by example – providing excellent studies of collaborative work environments (Heath & Luff, 1992) – and through the development of powerful concepts to open up work as distinct activities – e.g. articulation work, awareness and coordination mechanisms (Dourish & Bellotti, 1992; Gerson, 2007; Schmidt & Simone, 1996) – CSCW has greatly furthered understandings of how people engage in cooperative work and the role of technology herein. Not least, through the development of techniques to *make work visible* (Suchman, 1995) in order to foreground important aspects that need to be considered in regard to designing information technology to support the practices.

In my research, I am particularly informed by the research within CSCW showing how work is distributed on both spatial and temporal scales, how to follow artefacts (Star & Griesemer, 1989), the sociality and agency of technology (Akrich, 1992; Orlikowski, 2007), how sociological elements are inscribed in technology and the politics of technology (Star, 1991), organizational aspects of introducing IT (Kensing, 2003) and finally a general opening of 'the technological' as socially embedded devices (Suchman et al., 1998; Suchman et al., 2002).

## (Problematic) Implications for Design

Especially in recent years, CSCW has brought its techniques and concepts into the healthcare domain and greatly furthered the understanding of collaborative work and the role of IT herein (Berg, 1997; Fitzpatrick & Ellingsen, 2012).

Moving into the healthcare domain, CSCW notions and techniques has proven valuable in opening up understandings of medical work to appreciate the rich interactions making (up) collaborative work. Extending Strauss et al.'s (1997) ethnomethodological studies of medical work to make the accounts, the representations of work, available as resources for design.

However, as I will unfold below CSCW has never really managed to develop a framework or methodology that accomplishes what the field was initially created for. Although CSCW has, without a doubt, contributed with an incredible number of valuable and insightful studies, they have so far not developed a practice that actually manages to consistently integrate ethnographic inquiry and insights into realized designs.

In a recent review of the last 25 years of CSCW healthcare research, this argument is backed by longtime researchers Fitzpatrick and Ellingsen (2012), in which they note how "only a few went on to actual design explorations and even fewer on to building and deploying and evaluating systems in use" (Fitzpatrick & Ellingsen, p. 10). Many CSCW studies have not managed to move beyond the 'implications for design' that are written up as input to an imagined design team, or simply others scholars. This problematique has been central within CSCW, which I will elaborate on below.

The problematique that I point to has long been recognized within CSCW and related fields, where prominent scholars have proposed necessary changes, discussed effects and even debated if CSCW should completely drop the will to understand collaborative work through the realization of actual systems.

In his seminal work, Paul Dourish (2006) altogether questions the 'genre convention' of ending research efforts (each paper) with a canonical 'implications for design' section. He points to the anthropological origins of ethnographic inquiry, where the original analytical purchase seems to have been forgotten. In design-oriented fields, ethnography has evolved to a technique for mere data gathering, where it is seen as the job of the ethnographer or ethnographic fieldworker to travel to 'the field' (the use setting) and bring back reports on the practices in ways that convey the member's experiences as true to the setting as possible. This way, the defining characteristic of ethnographic investigation comes to its spatial-temporal organization – that “the ethnographer goes somewhere, observes, returns and reports.” (Dourish, 2006, p. 543). This strips ethnography of its, probably, most important element, namely its ‘analytic auspices.’

One field particularly known for its intensive explorations of the (inter)relations of design and ethnography, is Participatory Design (Blomberg et al., 1993; Greenbaum & Kyng, 1991; Schuler & Namioka, 1993; Crabtree, 1998; Kensing, 2003; Simonsen & Kensing, 2005; Pedersen, 2007; Binder et al., 2011).

## Participatory Design: Understanding and Intervening

Descriptions of the early history and the later formation of what is today Participatory Design are illuminatingly described elsewhere – even by the founding people (Bjerknes et al., 1987; Ehn, 1988; Simonsen & Robertson, forthcoming) . So, I will limit myself to make visible the shoulders that I am standing on by laying out the genealogy for the version of PD-informed design interventions that I engage with this thesis. Hence, I will only briefly touch upon the origins of the early democratic projects and how they have shaped the field into what it is today.

The desire to engage end users (union-protected workers in early projects) to have a say in the development of new technology, was primarily seen as only driven by a political orientation, where the disqualification and de-skilling of workers by management was seen as problematic. In this sense, PD began as a democratic project, to let the people affected by forthcoming technological changes have a say in the process. But indeed also as a way to overcome the many troubles and failed systems designed only from a systems engineering standpoint where management would dictate the changes needed and the functionality of the technology in terms of system requirements.

For insights into some of the early explorations of user involvement and how to design computer systems with direct participation of end users, please see e.g (Clement & Besselar, 1993; Greenbaum & Kyng, 1991; Schuler & Namioka, 1993). Clement and Besselaar give a historical review of the PD-approach. And for a modern overview of both the heritage and the newest orientations of the field, please see the forthcoming 'International Handbook of Participatory Design' (Simonsen & Robertson, forthcoming).

The pioneering studies that have explored how to combine ethnographic approaches and design practice, is what I build on and extend with the contribution(s) in this thesis. Through the early Scandinavian projects and later with the North American endeavours, PD has showed how to practice 'design interventions' where early prototypes of computer artefacts are utilized as inquiry devices to drive the research agenda. How we build on these is unfolded in paper 2 (Andersen et al., 2011b), where we write up and give an introduction to how STS-informed interventions can be performed to both drive research inquiry and evolve the designed prototypes in one and 'the same poignant moment.'

It is fair to say, that the principles pioneered in and through PD has had tremendous success, especially recently with a rise in commercial interest in learning about the tools, techniques and methods of how to integrate ethnographic inquiry and user participation in the design of future systems/practices[5].

What I will concentrate my positioning on here is the work within PD that have pioneered and explored techniques such as *design-by-doing* and participatory prototyping (Bødker & Grønbæk, 1991a, 1991b; Grønbæk et al., 1997) as well as the epistemological challenges of this and how to overcome them (Ehn, 1988). One path that binds workplace studies, CSCW, and PD together is their quest to explore ways to *make representations work* (Kyng, 1995). As I presented with the brief write-up of workplace studies and CSCW, they approach the challenge of making representations work by refining the core concepts of the fields and by learning more about why CSCW systems fail and the complexities of collaborative work.

PD has approached the problem of crossing the gulf from insights to design by developing creative and powerful ways to engage users of future computer systems in both the processes of understanding the work practices and designing support for them. In this way, PD has pioneered methods and techniques to move the explorations and try-outs of possible futures into the work practices. By including the people who are going to use and be affected by the design as co-designers.

In particular, the techniques of design-by-doing address the problems of representational design, as seen in CSCW. They do this by moving the design process closer to the use practice. However, they still have representational design at the core (Kyng, 1995). Later developments, however, argue for moving the design even closer (which I unfold in chapter 4). In paper 2 (Andersen et al., 2011b), we are in line with this trend by proposing to completely dissolve or disregard the boundary between design and use, and show how design can be done with sticking to the central and core principles of PD, but at the same time move the designs into the practices that are explored and changed.

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[5] E.g. EPIC Conferences, Co-Creation and Service Design communities, Kaiser Permanente's Innovation Center, and consultancies like IDEO and RED Associates.

### Phenomenological Influences on Design Philosophy

In Ehn's seminal work on 'work-oriented design of computer artifacts' (Ehn, 1988), he develops an extended design philosophy as part of the argument for (the need for) making design of computer systems a practice based on thorough phenomelogical knowledge of the work environments that are being designed for. Informed by a Heideggerian existential phenomenology of being in the world and by drawing on Wittgenstein's language-game metaphor, Ehn lays the groundwork for why the work practices that are being designed for should be approached as highly developed and skillful practices, where knowledge can only be learned thoroughly by doing the practice.

In other words, Ehn develops the philosophical groundwork for *design-by-doing* (Greenbaum & Kyng, 1991), whereby he opens the black-boxes of practice to designers and makes it clear that practice is highly phenomenologically bound and tacit. Dourish further argues for a phenomenologically-informed design discipline in his book on the foundations for practice and action as embodied, *Where the Action Is* (Dourish, 2004). Drawing both on the more classic phenomenology of e.g. Wittgenstein and Heidegger, but also newer ontological explorations into the realm of technology design, such as Wanda Orlikowski, Lucy Suchman and Bruno Latour, Dourish stress the importance of practical action over abstract theory and/or approaches from cognitive psychology (Dourish, 2004). Hence, embodied interaction and practice as lived experience (Suchman, 2007).

## Design-by-Doing: Prototyping Interventions

Central to PD's influence are the developments of design-by-doing techniques, where the processes of designing are moved closer to the use practice in efforts to cope with the challenges of making representations of work (Kyng, 1995; Suchman, 1994). Central arguments are found in (Binder et al., 2008, Kensing, 2003; Binder et al., 2011), which explore various tools and methods for moving the inquiry from the problematic representational techniques and into the use practice.

Guided by the principles of taking *work practice seriously* – that work *tasks are highly situated* and must be understood within their context – to emphasize *human actors over human factors* and that *work is fundamentally social*, design-by-doing techniques have been refined from the early 'approaches to prototyping', over explorations with mock-ups (Bødker & Grønbæk, 1991a, 1991b; Ehn & Kyng, 1991), future workshops (Kensing & Madsen, 1991) and paper prototypes and cooperative prototyping, to commercial and large scale software development projects (Hertzum & Simonsen, 2010). PD holds an impressive variety of techniques to represent work in ways to ease the transition or translation to stable version of computer systems. But my claim is, that a majority of PD projects still work to produce representations of work removed from the actual practices – although we have moved closer, there is still a bit of road left to travel. As also pointed to in recent works by Ehn (2008) and Hartswood et al. (2008).

How the hybrid version of design interventions, that I have developed and practiced during CITH, draw on the notion of interventions described in paper 1 and 2 (Andersen et al., inreview; Andersen et al., 2011b). To sum up, with design interventions I mean intentionally staged situations used to try out working prototypes and to enact improvised features as part of participants' work practices. As a concept, this is not a new phenomenon to PD. The pioneering studies at Xerox PARC (Blomberg et al., 1995; Suchman et al., 1998) as well as the Scandinavian approaches (Greenbaum & Kyng, 1991; Grønbæk et al., 1997; Kensing, 2003) all apply an interventionist approach to systems design. However, we employ a performative understanding informed by later developments in STS (Andersen et al., 2011b; Ehn, 2008; Halse & Clark, 2008; Hertzum & Simonsen, 2010), where we deliberately work with the understanding that the potentials for improved work practices are something that emerge collectively as we explore and configure the socio-material assemblages (Danholt, 2005). Thus, the collective engagement as a process is fundamental to participatory design (e.g. Blomberg et al., 1995; Greenbaum & Kensing, in press; Greenbaum & Kyng, 1991; Schuler & Namioka, 1993; Suchman et al., 1998). But, as I point to in part 3, a performative understanding of design interventions and the integration of prototypes into users' work practice foregrounds otherwise hidden activities and potentials.

Although the development of design interventions as situated moments of both social science exploration and technology development has brought about fundamental changes in the way systems are designed and users and stakeholders are engaged, there is still challenges to address if we are to succeed in combining the research and design protocols inherent in PD. (see e.g. Pedersen, 2007)

## Exploring Action Research and Design Science

In paper 3 (Andersen et al., 2011a), we present a CSCW analysis of how patients have become absent as part of the introduction of the telemonitored setup. By investigating how care and diagnostic work takes place for patients on a telemonitored setup and for patients without, we were able to show how patients in fact play crucial roles in the diagnostic work, and how the telemonitored setup did not allow for such collaboration anymore. We then discuss how we explored different design-driven ways of re-introducing patients into the setup again, while maintaining the benefits of being telemonitored. Relevant to the argument I build with this thesis, I want to foreground another important insight we learned from this study, not developed in the paper.

Following a more traditional CSCW approach, we found ourselves struggling with how to set up the study in the first place. Should we approach it as typical to the genre and organize the intervention as a 'before and after' study (this is at least as it is often written up, including our own paper 3). Which would force a protocol where we would begin by looking into how medical follow-ups took place with the patients present, then go re-design our prototype accordingly, and finally test out if the prototype actually changed the practice in the ways we were after.

By using a design approach (wanting to do design-driven research) we immediately faced questions of how analytical insights can be said to embody the characteristic principles and criteria for accountable, academic research, i.e. how to account for the reliability, validity, and, to a certain extent, generalizability of the studies?

We therefore entered a discussion on how we were able to talk about these concepts when doing research by design – for example in terms of validity, how do we ensure that there is corresponding consistency between what we set out to study and what the design prototypes actually explore?

When I frame our research as being driven by design I mean that we employ design as techniques for inquiry (this is unfolded in paper 2). Informed by the insights from our fieldwork we design prototypes to act as probes for further inquiry into issues of particularly interest. We use the prototype as a tool to engage in a dialectical relationship with the daily practices of patients as well as with software as a design material (Löwgren & Stolterman, 2007; Schön, 1983). This dialectical approach helps us refine our problem statements and hypotheses on how best to improve the treatment and care of ICD-patients as well as evolving our practical understanding of possible solutions.

At times we found ourselves paralyzed by not being able to figure out if a design move made by creative intuition or originating from an idea offered by a patient would disqualify the move as 'research'. Our problem persisted in the assumed narrow understanding of what would count as scientific research – i.e. positivist-informed, hypothesis-testing research. This held us back from engaging more honestly in our early interventions, because we were afraid of ruining the experiment if we suddenly reacted to a problem in the prototype or guided a health professional in using the prototype in the middle of the intervention. If the intervention was set up to test a certain scenario, then our engagement with the situation during the 'test' would pollute the setup and ruin the experiment.

During the interventions that created the foundation for paper 3 we literally held back on many occasions from intervening and correcting issues that would have improved the situation of use. For example, when the bioanalyst in the cases can't figure out how to use the dictation feature, we were not sure if we could just step in and help her out or if we should let the intervention run till its end before correcting things.

Problems like these, however banal they might seem now, really puzzled us for a long time. We therefore started looking for fields that addressed these issues and/or had developed methodologies of design-driven research. Before we reached out toward Design Research (Sanders, 2006; Sanders & Stappers, 2008), we visited the field of Design Science in hopes of learning from their experiences. Not only did I read up on the field, but driven by frustrations of not being able to combine the analytical and stringent moves of research and the creative moves of design I attended a course in Design Science run by two of the leading figures – Richard Baskerville (Baskerville & Wood-Harper, 1996) and Jan Pries-Heje (Baskerville & Pries-Heje, 1999).

Design Science has as its goal to bring design and research together in ways that allow for designed artefacts, primarily software-based information technology, to act as devices for inquiry into organizational change (Hevner et al., 2004). They build intensively on an action research approach (Baskerville & Wood-Harper, 1996; Checkland, 1998), where the research process (the intervention) is divided into a four-step process, going from *planning,* over *acting* to *observing* and finally *reflecting* (see paper 3, Andersen et al., 2011a).

Although this may seem appropriate, it forces moments of intervention and understanding to be strictly separated, leaving no opportunities for learning and adapting as part of the intervention. In other words, it freezes the crucial moments in and of the intervention, where the designed artefacts are formed and the collective configurations are tried out. In many ways this is due to design science drawing heavily on the behavioral sciences.

To illustrate my point, I provide a short empirical vignette from our research, where improvisation and my full engagement turn out to be crucial.

I was visiting on of the participating patients, Fred, who was part of an upcoming intervention, where we would try out how preparation from home would work. We had set up an upcoming intervention (I am aware that the intervention in some ways is already in motion at this time). We had managed to arrange that the health professional that would be seeing Fred, would read through his statements prepared from home prior to his meeting at the hospital. This was part of our study to explore the contours of patient 2.0 and as such Fred had the opportunity to become an active patient here.

However, sitting at home with Fred and his wife, we were talking about his expectations and experiences of being part of our study so far, and what he would like to ask the health professionals to prepare or have answers ready prior to his upcoming consultation. This was a completely new situation for him and all the patients in our study; the fact that they were suddenly able to guide and steer the consultation in a desired direction prior to their meeting at the hospital. Fred discussed with his wife their questions and concerns and which ones they found most important to ask. As it evolved, the wife convinced Fred to state some questions that he had felt too private to ask in the normal consultations. Fred then logs in to myRecord and begins to enter the questions. While he initiates the step-wise preparation we talk about other questions that he would like to ask. He puts on his glasses and begins to type in the second question, which requires him to explain a situation for the health professional who will be seeing him. But after some time, when he is nearly finished writing, he accidentally activates the back button in his Internet browser, which results in all his writings being lost. Fred gets really annoyed with me and the computer and tells me to just drop it all together. I reach over to take his laptop and I begin retyping what he had lost. Comforting him along the way – “we’ll be there in a minute. What was your last question?”

As I want to show with this case, I would not have been able to intervene in the ways that I did had I committed to a design science or strict action research process, because my role would then have been to explore how and in what ways the prototype supported the ‘a priori’ stated challenges. Without my engagement and my focus on what we were actually there for – to explore and let a version of patient 2.0 co-emerge together – we would not have succeeded in having any ‘prepared’ patients ‘ready’ for the intervention, but would ‘only’ have empirical data on how the usability of the prototype performed in the given situation at home with patients. It would merely have been a try-out of the prototypes readyness, which to us was less interesting. Frustrations as these to my disappointment with the types of findings that fields as design science produce. Had I not put myself into the situation, I would have brought back notes to our developer about needed usability changes to prevent users from accidentally deleting text entries due to browser-dependent issues.

Not being satisfied, we sought experiences from fields that treats this tension (between design and use) and works productively with it. One such field is design research. I unfold how design research informed our work with design(ing) interventions.

# Chapter 4

# On Design and Use

## Design Research and Artefactual Inquiry

This chapter follows up on the discussion of design-by-doing techniques within PD by introducing recent theoretical and methodical developments that argue to blur the boundaries between design and use. These works cut across the borders of PD, Design Research and Design Anthropology and they provide a vocabulary to discuss ‘design interventions’.

I turn to *design research* for two primary reasons. Firstly, to learn from the insights the field had produced in regards to using design (especially designed artefacts) as vehicles to drive research inquiry. Secondly, to tap into their epistemological discussions on the relations between processes of research and design.

As for the first interest, we turned to research on the deployment and redevelopment of Gaver and Dunne’s original thoughts on using cultural probes (Gaver et al., 1999) to explore different ways of engaging ethnographic inquiry. Others have later extended the concept of probes as both ethnographic devices and design materials (Mattelmäki, 2006). Loi (2007) builds on the work of Gaver and Dunne to suggest “creative, inspirational and provocative artifacts in research and development endeavours.” (Loi, 2007). Specifically, two of Loi’s probing tools are interesting to us as she extends the original probe. The cultural probe was primarily a tool and a technique to gather information and generate inspiration, but with ‘reflective probes’ (Loi, 2007) the probe is used to “create the conditions for reflective practice” (Schön, 1983) which take the form of “creative, ambiguous and inspiring artifacts” (Loi, 2007, p. 228). Secondly, ‘playful triggers’ gives examples on different employments of probes as ethnographic devices to "provide nuances and insights that a conventional process would fail to materialize" (Loi, 2007, p. 230).

In a review of different probes typically used as ethnographic devices at the 'fuzzy front ends of design processes', Mattelmäki describes three fundamental qualities that probes offer. Namely, they are *design-oriented* and have an *exploratory goal*; they are concerned with opening the *user's subjective world* through modes of *self-documentation* (Mattelmäki, 2005). The critical and art-inspired mode of inquiry embedded in most probes have clear parallels to the work in PD on e.g. applying 'provotypes' to question "concrete, everyday practice, by exposing current problems, calling forth what is usually taken for granted." (Mogensen, 1992, p. 31)

Within PD, recent developments in terms of using artifacts to materialize questions and/or make empirical data available for cooperative analyses are *design games*. Design games are playful ways to engage participants in the analysis of empirical material using elements and metaphors from board games, such as turn-taking, a physical game board, and game pieces (Brandt, 2006; Brandt & Messeter, 2004; Buur et al., 2000). Epistemologically, design games can be seen as a way to engage the work practices in ways that typical ethnographic accounts don't bring forth or are unable to materialize in the same ways. Furthermore, they are application of Wittgenstein's notion of 'language-games' which Ehn (1988) makes relevant to design in his philosophical explorations of design practice. Ehn emphasizes how any participatory design process is essentially a meeting of language-games, which denotes Wittgenstein's notion of practice and show how the world comes into being through the use of internalized 'language games'. With his famous statement, '*if a lion could talk, we could not understand him*,' Wittgenstein (1953, p. 190) illustrates how we are deeply rooted in our own practices and the problems of understanding someone who have a different backdrop. The concept uses the game metaphor to explain how language constitutes practice and how we follow and break (the) rules of a game when we enact our practices. Even if the lion could actually speak, he would make no sense to us because the social backdrop of the lion's existence is too different from ours. I mention this example, although historic and classic, to emphasize the importance of practice.

## Designing (in) Use

As described in paper 1, scholars have begun to explicate problems of staying in a representational mode of design, i.e. situations of design carried out away from the actual unfolding of the use practices. Even though we have managed to move the prototypes into being part of actual use practices, there is still a difference between the actual use practice and the practices of use wherein prototypes and design interventions are played out. Redström (2008) expresses this in terms of a difference between modes or acts of *defining use through design* and *defining use through use*. Design-by-doing techniques are an example of reaching the latter through tools belonging to the first mode where design happens mainly away from actual use situations. The first mode, 'defining use through design', includes design activities where use is defined at design time and where techniques are used to make a well-informed understanding about the conditions of the use practice. Not least, how users are configured and constructed as objects of and for design (Woolgar, 1991). Redström emphasizes that 'use before use' can never really be reached, but that we can design use through use, by what he suggest as *design after design* (Redström, 2008, p. 421) – thus arguing for more attention towards design at use time.

In CSCW and PD, Hartswood et al. (2008) explores such possibilities of mobilizing systems design within the context of use and develop an approach to design at use time, which they term 'co-realisation'. They synthesize the methods and techniques from PD and draw on Suchman's ethnomethodological argument of "working practice is lived experience, only partially representable" (2008, p. 395). The arguments put forth by Hartswood et al. (2008) resemble Star and Ruhleder's (Star & Ruhleder, 1996) emphasis on asking the question of '*when* is infrastructure' as opposed to the more typical, '*what* is infrastructure?'. Using 'when' underscores that an infrastructure, or design as in this case, can only meaningfully be talked about, when it is being performed and thus when it unfolds in use. That is, when 'design' is actually enacted and all the different entities and elements (inter)act and connect with each other.

As such, we are encouraged in various ways to consider and develop new strategies for designing in actual use practices.

A more contemporary strategy for practicing design interventions informed by posthuman ontology and performance theory is the design anthropological manifesto 'rehearsing the future' (Halse et al., 2010), which seeks to unite the practices of ethnographic fieldwork, design and use in moments where possible futures of the everyday are tried out in order to let opportunities emerge in the context in which they gain their meaning. Halse et al. outline a vision "where the new socio-material, exploratory, and participatory processes of articulating new promising futures is going." (Halse et al., 2010). I will illustrate how we are inspired by this approach to allow us to explore ways for STS-informed design interventions to instill theoretical concepts into the design process. That is, concepts that are informed by research, and not only directly informed by concepts originating from fieldwork, which are then explored with the design interventions.

## Re-Positioning Relations of Ethnography and Design

PD has famously explored relations between design and ethnography in efforts to render techniques of anthropologic fieldwork available and valuable to designers. (Blomberg et al., 1993; Blomberg et al., 1995; Simonsen & Kensing, 2005). Working on the borders of PD and Anthropology, Halse and Clark (2008) explores how to re-render productive relations between ethnography and design.

In PD and design research, the role of ethnography falls roughly into two modes. One mode renders ethnography a method to explore empirical phenomena borrowing the agenda from social science in general and where the aim is to understand the conditions of collaborative practices in more detail. The second mode operationalizes ethnography as a method to produce findings, which are then later rendered useful for design(ers) – although often critiqued to turn out as mere data gathering (Dourish, 2006).

As an emerging field design anthropology (Halse, 2008) could be said to re-make and re-negotiate the relation between fieldwork and design. Much in line with the thinking of Kimbell (2008) who invites ethnography to attend to practices in contemporary art and design. Thereby, shifting the role of fieldwork from being a primarily descriptive, sense-making activity with the aim of 'informing' the post-activities of designing to a far more experimental, exploratory and intervening activity, where design actions and ethnographic moves blur each other to build deeper insights into the situation at hand. The use of ethnography as the classic skill of anthropologists have long been adopted and adapted by design fields especially within workplace studies (Luff et al., 2000). However, the sensibility and empathy of the anthropological way are lost when ethnography is stripped from its analytical potential and applied solely as way to bring back reports from the fields. The original sensibility, ethics and intentional analytical in(ter)ventiveness (Marcus & Okely, 2009; Winthereik & Verran, 2012) are squeezed out, when ethnography is reduced to simple observational techniques.

Thinking through embedded questions, as inspired by design research, we are encouraged to adopt some of the anthropological uncertainty and sensibility by working with the materials to form representations that are not only geared to fulfill the desires of solving 'the problem', but to work with and towards forms of representations that are able to act as boundary objects and invite participants to engage in the ongoing interpretational tinkering and re-negotiation of meanings.

Special to the version of design anthropology developed by Halse, Clark and others (Halse & Clark, 2008) is the philosophical grounding within recent work in STS and ANT. They ground their approaches to design and ethnographic research on the performative ontology also laying the groundwork for ANT. As developed in paper 2, we similarly employ a performative understanding of design interventions as a way to extend more classic methods and techniques in PD. That is, as a way to overcome the problems that a representational mode of doing design research introduces and as a way to disregard the boundary between design and use, we work (hard) to mobilize a process of design in use (see also paper 1). To do this, we necessarily also employ a relational understanding of design research, which in turn introduces a potential for asking questions and performing answers in other ways than traditional PD and ethnography allow.

Below I end by introducing some of the key concepts in ANT and STS and with a brief case I point to some of the opportunities which this ontological shift provided our work.

# Part Three

## Drawing Things Together

*One works ad hoc and ad interim,*
*piecing together thousand year histories with three-week massacres.*
*The anthropologist, or at least one who wishes to complicate his contraptions,*
*not close in upon themselves, is a manic tinkerer adrift with his wits.*
(Geertz, 1995 in Becker, 1998, p. 9)

## Chapter 5

# Infusions of Posthuman Performativity

To develop my argument, I draw on a set of central notions from *science and technology studies*. Specifically, I am informed by the relational and ontological performativity underlying the endeavour of *actor-network theory* (ANT). With this chapter I introduce central notions of performativity drawn from ANT and feminist theory to explain how they open for an ontological synthesis of ethnography and design which allow us to instill and explore research-informed concepts by actualizing/performing them through the design of different collective configurations.

## Relational Ontology and Performative Ethnography

A performative and relational ontology entails that the world continually comes into being through its social and material performance (Callon, 1986; Halse & Clark, 2008; Pickering, 1995). A philosophical understanding fundamentally different from a positivist ontology and epistemology, which supposes we have privileged access to the world and its objects (and subjects) and therefore our knowing of and about them.

I have actively engaged in producing the empirical material through and in the project – the world with all its peculiarities was not waiting out there for me to uncover and bring home descriptions of how it really is, out there. Something that would presuppose my privileged and independent access to the outside world and allow me to percept it from a place of 'nowhere' – an ability provocatively called to by Haraway (1997) as requiring on to apply the 'god trick.' We are always, already, enmeshed in the world and will only be able to understand it from a situated and particular place – from 'somewhere.' I subscribe to a performative ontology, where methods do not 'just' describe reality, but are part of creating them (Law, 2004). Realities are made (Latour, 1999) and not independent of our apparatus that produce the reports of these realities. There is no gap, Latour says provocatively. Because there is no reality out-there to us unaffected by us. No reality ex nihilo. (Latour, 2004)

Drawing on developments in science and technology studies and feminist theory, actor-network theory suggest a general analytical understanding that the (social) world is seen as being performed in and through the outcomes and effects of fluid relations between human and nonhuman entities, thus also providing objects with agency. ANT is fundamentally a semiotic approach, which tells us how entities achieve their form as a consequence of the relations in which they are located – i.e. how the relations are performed (Law & Hassard, 1999). Through influential studies (Callon, 1986, 1989; Latour & Woolgar, 1986), ANT has developed a vocabulary to study and understand how realities are created through networks of connected actors. Agency is through this understanding *networked effects* (Law & Hassard, 1999).

To my argument, this socio-material attention invites a re-emphasis on nonhuman entities and technologies as central to the situation. For instance, technologies and practicalities (Andersen et al., in review). In particular it allows for an appreciation of concepts as constitutive components. Utilizing a performative ontology onto activities of design and use, Halse and Clark (Halse & Clark, 2008, p. 136) notes how "relational ontologies of use and design imply that the one does not come before the other; rather, they necessarily constitute each other." Making it impossible to think about design without imagining or applying ideas of use. As we note in paper 1, design interventions can then be understood as "consequence[s] of these activities and exist only as networked relations in action.

The design intervention, thereby, can only fully be understood as *performed* in, by, and through those relations (Law, 2004). This marks a shift in orientation which re-installs material agency and repositions tools and activities as co-agents in performative acts." (Andersen et al., in review)

Relevant to design, this posthuman and performative ontology entails that we, through our participatory design projects perform the situations and configurations that we want to study. In other words, we create what we study. I will make use of these insights in the following to suggest that we, then, could fruitfully take care in choosing to study relevant and theoretically informed matters of concern in order to, not only, create interesting futures, but make those inquiries interesting by embedding and exploring relevant and politically sensitive phenomena.

## Designing Matters of Concern

In his 2008 *Networks of Design* keynote, Latour (2008) explores the concept of design to suggest its embedded ethical and visual qualities. Latour suggests design to be especially equipped to take up the challenge of *drawing things together*. Design is also to re-design, as Latour states. To design never is to create ex nihilo. There are always, already socio-material assemblies to re-configure and designers are well equipped to take on this endeavour. Inherent in design lies an ethical dimension, because we are in designing skilled in choosing between 'good versus bad design' (Latour, 2008, p. 5). Therefore designing can be seen as to explore *matters of concern* opposed to being concerned with establishing *matters of fact* (Latour, 2004). In our case we are performing a sociomaterial assemblage of technology, patients, health professionals, hospitals, relatives, laptops, etc. that steadily materializes into a working Thing that enables us to explore the telemonitored and empowered patient.

Latour ends by formulating a challenge to designers to explore tools “that capture what has always been the hidden practices of modernist innovation: objects have always been projects; matters of fact have always been matters of concern.” Summing up, he ends by saying; “What I am pressing for is a means for drawing things together.” (Latour, 2008, p. 13)

Ehn (2011) addressed this challenge in his talk to the EASST community in 2010, by illustrating how the design research and PD communities take the challenge seriously and are trying in pragmatic and designerly ways to “put science and technology studies to work.” (Ehn, 2011, p. 52)

A posthuman and generative version of design interventions could serve as one approach to the challenge of how our designerly ways of approaching the object of design could be a way to shift from drawing things and objects, to *drawing things together*. And how we, with this ‘posthuman ontologically’-infused version of design interventions, are able to explore matters of concern in regard to designing support for the becoming of patient 2.0.

## Making Diagnostic Agents

To illustrate my point, I will give a brief example of how we utilize the design intervention as moments for exploring (re)configurations of patient 2.0 collectives. I would like to draw attention to how this approach enables us to explore an ethnographically-informed concept like ‘diagnostic agency’ (Oudshoorn, 2008) in new and fruitful ways by performing the concept as part of design interventions (i.e. design at use time).

In paper 3 (Andersen et al., 2011a), we write-up the results from a set of design interventions, where we explore the consequences of empowering patients to perform as *diagnostic agents*. A term introduced by ‘sociology of health’-researcher, Nelly Oudshoorn (2008), to describe the much invisible work that are done by patients, but which disappears from descriptions of the role of patients. Oudshoorn emphasizes how patients “are not just users of a new technology that requires instrumental skills, but should be considered as agents that have to perform all manners of articulation work to make these new healthcare services work.” (Oudshoorn, 2008, p. 276). Oudshoorn ends by foregrounding how the becoming of diagnostic agents depends on an intensive process of self-learning, where patients have to trust their own ability to make the right choices.

Informed by the notion of patient 2.0, we were inspired to explore how an enabling of patients as diagnostic agents would reconfigure the existing telemonitored setup and in which ways patients were able to take on the increased responsibility. Guided by the notion of diagnostic agents and our intend to make patients able to perform as such, we deliberately designed functionality into the prototype to not just allow for patients to tap into this new role at their own will, but we required them to prepare from home by completing a set of tasks (described in detail in paper 3). Among other things, the prototype requires patients to update and authorize their medicine profile, so that it reflects the medication they are actually taking at the moment. The prototype does not allow patients to avoid having to consider this.

As the prototype was part of the healthcare setup (after-design and in-use) this step came to reveal interesting aspects of medication management as well as intricate politics on the responsibilities of health professionals and patients. One patient (a retired general practitioner) participating in our project felt offended by having to sign-off on the medicine profile and questioned who would have the final legal responsibility if a patient mistyped medication or simply forgot to state an important change in medication. This showed to be a question with no easy answer and ended up involving the legal department of the hospital and the director of the Heart Centre.

The authorize-button, which enacted this new practice, then became an agent in showing us how medication management is a tinkered practice for patients and that patients communicate in entangled ways with their health professionals via the medication profile (illustrated with the second case in paper 2).

## Chapter 6

# Concluding Remarks: Prototyping Matters of Patient 2.0

Before I end I will summarize the argument that I develop with this dissertation by reiterating how I suggest we are able to draw things together in order to query into matters that are of particular concern.

Drawing from performative and relational ontology I argue for the practice of a hybrid version of design interventions, where PD-informed prototyping techniques explore different collective configurations, while at the same time querying into matters of concern through the performance of critical concepts inscribed into the collective assemblages.

Together with the write-up in these first parts of the dissertation, the papers illustrate how a synthesis of techniques from PD, Design Research and ANT can form a fruitful and hybrid version of design interventions that let us explore explicit and conceptually informed collective configurations by actually performing them in practice. By carefully setting up and orchestrating the performances of certain relations we are able to study the consequences of possible futures in ways that typical ethnographic accounts or design situations (e.g. workshops) do not allow for.

We do this by performing the relations that are needed to make the concept a reality. In other words, orchestrating and performing the collective needed to enable the enactment of a patient 2.0. Hence, in a performative view we create the situations that we wish to query into.

This hybrid version of PD can fruitfully be practiced as a research initiative with an honest aim to be socio-materially change driven. And this approach can work as a way to construct the field of interest while at the same time exploring how different possible future collectives might be – by doing them.

With this dissertation I have argued in favor of a view on PD research that is able to unite the practices of design and research by subscribing to a sociomaterial and performative ontology. It has been my point to show how to utilize design interventions as situations to perform concepts in order to explore analytical categories and at the same time explore configurations of future heterogeneous ensembles in an effort to move closer to a desirable collective of patient 2.0.

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# Part Four

## Publications

## Paper I

# Practicalities of Prototyping

Andersen, T., Moll, J., and Mønsted, T. (submitted). ***Practicalities of Prototyping***. Scandinavian Journal of Information Systems.

## Abstract

Prototyping is central to participatory design and has become one of the main ways of achieving project design ideals and user participation throughout the project. However, contributions tend to focus on developing techniques or report on the outcomes of prototyping projects – they rarely emphasize the mundane and background practical work, which plays a crucial role in making it possible. Informed by science and technology studies, we scrutinize two design research cases from healthcare to foreground the essential role played by *practicalities* in enabling us to practice prototyping and design interventions in healthcare. We show how broad categories of 'participation' and 'co-design' gets constituted by seemingly banal activities such as phone calls, collaborative excel sheets, calendars, the production of flyers, manual system integration, as well as setting up and negotiating appointments. With this paper, we argue that practicalities are crucial constituents in PD prototyping projects and thus should be explicit in frameworks for next practices in PD.

*Key words:* practicalities, prototyping, participatory design, design interventions, science and technology studies, healthcare

## Introduction

Participatory design (PD) has successfully advanced methods and techniques to bridge design and use. Kyng's (2010) timely remark, reminds us that most PD projects no longer talk much about workplace democracy, but focus on user participation and the results of design. Since the 1990s, the design ideals tend to deal with 'user involvement throughout the project' and 'prototyping' (Kyng, 2010). This is reflected in the Participatory Design Conference in 2010 where 11 out of the total 15 full papers use some version of 'prototyping'. Through the creation of prototypes and design concepts, users are actively involved to 'envision' or "simulate working in the future with the new system" (Bødker & Grønbæk, 1991; Kyng, 1995). As such, PD is incrinsingly employed to overcome the "design challenge of fully anticipating, or envisioning, use before actual use" (Ehn, 2008, p. 92).

However, instead of involving participants in design and 'use-before-use' (Redström, 2008) we are increasingly encouraged to open up for use as design or design at use time (Bødker & Petersen, 2000; Dittrich, Eriksén, & Hansson, 2002; Ehn, 2008; Henderson & Kyng, 1991; Karasti, 2001). This strategy positions design practice and the designed-for practice as collocated, rather than separated in time and space (Hartswood et al., 2008). It helps dissolve the boundary by extending the design process into the work practices of the participants.

In this paper, we subscribe to this strategy by employing recent developments of *design interventions* (Andersen, Halse, & Moll, 2011b; Binder et al., 2011; Hagen & Robertson, 2010; Halse, 2008; Halse, Brandt, Clark, & Binder, 2010). Rooted in Blomberg et al.'s (1995) 'work-oriented design' approach that combines field studies with case-based prototyping, we integrate prototyping to become part of the actual work situations in healthcare. By design interventions we encourage participants to improvise and enact possible futures and thereby explore socio-technical change in the making.

Being successful in uniting design and use and creating a shared practice requires a great deal of work. Making prototypes that are trialled as CSCW applications, and which is not inteded for individual use only, complicates the picture and introduces increased difficultites (see e.g. Bardram, 1996). The practical work of creating participation and continual use of working prototypes as well as all the underexposed work of setting up design interventions has been intensely present in our project. It seems that there is a whole category of hidden work, which is rarely foregrounded and explicitly discussed. By using the concept of *practicalities*, from Pedersen (2007), we want to bring forth what usually remains implicit to PD protocols and to illustrate the practical achievement it is to extend PD into the work practices of users.

Inspired by science and technology studies (STS) we employ a performative understanding of (the making of) design interventions. Instead of discussing idealized matters in abstract terms of e.g. participation and co-design, a performative understanding invites an emphasis on the *conditions* for the socio-material becoming of design interventions, i.e. the *practical activities and tools* that goes into making it possible.

With this paper we argue that an explicit dialogue on the crucial role of practicalities is paramount if we are to improve the ways in which we carry out design interventions and prototyping in PD. In many ways, 'practicalities' belong to the list of issues that demand more attention for the next practices in PD, which Kyng started in (Kyng, 2010).

By way of two empirical cases we present the necessary activities and artefacts created to maintain participation and make the design interventions possible.

## Design Interventions and Prototyping

Design interventions are intentionally staged situations used to try out working prototypes and enact improvised features as part of participants' work practices. This is not an entirely new phenomenon to PD. The early studies at Xerox PARC (Blomberg et al., 1995; Suchman, Blomberg, Orr, & Trigg, 1998) as well as the Scandinavian approach to systems design (Greenbaum & Kyng, 1991; Grønbæk, Kyng, & Mogensen, 1997; Kensing, 2003) all applied various interventionist approaches to systems design.

The continued appreciation for design interventions is often accompanied by a performative understanding of PD inspired by later developments in STS (Andersen et al., 2011b; Ehn, 2008; Halse & Clark, 2008; Hertzum & Simonsen, 2010). This implies that potentials for improving work practices are seen as something that emerges as an outcome of the process – not as something that is either predicated by users or designers (Danholt, 2005). The collective engagement as a process is, nonetheless, fundamental to PD (e.g. Blomberg et al., 1995; Greenbaum & Kensing, in press; Greenbaum & Kyng, 1991; Schuler & Namioka, 1993; Suchman et al., 1998). But, as we expand below, a performative understanding of design interventions and the integration of prototypes into users' work practice foregrounds otherwise hidden activities and tools applied.

As with design interventions, prototyping is an essential part of the PD toolbox. The concept of prototyping typically covers a wide range of definitions – from early paper-based mock-ups (Ehn & Kyng, 1991) to the iterative co-design and use of working systems (Bødker & Grønbæk, 1991). Traditionally though, prototypes have been applied primarily to either explore and clarify requirements or to evaluate a proposed solution (Floyd, 1984). In this view, prototypes are used to represent the use situation, communicate design decisions and facilitate participation. Prototypes are, however, increasingly used in design interventions as means to extend the design process into the use situation. In this way, prototypes become inseparable parts of the use situation and facilitate occasions of performative design interventions. They become devices of 'what-if' and allow new practices to be collaboratively explored and enacted.

As described in Andersen et al. (2011b) we integrate prototypes as part of the healthcare practices through design interventions to create "situations of enactment with opportunities to live out and explore change potential." By moving the design process into the use practice we find that practical challenges intensify. We believe it is crucial to consider these practicalities as part of reflections on the socio-material becoming of PD projects. If we do not articulate our efforts to move the design process into the use practices, we might slip into doing design detached from use or mere studies of use detached from design. We risk studying the prototypes detached from the work practice (design-before-use) or to study the practice 'as is' without the designed artefacts. Due to the essential but underexposed practicalities, we foreground the crucial role they play in making design interventions happen.

## On Practicalities

By bringing forth the 'hidden' work and the tailor-made tools created to extend PD activities into participants' work practice we illustrate the practical efforts of undertaking actual participation and co-design. The work of identifying, contacting and enrolling patients and health professionals as well as the work of staging design interventions demands continual attention and help from self-made collaborative tools. Practicalities are, as we will argue, not just *conditional* for the project, but *constitutive* to the PD practice.

To discuss this category of work, we turn to the field of science and technology studies (STS). STS has greatly furthered the understanding of technology production to show how it is a collective and socio-material achievement, inseparable from its practice of development. By dismissing otherwise categorical dichotomies, posthuman STS analyses have helped to show how the human and non-human, the valuable and the invaluable, the high profiled (project) and the invisible are constituted by local activities and apparently mundane tools and technologies (Jensen, Lauritsen, & Olesen, 2007). This micro-social questioning of well-known methods and techniques help to open up activities and foreground what would otherwise remain as black boxed phenomena, whose "meaning is settled so that one needs to focus only on its inputs and outputs and not on its internal complexity" (Latour, 1999, p. 304).

In their influential study of laboratory work, Latour and Woolgar (1986) re-introduce attention to the 'mere' physical stuff (in the laboratory) through analyses of how materiality constitutes all work processes; laboratory equipment, machines, desks, graphs, documents and scientific texts. In other words, activities that involve the orchestration of a wide range of literary and material arrangements as well as banal, everyday social interaction. They illustrate, that "it is not simply that phenomena *depend* on certain material instrumentation; rather, the phenomena are *thoroughly constituted by* the material setting of the laboratory." (1986, p. 64)

To our project, this socio-material attention invites us to open up well-established phenomena such as 'participation' and 'co-design' to be understood as being made up of many tools, various activities, and not least *practical work*. The design intervention, then, becomes inseparable from the activities and equipment that went into making it possible. Design interventions are, thus, a consequence of these activities and exist only as networked relations in action. Put differently, the design intervention can only be understood as *performed* in, by, and through those relations (Law, 2004). This marks a shift in orientation which re-installs material agency and repositions tools and activities as co-agents in performative acts, rather than passive backgrounded elements.

This approach makes it interesting to centre the attention on some of the black boxes in PD and look closely into the many times hidden work required to undertake a PD process that extends into work practices.

## Opening the Black Boxes of PD

Detailed accounts on PD projects that foreground practicalities in these ways are limited, but discussions that resemble the same goals are beginning to appear. Martin et al. (2009) investigate the everyday activities of achieving participation on a large scale implementation of an electronic patient record. They found that in order for the formal plan to work, a long range of "workarounds", "contingency plans", and attempts to keep the project "up-to-speed" were needed. The project leader's main activities developed into being the coordination of tasks and responsibilities, the day-to-day negotiations of conflicts and the difficulty in achieving desired participation on the project. This involved formal meetings, contracts, schedules, visits, but also informal conversations, emails, and telephone calls. Hartswood et al. (2008) propose the figure of the "IT facilitator" to engage in collaborative design as part of users' everyday practices by helping to solve aspects of using the system, seek clarifications, inform about new features, etc. The facilitator should be able to respond to "the practical exigencies of living with the system [and] capitalize on the mundane."

Bansler and Havn (2010) analyse a pilot implementation process in healthcare and identify three major difficulties that complicated the project and led to its failure. Two of the points accentuate what we would call practicalities; "Coping with unanticipated technical and practical problems" (insufficient number of PCs in the hospital, impractical locations, sidestepping and making printouts and many "trivial problems") and "ensuring commitment from users and their managers" (feeling of not being taken seriously, dissatisfaction, frustration and disappointment). Simonsen (2009) reports on his own experiences of being engaged in PD projects and emphasises two critical challenges for conducting action research. First of all, it is a time-consuming way of creating empirical data and risky as projects rarely evolve as planned. Secondly, it is "personally demanding and challenging". Action research requires that the researcher "[…] has a flair and competence for project management" . By definition, engagement and responsibility with personal stakes are a condition for being part of such projects: "I had to do something to keep the things running" .

While some of these accounts benefit from their ethnomethodological heritage in taking serious the minutiae and seemingly mundane practicalities of extending collaborative design activities into the use practice, Pedersen (2007) goes a step further in his discussion of PD research. By analysis of the practical becoming of a PD project in manufacturing, he argues not to take the "project as a given, as simply already there, but as a *condition* for doing research that needs to be established" (2007, p. 132). By scrutinizing the principled protocols of PD, he illustrates the important formative practicalities of doing design research and directs attention to the circumstances not typically accounted for in research projects – e.g. explicating the constitutive factors for setting up participatory design activities. Pedersen (2007) shows how insights are only made 'observable-reportable' by way of various materials, such as documents, meetings, summaries, images, booklets, deliverables, design artefacts, the project charter, schedules and more, as well as the immense work that goes into the enrolment of participants; arranging meetings, the many email correspondences and phone calls.

This shifts the attention towards the *invisible work* and the hidden *artefacts* (Star & Strauss, 1999) that go into the socio-material enactment of design interventions. In the words of Bowker and Star, it involves "foregrounding the truly backstage elements of work practice" and taking a closer look at the "boring things" of PD (Bowker & Star, 2000).

## [Project Name]

For nearly three years (2008-2011) we have been engaged in the design and use of two web-based prototypes in healthcare. The work presented here is part of the research and development project *[project name]*, where we engaged health professionals and heart patients with an implanted ICD (advanced pacemaker) in the Copenhagen region in Denmark. Here, care of patients with an ICD is distributed according to medical specialty. This means that the Heart Centre at the Copenhagen University Hospital is responsible for ICD-related care such as implantation and continual telemonitoring of ICD-devices, whereas the local hospitals are responsible for the medical care.

The network of health professionals who monitor and deliver healthcare is therefore inter-institutionally distributed with patients spending most of their time away from the hospitals. This disconnection of time and place challenges communication and makes organising participatory prototyping processes with design interventions even more cumbersome. From our fieldwork on telemonitoring practice, we learned that patients at home feel poorly informed about their ICD device status (e.g. battery life and registered heart arrhythmia), while bioanalysts who monitors their device transmissions lack information about the patients' interpretation of their own condition (out of breath, abnormal heart beat, etc.). When cardiologists prepare for consultations, they lack quick access to clinical information such as patients' health history and status. Hence, improving possibilities for sharing information between distributed patients and health professionals became a fundamental part of the co-design and use of two collaborative prototypes:

*myRecord*: A patient-centric web-application that enables patients to prepare for consultations and device follow-ups, whereby bioanalysts and cardiologists are supported in decision making.

*coSummary*: a cardiologist-centric web-application supporting distributed cardiologists to prepare for consultations by providing a clinical summary of relevant information from the patient's trajectory.

Next, we present two case stories of how we employed design interventions with myRecord and coSummary to explore the potential for change. The cases exemplify how the prototypes are being co-designed to support patients and health professionals prepare for improved interaction. However, instead of emphasising the empirical insights (for this see [author(s) ref]) we deliberately downplay them to foreground what it takes in practical terms to set up and organize design interventions, in an effort to signify the hidden, but important, role of practicalities in PD.

## Creating Conditions for Design Interventions

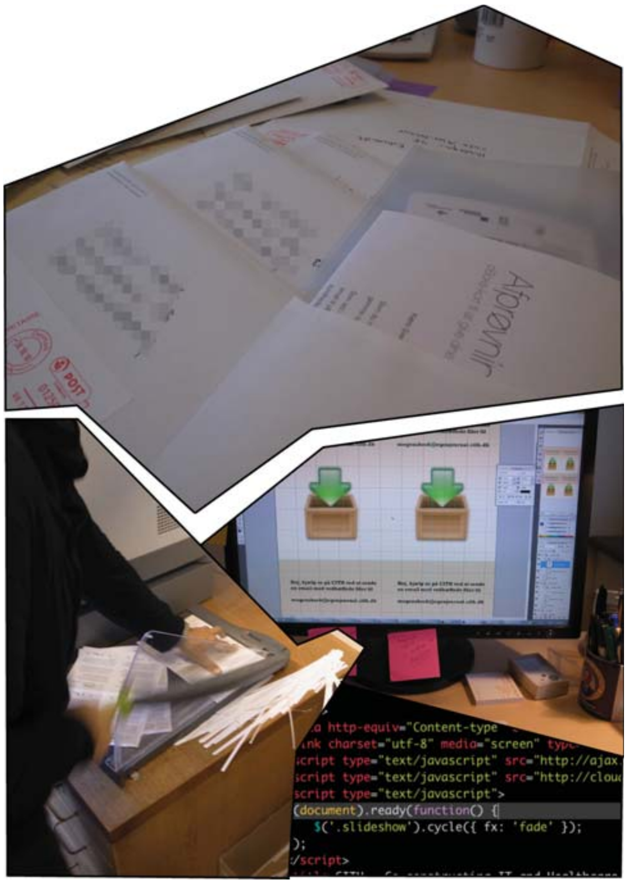
Prior to any design intervention, it is necessary to have identified, contacted and enrolled both patients and relevant health professionals. The success of establishing access and managing the conditions for participation (i.e. creating interest and commitment) becomes the sine qua non for undertaking a prototyping process with active users. This first set of practical tasks turned out to be more challenging than initially expected. Ideally we wanted a minimum of 25 patients to engage a realistic situation of use. But we quickly realized that project criteria, i.e. patients' ability to use a computer/internet, having healthcare meetings in the near future, and living in 'bike-range' from the university, were necessary for establishing possibility for a continuous process of design and use of myRecord. Project criteria like these then became practical concerns we had to incorporate into our process of identifying, selecting, and contacting patients.

Creating the first group of participating patients took several meetings and phone conversations with health professionals at the Heart Centre and the local hospital. Generating the initial list of patients to contact was demanding as it involved setting up appointments with cardiologists, consulting various systems, applying our filter (age, sex, reason for ICD etc.) and using the health professionals' familiarity with the patients (she is no longer too ill to participate, he is friendly, talkative, might be interested). At local hospitals they do not differentiate between patients with an ICD and heart patients in general, since they are focused on medical treatment. So we arranged with the cardiologists to keep an eye out for potential patients on every consultation.

Unfortunately, these ways proved unproductive, because we were dependent on the cardiologists to *remember to* ask patients. As a consequence, we began exploring other strategies of creating interest and ways to enrol patients for participation.

### Creating Interest Through Flyers and Website

One strategy was to create increased awareness about the project by enabling our call for participants to be distributed and spread across hospitals and institutions. This involved the development of a project website and A5 flyers promoting the project with the heading "Would you like to help us?" Consequently, creating the website and the flyers involved a lot of practical work that are usually left out of descriptions of PD practice. These practicalities, however, are fundamental to the becoming of a project, or in our case, actually having users of myRecord and thereby making design interventions possible. This involved to hire and collaborate with a graphical designer to create a decent layout that would provide an official and compelling look, coordinate and take photos of researchers on the project, write informing texts about the project, set up a SkypeIn phone number with an online voicemail, get digital logos of the participating institutions, program the website, find an appropriate webhost as well as layout, print, and cut 600+ flyers.



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a http-equiv="Content-type
ink charset="utf-8" media="screen" type
script type="text/javascript" src="http://ajax
script type="text/javascript" src="http://clou
script type="text/javascript">
(document).ready(function() {
    $('.slideshow').cycle({ fx: 'fade' });
);
/script>
```

Collage 1: [Clockwise] Mailing out flyers and invitation, creating graphic layout, programming website, cutting cardboard flyers

The website and flyers proved particularly fruitful when we combined them with a large paper-based questionnaire that was sent out to the entire pool of ICD patients (500+) in the Copenhagen region. We snail mailed a flyer (and the website URL) with each questionnaire, querying for participation on the [project name], everyday use of computer/internet, email etc. Soon after, a couple of patients showed interest on email and we started to get messages on the voicemail. The entire responses on the questionnaire were transcribed to generate a willing-to-participate-in-[project name].xls excel spreadsheet that became a crucial tool for further selecting and contacting patients.

### Managing Documents and Enrolling Patients

We applied another strategy to ensure participation of patients who have had their ICD implant recently, because we found their information needs and activities to be quite different from experienced ICD patients who had become experts. Bringing about flyers we went to information meetings for new ICD patients and explained about the project. We also made an agreement with a secretary at the Heart Centre to filter out the referrals from local hospitals. Still, identifying heart patients who were scheduled for ICD implantation meant engaging a lot more practicalities. Before continuing, we needed clearance from the cardiologists to act as non-health professionals. We discussed the ethics of approaching patients and how to explain the project, their role and that they at any time could opt out. Then, we had to agree with the secretary what filter to apply when sampling referred patients. After a while, the secretary started to develop her own calendar-annotation to manage possible project participants and filing referrals so she could easily list patients who we could eventually contact, when we called her every Friday at 10 a.m.

Collage 2: [Clockwise] Patient preparing for consultation from home, sampling referred heart patients with secretary, project group meeting identifying and updating documents, coordinating intervention with bioanalysts

The project criteria evolved to ensure that we would have enough time to contact patients before hospitalization (min. one month). This, in turn, involved the secretary to skim the referral to check whether the patient would not be too traumatized and in a position socially and physically to take part in the project. Due to the increased complexity in the filtering criteria, we developed a new document, referred-ICD-patients.doc to collaboratively manage new patients.

The willing-to-participate-in-[project name].xls and the referred-ICD-patients.doc generated new practical tasks of further identifying, contacting and enrolling. Participation now turned from being discussed on project meetings into full weekly workshops, where we worked on selecting who to contact next (combining empirical and project criteria), what to tell them and what to remember to ask. This gave rise to new collaborative documents including another spreadsheet, sampling.xls. Sampling.xls supported the communication and coordination of who are enrolled (name, contact information, work email etc.), when and where are the next healthcare meetings, and important annotations (e.g. 'is out travelling the first weeks of January', 'only using computer at work', 'talked to the wife who seems kind', 'didn't pick up the phone'). We also created a remember-to-tell-the-patient.doc document to support what to say and ask for when emailing and calling patients.

Enrolling patients became a separate class of activities, which later started to have its own calendar time allocated (in an online project calendar) to let researchers on the project actually make calls e.g. after work hours, have time to reply on emails, listen to the SkypeIn calls as well as print, stamp, mail and manage letters of consent.

In retrospect, we would not have succeeded in conducting design interventions of myRecord and coSummary without closely pertaining to the practical work of planning, setting up and creating the conditions for participation. The many meetings, activities, the different collaborative documents, the Internet, the flyers and the project website all came to be essential in this endeavour. Having enrolled users on the project was, however, just the first step of staging the design interventions. As we illustrate in the coming two cases, it takes even more practical work to facilitate co-design as part of design and use.

## Case I: Enacting Dictation Work

From the beginning of the project, patients and health professionals expressed a strong wish to improve communication among each other. Specifically, patients asked for more elaborated and personalized feedback on telemonitored device follow-ups, but due to tight schedules and limitations in IT systems, the bioanalysts at the Heart Centre worked by the principle that "*no news is good news*" and by mailing standard letters stating "*the system has been found well-functioning.*"

On these grounds, we began to co-design a new practice that would allow each patient to prepare for device follow-ups by writing specific questions and symptom experiences, while enabling Erin, the bioanalyst, to make personalized replies (for more details see Andersen, Bjørn, Kensing, & Moll, 2011a). Erin was a bit sceptic though, as she was worried that it would be too time consuming to address each question for every single patient.

To accommodate these wishes – i.e. to allow patients to communicate questions and comments, and enable the bioanalysts to easily deliver personalized and individual replies – we experimented with a dictation-feature in myRecord that would sidestep the current time consuming work of typing, printing, and mailing replies. As we did not have access to the hospital's existing dictation system, nor resources to develop one from scratch, we decided to circumvent this challenge practically by using a dictating machine to integrate the functionality of making audio-replies to patients.

### Staging the Dictation Feature

As simple as it might seem, it involved substantial amounts of practical work to set up design interventions that would allow for co-design and experimentation of the dictation feature as a seamless and fully integrated part of myRecord. First we needed to develop the feature in myRecord (sketch, find an open source audio player, write code, and test) so that patients could annotate a limited set of questions/comments and receive audio and transcribed replies on device follow-ups. Next, we settled on a date for the design intervention with the bioanalysts and began to enrol patients. Since the design intervention was part of the bioanalysts' everyday practices of attending to all incoming transmissions we had to coordinate patients to make a device-transmission from home on the evening prior to the intervention. We wrote emails to all users of myRecord promoting the new feature, recorded and implemented 'help-videos' in myRecord describing step-by-step usage of the new feature.

We succeeded to get acceptance and commitment of using myRecord from 19 patients. To ensure that they all remembered to enter the necessary data, we phoned six patients who had not yet used myRecord on the evening prior to the transmission. Besides ensuring participation, we also learned some of the reasons that prevented patients in carrying out transmissions and using myRecord (e.g. not clicking send, "where is my password" and "I have no landline telephone and have to go to the neighbours to make the transmission").

Another practical caveat became present when faced with the security precautions typically found in healthcare organisations. Although we had developed (sketched, written code, and tested) a separate myRecord module for health professionals (with secure user management), we never succeeded to get acceptance from the IT departments to let myRecord pass firewalls and other security setups at the hospitals. In response, we started to create and bring a *myRecord pack* including paper printouts of all patients' preparations and a laptop running myRecord (with its own mobile data connection, since only patients' laptops were allowed on the hospitals wireless connection).

### Intervening with the Dictation Feature

To illustrate the significance of the background work and mundane tools in constituting the design intervention, the following case shows how it enabled Erin to explore types of communication that could improve patient care. At the Heart Centre, on the day of the device-follow-ups, half way through the list of transmissions, Erin becomes alert when she correlates a patient's medication list in myRecord with an annotation of "shortness of breath". She explains: "since the patient receives medical care at another hospital, I would assume that he's already enrolled in a program at that hospital and therefore I wouldn't do any further." (audio transcription, Heart Centre, November 10, 2010)

But after talking back and forth with the design researcher discussing design opportunities for future support in situations like these, Erin decides to use her ability to dictate a message, not for the patient, but for the cardiologist at the local hospital:

"Hi, it's Erin from the Heart Centre. This is for [the local hospital] who takes care of [patient name]. Cordan was prescribed for him in August, but now he reports 'shortness of breath' and that he feels a bit dizzy [based on the patient's comments in myRecord]. But anyway, he is on Cordan and it looks like he's having increased shortness of breath. There haven't been any 'events' or anything, so Cordan has helped. Somehow though, he ought to be examined sooner than otherwise planned." (audio transcription, Heart Centre, November 10, 2010)

In this snippet, Erin makes use of the possibility to dictate messages and suggests a cardiologist at another hospital to have a patient examined "*sooner than otherwise planned.*" Enabled by the ability to 'seamless' dictate messages to patients, Erin designs and introduces a new practice by enacting communication to actors, that we did not have in mind prior to the intervention.

Collage 3: [Clockwise] Cardiologist reviewing a case during the intervention, transcribing voice recording, making help-videos, ad-hoc recording setup

After the design intervention at the Heart Centre, the practical work of actualizing Erin's work with myRecord as an integrated part of patients' use, continued. Each audio reply had to be edited and cut (health professionals are often used to a system where they can pause and reflect while they dictate – or simply say ‘delete’ into the voice recorder). Next, we transcribed each reply for patients to read as text, converted, and uploaded the audio-file and the transcribed text to the corresponding patients in myRecord. The message to the cardiologist was moreover successfully delivered after several emails to secretaries and nurses, phone calls explaining about the project for at last to get the acknowledgement that a cardiologist had received the message. A significant merit of engaging health professionals and patients as closely as we practice in interventions like these, are that they come to perform as co-designers. They are part of exploring the possible future work practice by *doing* the new practice. Their actions, feedback and critique are important parts of co-creating myRecord. As we seek to illustrate with this case, the practical work was crucial in constituting the success of this design intervention.

## Case II: Enacting coSummary

In a second case we set out to explore the possibilities for assisting cardiologists in preparing for patient consultations. Patient information is currently stored in multiple information systems at different hospitals, which makes preparation a time consuming task. While the backbone of the information infrastructure is the patient record (a very large paper folder) and in particular the progress notes (short, dictated summaries of patient encounters), cardiologists also need to consider information stored in other dedicated folders or databases. In addition, cardiologists often have limited access to relevant patient information from other hospitals.

In a series of co-design workshops, cardiologists from the Heart Centre and a local hospital suggested that they only needed to share a small subset of information, and that some information produced at one hospital is often neither particularly relevant nor fully comprehensible for health professionals at other hospitals (due to a high degree of professional specialization (for more details, see Mønsted, Reddy, & Bansler, 2011). In response, we collaboratively sketched the layout of coSummary, a cardiologist-centered web application that enable distributed cardiologists to share selected clinical data. coSummary is designed to explore the assumption that a summary could in fact be composed by a collection of highly concise key indicators of a patient's clinical condition and if this would enable cardiologists at consultations to quickly gain a sufficient overview of the patient's current condition. The cardiologist however had one significant concern: coSummary could potentially add work intensive tasks to their duties. Would coSummary be so advantageous that cardiologists would continually use it?

By making coSummary part of the actual consultations, we were able to experiment with these assumptions by silently posing the question '*what do we really need to share?*' and to explore the enactment of future potential. This meant to develop a working prototype of coSummary and to stage a series of design interventions covering the full cycle from producing a summary with clinical data to using/updating the summary at consultations. We wanted to challenge the cardiologists' assumption that highly structured data could form a meaningful link between their local practices. We therefore let coSummary pose strong restrictions by validating the data that was typed in. The result was a highly structured web form consisting of 46 input fields, where the main part only allowed the cardiologists to select from five options or type in a specific year as four numbers.

### Staging Distributed Cooperation with coSummary

Prior to the design interventions we had to identify patients with an upcoming consultation and then arrange details with the respective cardiologist and secretary. We were able to do this through myRecord, because we implemented a feature for patients to enter their healthcare appointments. While enrolment of patients was well supported by myRecord, making appointments with cardiologists proved to be cumbersome and required insisting practical work.

In this case we called the cardiologist six months prior to an intervention to carefully explain the relevance of the intervention and the possible benefits for ICD care, but as he was unaware of the project beforehand he was not particularly interested in participating. To legitimize our endeavour we had him contact – through numerous phone conversations and emails – a highly esteemed cardiologist already on our project. This only convinced him partly. The pivotal step turned out to be that the myRecord-patient was so keen on the experiment that she requested him to take part. The cardiologist gave his consent to let the design intervention occupy an extra 15 minutes.

To prepare for the consultation a summary had to be produced. These design interventions were planned to take place at cardiologists' offices. To enable them to create the summaries we had to insure that the relevant medical records were on the table, so to speak, and that access to relevant IT systems and coSummary was possible. This involved contacting secretaries to help procure the necessary documents – typically taking five days because of manual and non-automated procedures (see e.g. Nathaniel & Wall, 2008). Similar to the dictation case, intervening with coSummary was met with some friction from hospitals' IT platforms and security policies. The hospitals' older desktop computers with outdated web-browsers prevented coSummary to run, and since we did not have sufficient resources to ensure full browser compatibility, we worked around these barriers by running coSummary on our own laptops via a mobile broadband connection. This solution worked quite well and became a conventional workaround.

Collage 4: [Clockwise] coSummary (printout) in use during patient consultation, early co-design workshop, cardiologist sketching the re-designed coSummary, coSummary in use at cardiologist's office

At the consultation interventions we faced practical challenges of being constraint on time: only 15 minutes were allocated before consultations, which we used to give instructions for use of both coSummary and myRecord. For this, we developed a checklist.doc to make sure we got around the most important features of coSummary – background information on the prototype, basic instructions to the functionalities, etc.

### Intervening with coSummary

To illustrate how practicalities constitute the design and use of coSummary, we turn to a situation where a cardiologist struggles to find the specific year of a patient's ICD implantation. Sitting in his office and working on producing a summary, the cardiologist at one point needs to enter the exact year in four numbers into coSummary. He searches for the year by quickly skimming through the progress notes in the patient record and by looking up information in the hospital's cardiatric database. This gives him a broad idea about when the implantation took place, although he does not manage to locate the exact year as required by coSummary. The data he is looking for is, so to speak, drowned in the wealth of information contained in the record.

As 13 out of 46 input fields in coSummary requires a year as input, it becomes clear to the cardiologist that entering data with this level of specificity will simply be too time consuming. The actual work (use) of producing a coSummary makes him reflect on his routines. He confirms that he usually looks for this kind of information during consultations, but it is not necessary for him to know *exactly* when the patient had a device implanted, only *circa* when – as this is enough to determine how established the treatment is, which in turn implies how experienced the patient is, and so forth.

When we later raised the issue at a design workshop with cardiologists from both the Heart Centre and a local hospital they all agreed to allow more inexact data. We then collaboratively (re)designed the feature in coSummary to allow each cardiologist to mark a specific field as 'unsure' and add free text comments – e.g. an approximation of the implantation. This way, cardiologists would have to spend less time finding specific information while still being able to produce a sufficient summary for consultations.

By means of design interventions we were able to address the question of *what do we really need to share* through the actual use of coSummary. But, as we argue, what really allows the coSummary to pose the question is the collective manoeuvring of all the background activities and tools that end up constituting the design intervention. Without attending to all the practicalities there would not have been a coSummary at all.

## Conclusions

With this paper we reflect on our experiences from uniting design and use in a participatory design project in healthcare. By foregrounding the mundane activities of staging design interventions, we show how practicalities are an essential category of work. Even though PD clearly recognize that projects are socio-materially performative, meaning that change is achieved and constituted through the collective efforts of both human actors, artefacts and design materials, we argue that the significance of practicalities in the making of design interventions are still too often undervalued and unintentionally left out of PD accounts.

Informed by the work of Pedersen (2007), we draw on insights from science studies to open up the black boxes of concepts like *co-design* and *participation*. 'Co-design'- ready health professionals and patients are not just out-there a priori to the project (quote from a private conversation with Jens Pedersen). Instead, they need to be performed in, by, and through 'invisible' work and a myriad of helpful tools and techniques. We therefore suggest that we recognize *practicalities* as a crucial category of activities and engage a more explicit discourse on the socio-material efforts that not only conditions, but constitute design interventions.

We exemplify this by foregrounding the underexposed background work and the tailor-made tools that enable the design and use of two prototypes in healthcare. In the first case we showed how we succeeded to actualize (not just simulate) a new way to practice telemonitored follow-up of patients. During the design intervention at the Heart Centre, Erin, the bioanalysts, enacted and improvised a different way to communicate with patients. Whereby, she successfully co-designed a new feature of myRecord. In the second case, the cardiologist's use of coSummary actualized an important re-design, allowing another to benefit from coSummary. Through the use of the working prototype, the cardiologists enacted the new practice of distributed cooperation by sharing important information on a patient with coSummary.

Our point here is not to illustrate the favourable outcome of our design interventions, but that they would not have happened without the mobilization of a broad range of practical work and customized tools. Co-design in our examples emerged as the performative effects of a collective of tools and activities used to stage the design interventions.

In the coSummary case, medical records, hospital IT systems, coordinating health professionals and the rescheduling of consultations were all constitutive in making co-design a reality. Without the workarounds to get the prototypes running and without actively involving the esteemed cardiologist to convince her colleague to participate, the design interventions would not have actualized. It is the same story with Erin, the bioanalysts at the Heart Centre. Here, the voice recorder, the open source audio player as well our encouragement to try out the new feature is what collectively makes co-design a reality. Likewise, there would not have been any newly implanted ICD patients to enrol on the project had we not convinced the secretary to routinely call her every Friday at 10 a.m. to have her weekly list of potential candidates – in other words no sampling.doc to make enrolment a possibility.

*Participation* on our project is, therefore, strongly related to all these activities and overhead work typically not accounted for in PD – but probably discussed a whole lot on most projects. Participating patients and cardiologists had to be interested in becoming users, but "interest was more a verb than a noun. Interest were not a given but rather evoked, sustained and sometimes lost" (Pedersen, 2007, p. 115). 'The prototypes' only *come into being* through the relations to health professionals, committed patients and their use. They only 'work' because we, collaboratively, succeeded to actualize participation.

By the cases in this paper, we argue that the strong relationship between the mundane activities, the practicalities, and the making and constitution of the design intervention should not be disregarded. Without close attention to the background work there would not have been any interventions. Without persistent efforts to enrol and coordinate health professionals in producing and using the prototyped summaries, there would not be a coSummary in any meaningful way – only a detached prototype of a projected future. With the cases we show how the practicalities play an important role in constituting the design interventions and our argument is that practicalities cannot meaningfully be discriminated from the activities typically described in methodical accounts on design interventions. Practicalities are not a detached class of work, but an inseparable part of the socio-material collective that constitute design interventions and should thus be included in debates on frameworks that deal with the next practices in PD.

## Acknowledgments

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# Paper II

# Design Interventions as Multiple Becomings of Healthcare

Andersen, T., Halse, J., Moll, J. (2011): ***Design Interventions as Multiple Becomings of Healthcare***, Nordes ’11: the 4th Nordic Design Research Conference – Making Design Matter. Helsinki, Finland, May 29 -31, 2011. (11-20).

## Abstract

Research on design of IT traditionally treats the production of scholarly knowledge and the design of new systems as related, but separate processes.

We propose the fruitfulness of practicing a closer relation informed by interventionist design research (appreciating a problem through attempts at solving it) and actor network theory (reality is enacted and constructed through our engagement). Through three concrete design interventions with cardiatric healthcare, we illustrate how diverse agendas of sociological inquiry and practical design considerations are intertwined and come to enact healthcare in specific ways. We suggest this as a *strategy of multiple becomings*, wherein assemblages of patients, health professionals, diseases, information technology, prototypes, and design researchers together perform shifts between promoting new practical design solutions and raising novel questions on the socio-material complexities of healthcare.

## Introduction

When the cardiologist-patient consultation was coming to an end, the design researcher intervenes to propose a new design-research concept in *myRecord* – a web-based prototype of a patient-centric health record.

Design researcher: *"There is one more thing. We've created what we call 'assignments', which are a little experimental, but in your discussion with Karl [heart patient] you indirectly ask him to do some tasks – that he must keep an eye on this and that – so, what should he write down [in myRecord]?"*

Cardiologist: *"Oh – Yes, okay [...] Karl, we've talked about that you need to find out how your breath is. This means that you every day have to go out on the street and walk until you need a break. Then it'll say [in myRecord]; Monday 50 m., Tuesday 50 m., Wednesday 45 m., Thursday 70 m. – anything [...]"*

Karl strives to follow the cardiologist's suggestions and almost daily for three weeks he records his weight and blood pressure in myRecord (picture 3). However, as the logbook in myRecord reveals, he is too weak to measure his walking distance. As we elaborate further in the case of 'Patient Homework', this snippet is meant to illustrate how design interventions enable us to enact entanglements of sociologically-inspired inquiries in healthcare practice and explicit and change-driven promotion of new design-research solutions for improved healthcare. Through design interventions new relations are performed in assemblages of healthcare professionals, diseases, information technology, prototypes, design researchers, and theoretical conceptualizations and themes from IT research in healthcare. We suggest that conventional approaches to knowledge production within the primary fields that do IT (design) research in healthcare, such as Computer-Supported Work (CSCW), Information Systems (IS), and Participatory Design (PD) can be fruitfully complemented by more interventionist approaches as practiced within contemporary design research (Medical Informatics is focused on evaluation of IT and less on the design process, thus not included in this positioning). By three cases of design interventions we engage multiple interests within interventional assemblages and show how new relations are performed between concrete design proposals and more theoretically conceptualized inquiries. We report from a PD project entitled Co-constructing IT and Healthcare (CITH), engaging heart patients and relatives, health professionals and us (design researchers) for nearly three years (2008-11) to explore and experiment with re-organizing current work practices through the design and use of seven hi-fi versions of myRecord ('Egenjournalen' in Danish). myRecord is essentially a prototype of a personal health record (Kaelber et al., 2008) – a patient-centric, collaborative, web-application that enables heart patients to produce, collect and share health related information with health professionals and other patients in their network (for details on CITH and myRecord see Andersen et al., In press).

## IT (Design) Research

Practicing interventions are not new to PD, CSCW, IS, or human-computer interaction (HCI). However, we find that design interventions as performative arenas for explicit instantiations of theoretical conceptualizations and themes are not thoroughly discussed. By employing design interventions we argue that a closer relation between, not only research and design but multiple logics come into being. Early studies at Xerox PARC (Blomberg et al., 1995; Suchman et al., 1998) as well as work coming out of the Scandinavian approach to systems design (Bødker and Grønbæk, 1992; Mogensen, 1992; Kensing, 2003) took on experimental and interventionist approaches to design and research. Influences from action research (Checkland and Holwell, 1998) and intervention theory (Argyris, 1970) pushed for intervention, which is much appreciated in PD today. In PD, methods and techniques from design practice are employed to support a combined research and development process. However, PD is mostly concerned with research on methods and techniques for the practice of participatory and democratic design and contributions rarely emphasize methodological discussions. The episteme of classic PD work could be argued as subscribing to Schön's (1983) reflective practicum, wherein problems are made intelligible only through attempts at solving them.

In CSCW, ethnography and qualitative methods are highly developed and the debate on workplace studies' role in IT design has been heavily debated (cf. Crabtree et al., 2009; Dourish, 2006; Plowman et al., 1995). It is widely argued that detailed analyses of work and technology-in-use create 'insights', 'implications', and 'recommendations' to *inform* system design (Plowman et al., 1995). A view that is also reflected in Crabtree et al.'s critical argument favouring ethnomethodologically-informed ethnography in systems design: *"Our purpose is to inform systems designers – i.e., those parties who are actively involved in the development of computing systems and applications […]"* (2009, p.879). The practice of doing research (ethnographical work) and designing IT are traditionally kept as separated processes in studies that actually argue for the promising results of integrating research and design of IT (Luff et al., 2000; Crabtree et al., 2009). While the proponents of joining ethnographic practice and design are increasing (Wolf et al., 2006; Halse, 2008; Karasti, 2001; Simonsen and Kensing, 2005; Zimmerman et al., 2007), the debate on the role of ethnography in design of IT continues (Button and Harper, 1996; Crabtree et al., 2009).

Within IS, action research and design science seek to accomplish change relevant to practice by proposing a closer relation between the study of organizational work practices and the design and implementation of relevant IT artefacts (Hevner et al., 2004; Baskerville and Wood-Harper, 1996; Checkland and Holwell, 1998). However, the heritage from behavioural science combined with a wish for hypotheses-driven rigour renders the process of designing secondary, in that the artefact comes to play the role of a utility that (only) *"allows [for] many types of quantitative evaluations […], including optimization proofs, analytical simulation, and quantitative comparisons with alternative designs"* (Hevner et al., 2004, p.77). Karasti (2001, p.211ff) critiques these disciplinary dichotomies i.e. descriptive vs. prescriptive, present vs. future, understanding vs. intervention and argues for a more *"appreciative intervention [which] calls for envisioning images of future system and context through a recognition of presence and change intertwined in the existing ways of working."*

In design research and increasingly in HCI, design practice is argued as a fruitful vehicle to drive research inquiries (Wolf et al., 2006; Zimmerman et al., 2007). Proponents of critical design (Gaver et al., 2004) use designed artefacts to 'instantiate' philosophical ideas whereas the design process becomes a necessary mode of inquiry. In this paper, we subscribe to a design research program and propose design interventions as situations of enactment with opportunities to live out and explore change potential as well as *"open new ways of conceiving the world"* (Halse, 2008, p.2). We claim that in one and the same poignant moment, understanding and designerly creation co-exist as inseparable modes of socio-material knowledge production.

## Strategy of Multiple Becomings

Koskinen, Binder and Redström (2008) review how researchers integrate design experiments in their research inquiries. Through three categories, *lab*, *field* and *gallery*, they describe how *"design researchers have developed several approaches that integrate design-specific work methods into research."* They make a division along the lines of traditional scientific methodologies and the arts, and argue that design research has been practicing extensions and sophisticated variations to more established institutional approaches to research. In later contributions the three categories converge and this could be seen as a movement towards design research achieving a degree of maturity, with less need to honour standards in other disciplines. Mattelmäki and Matthews (2009) expand this point and focus on the practical concerns of how those differences play out in a diverse set of ways. They recognize that Frayling's notion of *research-through-design* unites many and stress that it should not be seen as a method, but rather as a family of heterogeneous approaches to design research (2009, p.9). Their affinity lies in considering the design project, process or artifact as fundamental to the research contribution.

With this paper we propose design research as a making of explorative assemblages of not only 'design' and 'research', but multiple entanglements of patients' and health professionals' practices, diseases, information technology, prototypes, and design researchers. In particular, as we sketch out below, we are inspired by later developments in actor-network theory that treats 'being' as inherently performative and holds multiple interdependent realities (Law and Hassard, 1999; Pickering, 1995; Barad, 2003).

### Design Interventions and myRecord

On the CITH project we have engaged an interventionist approach as a way to extend classic PD with a more critical mode of design research-led inquiry. In the outset of the project we sat in on medical consultations, overlooked heart surgery, followed patient referrals in between hospitals, and observed work practices in several cardiac wards. We interviewed secretaries, nurses, doctors and bioanalysts on three related hospitals and visited patients and their families in their homes. A couple of months into the project, we began to put more emphasis on introducing proposals and discussions of premade and in-the-moment ideas of (IT) solutions as well as carrying out participatory design workshops. Alongside these activities we studied the literature on IT research in healthcare, e.g. (Mol, 2008; Berg, 1997; Pratt et al., 2004; Aarhus et al., 2009), and discussed how we could integrate a mode of inquiry that would add to the academic discourses found in the literature, but also how we could enact them concretely in the process.

This endeavor was particularly enhanced when we, a year into the project, introduced action cycles and turned the project into a cooperative prototyping process of a patient-centric web-application. It kick-started a long range of design interventions with myRecord wherein we engaged different health professionals and heart patients in various situations and locations. What moreover followed was many internal meetings and workshops where we inscribed theoretical conceptualizations and themes in myRecord through discussions and co-sketching interactions and wireframes. Typically, as continuations to ongoing dialogues with patients and health professionals we carried out co-design and use sessions at patients' homes. We then followed patients to consultations as observers of use but also as design research advocates enacting explorative and critical inquiries. The interventions, then, became a space for the simultaneous enactment of multiple logics, interests, and ideas. Our strategy of applying design interventions became instantiations of what Law (2004) calls *method assemblages*. By staging situations of (creative) use in realistic healthcare situations we were able to intervene and cooperatively interweave the current with enactments of new instances of healthcare. Moments, where not only relations between practices of 'design' and 'research' were performed, but multiple becomings of healthcare (Mol, 2002). A lot of work went into preparing for the interventions to allow for the otherwise absent (in the situations) to possibly become present. Priority was put on loading each intervention with the possibilities to enact patients' and health professionals' wishes as well as to enact and explore questions such as 'how to make patient participation a resource in diagnostic work?' and 'how to support patients' invisible work of bridging interinstitutional care?' (cf. Unruh and Pratt, 2007).

In the following, we present three cases of design interventions with myRecord in cardiatric healthcare, to show how an interventionist approach can be employed as means to enact and inquire into different healthcare practices together with empowered patients.

## Case I: Managing by Concealing

From our fieldwork on medical consultations we learned how precious time is spent at each meeting on 'getting to the point'. During the consultation, the physician and the patient work together to reach a shared understanding of which issue(s) should be made central to the consultation, and thereby the diagnostic work. The physician is constantly searching for indications of symptoms or other information vital to perform the diagnostic work. Patients often arrive with a set of (not yet fully conceived) questions regarding their health situation and recent experiences. However, once the consultation begins, we found that most patients were overwhelmed by the urgency of the situation and often held back or simply forgot to present their own questions. The different reasons for this ranges from patients forgetting or thinking, *"it's probably not that important anyway"* to feeling self-conscious about the very private character of their concerns (e.g. questions regarding either marital problems or issues of intimacy caused by their disease).

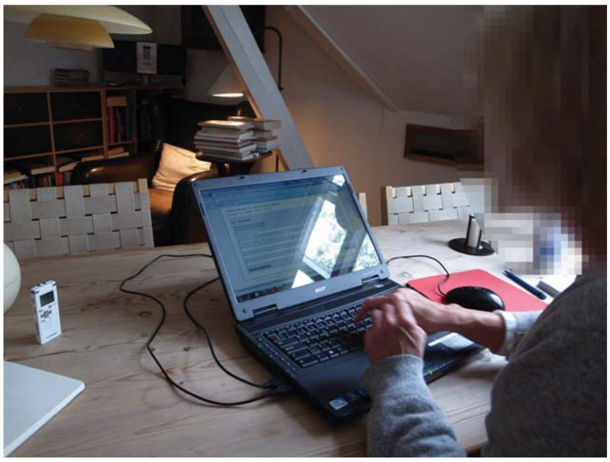
As our understanding of healthcare work practices matured through our initial fieldwork, we were inspired by Berg's (1997) analyses of medical work. In particular, how he characterises the work of physicians. Berg draws on the work of Fujimura (1987), who demonstrates how scientists make research problems doable through the iterative and seemingly mundane processes of continually aligning and reorganizing their work. Berg presents the work done by physicians during consultations as ways of making patients' problems manageable. Work that is *"characterized by the smooth interweaving of 'social' and 'medical' issues"*, in which patient-problems are transformed into 'doable' problems (1997, p.137). Berg shows the distributed character of medical work and stresses how *"the transformation of a patient's problem into a 'doable' problem is not a cognitive reconceptualization of the patient's case, but a collective achievement of an interlocked assembly of heterogeneous entities"* (ibid.).

To understand the consequences of this making and becoming of manageable patients we chose to explore the ways in which we could design support for patients to become more manageable for the physicians. From the physician's perspective, this would mean having important information about the patient ready-to-hand (Ehn (1988) and Dourish (2004, p.109) invite Heidegger's notion to inform systems design) before the consultation, including the specific questions and symptoms the patient would like to discuss. We were curious to see how, if at all, the new way of patients preparing for consultations would be useful or just be considered 'more work'.

### Design Intervention

The following case illustrates how the interventional setup and the use of myRecord worked as a way to query into aspects of patient manageability, and in particular how the intervention unexpectedly taught us the ways in which a patient take active part in collaboratively making the situation more ‘doable’.

Mary (aged 54) and the design researcher, Jonas (aged 30), are sitting in her living room in front of her laptop, preparing for her upcoming consultation at the Heart Centre. Mary is going through the step-by-step preparation which involves answering a set of predefined questions, updating and approving her medication list, and indicating if she is experiencing any of nine specific symptoms.



Picture 1: The design researcher and Mary sitting in her home, preparing for the upcoming consultation

Lately, she has been feeling that her heartbeat is too rapid and is worried about the stabbing pain she sometimes experiences. Going through the symptoms section, Mary initially ticks ‘abnormal heartbeats’, but then pauses when she is to indicate whether the symptom appears during ‘heavy’, ‘medium’, ‘light’ or ‘no physical activity’.

Mary: *”Hmmm, I would say… it’s this one [pointing at ’during no physical activity’]… Not necessarily during physical activity.”*

Design researcher: *“Ok… so, that would mean you experience it at rest?”*

Mary: *”Not necessarily. It can come at any time. At rest or, for example, when bicycling or walking. But there is no category to capture that…”*

Design researcher: *“You would need a new category then?”*

Mary: *”Yeah, because if I state that I experience it during physical activity, then one would think that I have arteriosclerosis… which I do not! It can come at any time. But there is no category to capture that. Then it would easily be misinterpreted if I state that I experience abnormal heartbeats during physical activity –which is when the heart is at work – because that would typically indicate problems with stiffening of the arteries.”*

Design researcher: *“I see. And when you so confidently state that it’s not arteriosclerosis, it’s because you somehow know and you therefore don’t want to indicate it?”* (audio transcription, Mary’s home, October 8, 2010)

To this, Mary explains how she has been suffering from abnormal heartbeats for a long time, and how she went through an extensive examination a couple of years back, which explicitly concluded no problems with her arteries. And as she states, *“If I then indicate it, the treatment will be different.”* Mary finishes the preparation by selecting the option, ‘during no physical activity’.

## Multiple Becomings of Healthcare

As the intervention teaches us the patient explicitly refrains from indicating a specific nuance of an important symptom, whereby she actually ends up concealing information from the cardiologist. Mary’s decision is based on her anticipation of what they will probably conclude again, which she knows is incorrect based on her earlier examinations. She specifically engages in the process of making her situation manageable for the cardiologist, but interestingly by taking steps to avoid the consultation from going in a, for her, worthless direction.

As regards to constructive insights for design, we come to understand that the symptom component should be redesigned to allow patients to briefly describe the situation in which they experience a particular symptom. Fixed symptom categories do not always enable the patient to provide sufficient diagnostic information, as we have also learned from Bowker and Star (1999). Most importantly though, with the intervention and Mary’s use of myRecord, she starts to manage her physician by performing herself as an essential and guiding part of the diagnostic work, possibly to increase the manageability of her own case.

## Case II: Bridging Interinstitutional Care

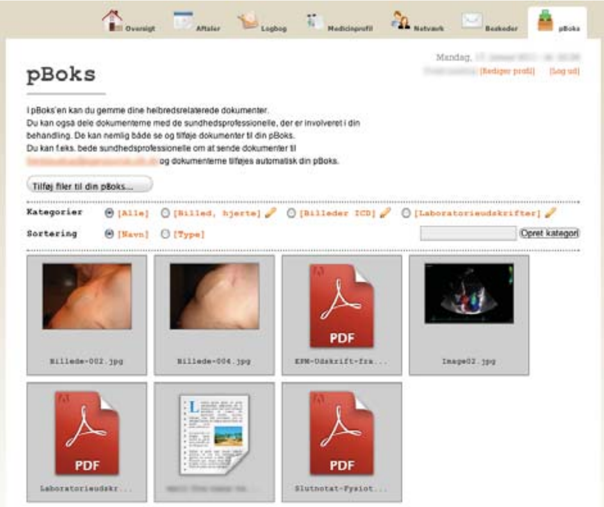
When treatment and care is distributed between institutions, as is the case in our study, the patient often becomes an even more central actor in managing and ensuring continuity of care. As argued by Unruh and Pratt (2008) one key task for such patients becomes to *bridge interinstitutional care*, whereby patients work to manage and bring together information from different sources in the distributed network of care institutions. Unruh and Pratt show how this type of work transforms the patient into an *information courier "shuttling medical information from one institution to another."* (2008, p.38) Having encountered similar situations numerous times during the interventions, we wanted to explore the phenomenon of bridging interinstitutional care further, in a more performative mode. Through several smaller workshops we, and the web developer, sketched and implemented a personal digital document archive (pBox) in myRecord to enable patients to easilier become information couriers. pBox enables patients and health professionals to archive and share documents easily. By storing documents in their pBox, patients ensure health professionals' contionous access to their documents. To illustrate the use of the intervention to explore 'bridging interinstitutional care' by co-enactment, consider the case of Fred who, through the intervention and myRecord, succesfully interrelates the diagnostic work between two heart clinics at different hospitals.

### Design Intervention

A week prior to the consultation the design researcher, (Jonas, aged 30), is visiting Fred (aged 57) in his home to promote and encourage him to use myRecord's pBox (picture 2) to prepare for the upcoming check-up with his nurse. Fred's wife has joined the conversation and the chat goes on for close to an hour. The design researcher asks Fred if there is anything in particular he would like to discuss with his nurse. While they talk the design researcher pays particular attention to questions or issues that myRecord could support Fred in querying further into. At one point, Fred raises an issue in which he is confused with having received contradictory feedback on two identical scans of his heart done at two different clinics. The two statements report on the state of his heart and its strength, and are both based on echocardiographical scans of his heart. One statement reports he is doing well, in that his 'heart capacity' has increased from 10 to 25 per cent. However, the other statement concludes that his heart is enlarged to compensate for the non-functioning area. *"What am I to make of this? How can they be so different, when it's the same (type of) scan?"* Fred says slightly disillusioned. *"Am I doing progress or not?"*

The design researcher suggests that Fred upload the scan and statement from the other clinic and then use myRecord to raise his question. With help from the design researcher they formulate the questions for the nurse and upload the echocardiographic scan to his pBox together with the e-mail from the other heart clinic stating the conclusion about the enlarged heart area.

An hour prior to the consultation the design researcher meets with the nurse to explain the setup and hand her printouts of Fred's preparation and the uploaded images to simulate that myRecord is an integrated part of her daily routine. Half an hour into the consultation the nurse looks at Fred's preparation, including his questions. They reach his third question, where he correlates the statements from the two clinics, which reads: *"[Name of cardiologist] has scanned my heart and tells me that the well functioning area is enlarged, because it compensates to make up for the non-functioning areas. How does that fit with your recent statement that my capacity has improved from 10 to 25 per cent? (please, see the attached e-mail in my pBox)."* (myRecord transcription, November 2010)



pBoks

I pBoks'en kan du gemme dine helbredsrelaterede dokumenter.
Du kan også dele dokumenterne med de sundhedsprofessionelle, der er involveret i din behandling. De kan nemlig både se og tilføje dokumenter til din pBoks.
Du kan f.eks. bede sundhedsprofessionelle om at sende dokumenter til [redacted] og dokumenterne tilføjes automatisk din pBoks.

Picture 2: A screenshot of Fred's pBox in myRecord

After having consulted Fred's documents, the nurse agrees about the peculiarity of the two different conclusions on the same type of scan. But as she explains, she is legally hindered in obtaining information from the other heart clinic. She therefore asks Fred to obtain the information and then upload it to his pBox, where she is able to access it. Fred shakes his head indicating that he finds the situation a bit peculiar, but agrees to do it.

## Multiple Becomings of Healthcare

With the intervention as arena, prepared by the design researcher's practical alignment of various actors including the pBox in myRecord, Fred enacts a connection between the two institutions.  The new connection, where one clinical facility is confronted with another's different reading of 'the same' scan, concretely come to exist through his performance with myRecord. With the pBox in particular, he establishes relations that did not exist before by bridging two institutions that were not able to communicate. In this way he performs a *diagnostic agent*, as he takes part in carrying out this essential, but often invisible work of aligning and reorganizing interinstitutional information (Oudshoorn, 2008, p.276). The intervention evolves from the initial inquiry into pBox as a tool to support the enactment of the patient as information courier to an exploration of the patient's role in detecting, preventing and recovering from ambiguous medical situations (Unruh and Pratt, 2007). In this sense the case becomes a concrete example of how responsibility is delegated to the patient. To continue the process of 'finding an answer' to Fred's diagnostic question, Fred not only has to act as a courier *"shuttling medical information from one institution to another"*, but has do more work to connect the two health professionals (institutions) in order to enable collaborate diagnostic work. Moreover, the case also brings us concrete design insights in how to enhance the pBox as a tool for health professionals. Through the situation, we learn that the pBox needs to support subscriptions to and the ability to classify content from a single health professional or institution.

## Case III: Patient Homework

This third case recalls a design intervention in a cardiatric consultation at the Heart Centre between the heart patient, Karl (aged 68), his wife, a cardiologist and a design researcher (Tariq, aged 30). It is the elaborated case from the paper's introductory snippet. Herein, we illustrate how the theoretical concept of 'homework' is made and becomes generative in multiple ways.

Grøn et al. (2008) coin the notion 'homework' to critically accentuate implications of the political shift in the organization of healthcare. They refer to the work issued by the healthcare system, but practiced in patients' homes. Here, patients are increasingly expected to take on more responsibility, which in turn becomes more patient work (Oudshoorn, 2008) and often collides with their everyday lives and unstable health. Field studies and Grøn's argument drew Aarhus and her group (2009) to make it a design principle in their project – not to add to the amount of homework in the development of an 'eDiary' for diabetics. However, others argue that active patient involvement generate greater improvement in health and patient satisfaction (Street et al., 2005). Being aware of this discourse, we deliberately wanted to sketched and implement 'patient assignments' in myRecord to critically inquire into consequences of letting cardiologists give patients' assignments and open up the space for multiple interpretations of homework to be performed. It moreover engaged design inquiries such as; *which features in myRecord are necessary, what data, and which text fields and buttons should we include?*

### Design intervention

In the design intervention, the cardiatric consultation, Karl and a cardiologist are having an intense discussion on whether or not Karl should be re-hospitalized and go through a high risk operation. The day before the consultation, Karl used myRecord at home to prepare for the consultation and the cardiologist read it before they meet and uses it many times throughout the consultation. During 43 minutes they discuss how Karl experiences shortness of breath and dizziness after the most recent operation. Their dialogue expresses their collective project of deciding on three optional moves, all based on Karl's interpretation of his health condition. After an intense conversation they still cannot make a decision and agree not to do anything, but let Karl stabilize and meet again in two weeks. When everybody stood up and were about to leave, the design researcher (Tariq, aged 30) intervenes and explains the idea of 'patient assignments' and asks if the cardiologist would give Karl a task to complete at home using myRecord.

The cardiologist immediately says: *"Oh – Yes, okay [...] Karl, we've talked about that you need to find out how your breath is. This means that you every day have to go out on the street and walk until you need a break. Then it'll say [in myRecord]; Monday 50 m., Tuesday 50 m., Wednesday 45 m., Thursday 70 m. – anything [...]"*

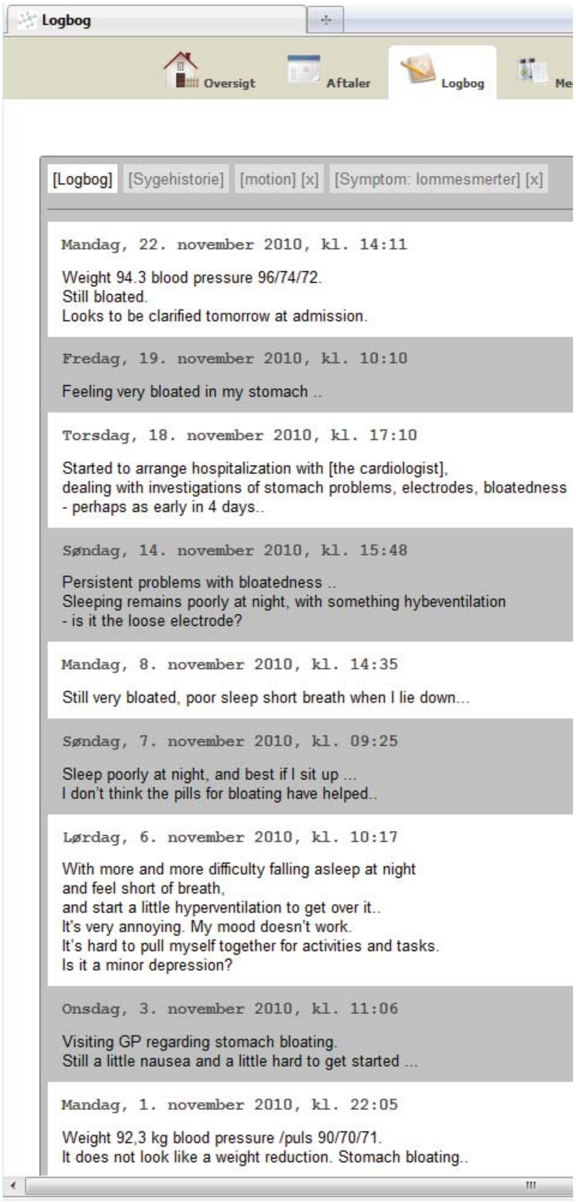
*"You see, it would be nice for me to have a very specific test, where you've gone out and seen how far you can walk - it need not be every day - let's say two times a week. But some tasks ... But then I want concrete answers to it that way. Walking distance, weight and blood pressure."* (audio transcription, the Heart Centre, October 29, 2010)

Later that day, the design researcher enters the task into myRecord and almost daily, for more than three weeks, Karl writes his weight and blood pressure in the logbook (picture 3). However, he never writes about his achieved walking distance, but one time he mentions: *"My mood doesn't work. It's hard to pull myself together for activities and tasks. Is it a minor depression?"* Instead, Karl's logbook entries (picture 3) reveal that his stomach bloating increases and that he *"started to arrange hospitalization"*. Despite the increased attention from health professionals, Karl was admitted to the hospital after twenty days and he immediately stopped using myRecord.

## Multiple Becomings of Healthcare

When analysing Karl's symptom log, his writings throughout three weeks (picture 3) also mirror what the cardiologist emphasized as important diagnostic information decisive for operation. Yet another, very important, diagnostic information that Karl performs could be characterised 'non-use' (Oudshoorn and Pinch, 2003) or non-completion of the walking-distance task. As a patient his active use and enactment of homework was dependent on developments in his illness and, as the case illustrates, he could not begin the task of measuring walking-distance – apparently because of his stomach bloating and physical and psychological discomfort. As such, changes in his health condition conflicts with his ambitions of writing in his Logbook. Eventually, Karl becomes unable to carry out that part of the assignment. Also, as soon as he got re-hospitalized he stops all activities of myRecord use.

The assignment in myRecord is still there but Karl is no longer able to engage the underlying logic of performing a responsible and cooperative patient. He is hospitalized and hence, patient 'non-work' or 'non-use' might be considered essential categories and made as concrete components of the socio-material conceptualization of patient homework? As of constructive insights for design, this case and other similar interventions suggest that patient homework might benefit from enabling patients to signal that they have become unable to carry out or 'hand-in' homework. Maybe homework and assignments are less fruitful notions when considering design for a socio-material reconfiguration of healthcare? Perhaps the concept of 'patient work' (Strauss and Fagerhaugh, 1997) does a better job when engaged in myRecord – and consequently enactments of another healthcare and different practices?



Mandag, 22. november 2010, kl. 14:11

Weight 94.3 blood pressure 96/74/72.
Still bloated.
Looks to be clarified tomorrow at admission.

Fredag, 19. november 2010, kl. 10:10

Feeling very bloated in my stomach ..

Torsdag, 18. november 2010, kl. 17:10

Started to arrange hospitalization with [the cardiologist],
dealing with investigations of stomach problems, electrodes, bloatedness
- perhaps as early in 4 days..

Søndag, 14. november 2010, kl. 15:48

Persistent problems with bloatedness ..
Sleeping remains poorly at night, with something hybeventilation
- is it the loose electrode?

Mandag, 8. november 2010, kl. 14:35

Still very bloated, poor sleep short breath when I lie down...

Søndag, 7. november 2010, kl. 09:25

Sleep poorly at night, and best if I sit up ...
I don't think the pills for bloating have helped..

Lørdag, 6. november 2010, kl. 10:17

With more and more difficulty falling asleep at night
and feel short of breath,
and start a little hyperventilation to get over it..
It's very annoying. My mood doesn't work.
It's hard to pull myself together for activities and tasks.
Is it a minor depression?

Onsdag, 3. november 2010, kl. 11:06

Visiting GP regarding stomach bloating.
Still a little nausea and a little hard to get started ...

Mandag, 1. november 2010, kl. 22:05

Weight 92,3 kg blood pressure /puls 90/70/71.
It does not look like a weight reduction. Stomach bloating..

Picture 3: A screenshot of Karl's logbook entries in myRecord
[Entries are shortened and translated from Danish]

## Discussion

One of the questions treated in this paper and particular to this discussion is *how one can study something that does not yet fully exist without relying entirely on speculation*, but retaining an open ethnographic curiosity towards what is evolving as important in the field under study. A basic challenge in much design research is how to move from a primarily documentary mode of descriptive knowledge generation to sketches and enactments of possible attractive future alternatives. Instead of focusing on this movement as a transfer or translation from one kind of documentary knowledge to a different kind of speculative knowledge, we draw on approaches from design research that seek to deconstruct this principal distinction: *"The central problem is that the challenge [...] is articulated as a gulf to be bridged between observations and interventions."* (Halse, 2008). Halse argues that this often articulated 'gulf' is an outcome, rather than a premise for design. Our empirical cases from healthcare fit this argument well, in the sense that they too work to destabilize some of the conventionally opposing categories of understanding and intervening.

The design interventions point to an ongoing controversy regarding the role of the experiment in design-oriented IT research. The case examples do not live up to the paradigm of purely empirical observational ethnographic research outlined for example by Hammersley and Atkinson (2007) or as practised within ethnomethodologically informed workplace studies (Luff et al., 2000; Crabtree et al., 2009). Nor do the examples live up to purely empirical experimental research where fixed and isolated variables are sought to ensure that the experiment can be reproduced with reasonably similar results. Instead the examples reveal the unsettled status of the experiment and show how the interventional assemblages enact quick shifts in the mode of inquiry: from suggesting and promoting myRecord as a relevant solution to a practical problem, to raising new questions about the socio-material complexities of healthcare.

The assemblage instantiates new practices that incorporate diverse agendas, without trying to purify categories of 'design' or 'research'. The notion of design intervention as we treat it here is meant to challenge a commonly held simplistic dichotomy between 'the existing' and 'the possible'. The intended goal of this project is as much to understand how cardiatric health care may *become something else* by means of IT as it is to create an accurate account of how it really is, when new technologies are introduced.

The setup in these examples is far from stabilized and the issues under inquiry are changing during the intervention itself: from testing the relevance to practice and usability of a particular design feature to exploring what might be gained from enacting a theoretical concept such as 'patient manageability' and 'homework'. The status of the prototype can change during the intervention itself, because it is so explicitly entangled in the unpredictable interventional assemblage of e.g. patients (who may reject to use it), clinicians (who may feel challenged) and design researchers (who report to several distinct research communities); sometimes it seems as if the research questions serve the purpose of building a better prototype while at other times the prototype appears as a mere occasion for scrutinizing healthcare.

A terminological challenge to research-through-design is that it could imply that design is a passage, whereas research is what passes through to the other side. We do not wish to invoke this particular meaning according to which means and ends appear as pre-given distinctions. While it is not only very difficult to dissect the event and claim strong distinctions between 'existing practice' and 'projected future practice', or between 'observation' and 'experimentation' in the case examples, we find it more fruitful to avoid these dichotomies all together. The seemingly oppositional characters of *describing what is* and *intervening with new proposals* may appear commonsensical, but often become obstacles for integrating research and design efforts. (Sanders in Halse et al., 2010, p.116-120). Instead, the idea of time as emergent and open, (Pickering, 1995; Law and Hassard, 1999; Barad, 2003; Latour, 2004; Whitehead, 1979) allows us to expand the implications of *the present* as a moment of unsettled opportunities, a process of creative becoming.

Our claim is that myRecord as a prototype cannot be reduced to a methodological step towards discursive insights and conversely that our research insights about cardiatric health care cannot be evaluated without close reference to the embodied encounters with this particular working prototype. Because myRecord is fundamentally inseparable from the assemblage that enabled the particular kinds of interaction recounted in the examples of this paper. There are certain difficulties involved in employing design interventions as a design research strategy for exploratory questioning of a given topic rather than exclusively to test solutions. Long-standing ideals of accounting for the world 'as it is' and 'independently of the process of inquiry' are impossible to uphold with such blurred and changing distinctions between the subject, object and method of study. Above all, the interference with the subject matter by interests embodied and promoted by the individual design researcher makes this type of design intervention very hard to explain in the conventional scientific terms of validity and generalizability.

To practice this kind of design research requires researchers who are willing and able to make quick and improvised shifts in their attitude towards the research situation, rather than rely on rigorously defined methodological frameworks or step-by-step procedures. Making a daring move to present unfinished ideas to foreign project stakeholders must go hand-in-hand with humble and curious moments of listening and observing with an open mind in order to facilitate an authentic encounter between genuine concerns and projected possibilities. To appreciate the unsettled role of the assemblage of the design intervention, it is necessary to pay close attention to the bodily presence of the design researcher and his or her often intuition-based interferences with the parameters of the design intervention: not as contamination of the situation nor an interference with the object under observation but as an intrinsic quality of the practice-based inquiry.

## Conclusion

With this paper we propose that the conventional approach to knowledge production within the fields of IT research in healthcare, such as PD, CSCW and IS, can be fruitfully complemented by a more interventionist approach. We suggest this as a *strategy of multiple becomings*. Furthermore, we advise that a constructivist stance towards 'being' as process will allow a reconciliation of understanding and intervention, present and future.

Through three cases of design interventions we have shown the mutual connections between design proposals and the more discursive space of 'understanding healthcare'. The argument has been based on a foundational unsettling of both the mode of inquiry (observational *and* interventionist) and the role of the prototype (a solution to be evaluated *and* a research tool to generate new questions). In this light, the intervention is a manifestation of a projected reality, where a partly imaginative prototype (yet very concretely present) meets a patient willing to project her concerns and aspirations onto the prototype, whereby the lived practice that unfolds during the event entails both enactments of the past and enactments of the future. Through the emphasis on embodied encounters, design interventions present a concrete opportunity to practice and explore possible alternative realities before they are fully realized. Rather than postponing the materialization of new opportunities until the requirements are specified, we suggest to begin by instantiating ideas and hypotheses, while they are still only vaguely defined.

The design intervention is a way to supplement well-proven methods for questioning, such as ethnographic fieldwork with enactments of more material articulations of hypotheses and questions. The design intervention is an experimental inquiry that positions itself in-between what is already there and what is emerging as a possible future. With the design intervention, the assemblage allows for the multiple becomings of healthcare.

## Acknowledgements

We are grateful for the valuable collaboration with the patients and health professionals at the Heart Centres at Copenhagen University Hospital, Bispebjerg and Hvidovre Hospital. We thank Jeanette Blomberg, Melissa Cefkin, Peter Danholt, Finn Kensing, and two anonymous reviewers who provided useful comments and pointed out essential literature. CITH is a 4-year project funded by the Danish Council for Strategic Research grant #2106-07-0017

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## Paper III

# Re-Introducing Patients as Diagnostic Agents

Andersen, T., Bjørn, P., Kensing, F., and Moll, J. (2011): ***Designing for collaborative interpretation in telemonitoring: Re-introducing patients as diagnostic agents***. International Journal of Medical Informatics 80(8), pp. 112-126.

## Abstract

*Purpose*: We investigated why clinicians experience problems interpreting implantable cardioverter-defibrillator (ICD) data when the patient is absent, and we explored how patients could be re-introduced into the socio-technical setup of telemonitored interpretation practices.

*Method*: An action research study with a design interventionist perspective was conducted to investigate the telemonitoring arrangement for chronically ill patients with ICDs and to identify the nature of the collaborative practices involved in ICD data interpretation. We diagnosed the main challenges involved in collaborative interpretation practices. These insights were used to re-design the socio-technical setup of the telemonitoring practices by designing and building a web-based, patient-centric, collaborative application, myRecord, to re-introduce the patients as active participants to the telemonitoring setup. Finally, we introduced the application into the telemonitoring practices at a Danish University Hospital and evaluated the new practices and the collaborative technology related to the transformed role of the patients.

*Results*: The interpretation of ICD data is a collaborative practice engaging clinicians and patients and involving three separate collaborative processes: *interpretation of numbers*; *interpretation of general condition*; and *patient's interpretation of own condition and ICD data*. In a collocated setup, these three interpretation processes are entangled and seamlessly interrelated. However, in the current telemonitoring setup, only the interpretation of numbers process is fully supported, neglecting the two other processes, and, in particular, the role of the patient. This lack of support makes the interpretation practice difficult and time consuming. By re-introducing the patient into the socio-technical setup of telemonitoring through myRecord, our design acknowledges the collaborative nature of the interpretation process. However, re-introducing the patient transforms his or her role, thus leading to new transformed telemonitoring practices, different from both the pre-existing telemonitoring setup as well as from the collocated setup.

*Conclusion*: Telemonitoring practices of patients with ICDs involve three entangled collaborative processes, whereas existing socio-technical setups only mediate one. myRecord is designed as an add-on collaborative technology to mediate the two remaining collaborative processes. We argue that the application solves some of the problems with ICD data interpretation inherent in telemonitoring practices by providing a collaborative, asynchronous space for healthcare practitioners and their patients to mediate the two processes that are

otherwise lost in the telemonitoring situation. Our new socio-technical design setup also transforms the role of the patient considerably, thus new studies should take these insights into consideration.

## Summary

What was known before the study:

- Telemonitoring transforms healthcare practices in unanticipated ways.
- The use of ICDs (implantable cardioverter-defibrillator) for patients with chronic heart diseases is increasing, and the practice of telemonitoring ICD data is emerging.
- In order to understand how telemonitoring practices influence the interpretation of ICD data, we need to investigate how such practices are acted out in both collocated and distributed settings.

What the study has added to the body of knowledge:

- An illustration of the socio-technical transformation of work practices and technologies during the interpretation practices of telemonitoring ICD data.
- An understanding of the three essential entangled interpretation processes involved in monitoring ICD data.
- Illumination of how two of these processes are neglected in the current telemonitoring setup.
- How to design for patients as diagnostic agents in collaborative telemonitored interpretation
- Insights into how the design of a collaborative socio-technical information technology (IT) solution can turn patients from passive sources of bodily device data into active diagnostic agents.

## Introduction

Health care is an inherently collaborative effort where multiple healthcare practitioners and patients collaborate in practices of diagnosing and treating health problems. Because of the collaborative nature of healthcare work, the technologies we design and bring to the setting should be thought of as collaborative technologies supporting collaborative work. Computer Supported Cooperative Work (CSCW) research is the "endeavor to understand the nature and requirements of cooperative work with the objective of designing computer-based technologies for cooperative work arrangements" [1, p. 11]. CSCW researchers have been investigating the collaborative practices within health care for two decades [2], yet the changing nature of health care, combined with new technological opportunities, continues to extend this research field and bring new challenges [3]. Implantable cardioverter-defibrillators (ICDs) are one of the new technologies changing healthcare practices for patients with heart problems. An ICD is an advanced pacemaker that can be implanted in patients at risk for sudden cardiac death due to ventricular fibrillation. It is designed to deliver electric shocks to restore the normal heart rhythm. The ICD also records data about detected arrhythmic events as well as selected overall conditions of the body. For example, some ICDs can provide information about rising fluid levels approximately 14 days before ordinary methods would detect the indications. The purpose of collecting these ICD data is to continuously monitor the chronic condition and to support decisions about whether or not particular interventions (e.g., change in medication or re-programming of the ICD) should be initiated.

Monitoring ICD data is basically a practice of collaborative interpretation where multiple healthcare practitioners and the patient together investigate the data, identify possible issues, and decide whether to take action. The monitoring activity traditionally took place collocated, where the patient traveled to the healthcare facility and advanced machinery read the ICD device, the output from which then formed the basis for data interpretation. However, in recent years ICD technology has started to include telemonitoring opportunities. Telemonitoring has transformed the practices of interpretation and use of ICD data, and some of the current ICD telemonitoring systems allow the patient to be located globally while being monitored locally. In this way, the monitoring and treatment of chronic heart failure patients with ICDs has become a global health activity.

We know that technology transforms practices in unanticipated ways [4]. However, because ICD telemonitoring technology is fairly new, its effects on the activity of data interpretation have not yet been documented. While investigating the telemonitoring practices, we quickly realized that one consequence of telemonitoring was that the patient became absent from the interpretation practices, which was identified as problematic for the clinicians. Thus, in this paper we investigate why clinicians experience problems interpreting implantable cardioverter-defibrillator (ICD) data when the patient is absent, and we explore how patients could be re-introduced into the socio-technical setup of telemonitored interpretation practices.

Applying the action research methodology [5], we initially found that ICD data interpretation in the collocated setup was, in fact, a collaborative practice between the clinicians and the patient, that it comprised three seamlessly entangled processes, and that the current socio-technical telemonitoring setup only supported one of these processes, neglecting the role of the patient. Next, we designed an add-on patient-centric web-application, myRecord, with the aim of re-introducing the patient into the data interpretation process. The new socio-technical setup was then evaluated by both the healthcare practitioners and the patients. In this way we went through a whole action research cycle of understanding, intervening, and evaluating [6], and, finally, we reflected on the transformed role of the patient.

The paper is structured as follows. First, we present previous work on patients as active participants in telemonitoring practices and interpretation. Then, we present the action research methodology including data sources and methods of analysis. Then we show the results in three parts: understanding the interpretation work, intervening through design, and evaluating the intervention. This is followed by a discussion and, finally, we offer a conclusion.

## Previous Work: Collaborative Effort in Telemonitoring

Collaboration occurs when multiple people are mutually dependent in their work, and it “is constituted by the interdependence of multiple actors who, in their individual activities, in changing the state of their individual field of work, also change the state of the field of work of others and who thus interact through changing the state of a common field of work” [7, p. 4]. The interaction between healthcare professionals and patients in the process of monitoring chronic illnesses is a long-term, collaborative effort. However, most research on telemonitoring tends to neglect the collaborative aspect and instead focuses on how treatment can be more cost efficient [8, 9], or how monitoring might reduce the risk of mortality among heart failure patients [10-13]. Moreover, research on how IT might improve the communication and information access within home telemonitoring is sparse [14]. While we do appreciate the mainstream research in telemonitoring, we believe a vital element of telemonitoring is being ignored: collaborative effort.

Few researchers [15, 16] appreciate the collaborative engagement in telemonitoring practices and few have investigated the inevitable transformation in the cooperative work caused by new technologies. Kaplan and Fitzgerald [16] investigate remote intensive telehealth care and provide interesting observations, but they explore the collaborative practices between dispersed healthcare practitioners and not the monitoring of patients. Bardram et al [15] found that telemonitoring technologies transformed the practices by changing the division of work between the physician and the patient, placing new work tasks on the physician in terms of time and effort used to monitor, and that the communication patterns were transformed from a contextual, rich conversation to asynchronous messages [15]. New technologies transform medical practice, and studies have pointed to how the integration of new technologies leads to redistribution rather than reduction of work [e.g. 17].

Patients are an essential part of the collaborative engagement in the telemonitoring context, and it has been argued that patients are able to act as diagnostic agents in such setups [18]. Being a diagnostic agent, essential work is redistributed from the healthcare professionals to the patient, and often this new type of work disappears from the formal descriptions of telemedicine [18]. When patients become "absent," their condition is separated from the context of their bodies, and the "condition" becomes represented through particular forms of representation such as images and graphs [19]. This means that the healthcare practitioners must rely solely on representation to make sense of the context, which is a huge change from the practice in collocated settings.

Previous design-oriented research on telemonitoring practices suggests different technical web-based solutions for telemonitoring technologies, where the patient and the healthcare practitioners, through one portal, can reach the clinical data collected in the patient's home as well as the patient record [e.g. 20]. However, while these kinds of studies are purely technically oriented, typically referring to laboratory installations, they do not take into account all of the organizational, as well as the technical, issues related to the real-life context that is included in our study. Even though previous design-oriented telemonitoring research tends to focus only on the technical aspects of the telemonitoring process, there is a trend in medical informatics [e.g. 21, 22-24] toward more patient-centered approaches and the design of computer supported cooperative systems [14, p. 570]. Our work is part of this trend.

### Research Setting: The CITH Research Project

The study presented here is part of the larger research project, Co-constructing IT and Healthcare (CITH). Through this project, we explore communication and collaboration across institutional and professional boundaries in heterogeneous settings within healthcare. The CITH project analyzes existing collaborative practices among heterogeneous actors who manage patients with an ICD. The project aims at "designing, developing, and evaluating IT applications and services supporting the work of both healthcare professionals and patients" [25]. The authors are part of an interdisciplinary group with backgrounds in Cardiology, Health Informatics, Computer Science, and Sociology. We have also engaged ICD patients as active participants in defining the aim of the project as well as in its analyses, design, and evaluation activities.

### The Organizational Context

The care for ICD patients involves multiple participants, including patients, relatives, general practitioners, lab technicians, bioanalysts, heart specialists, device specialists, nurses, clerks, social workers, etc. The main work takes place in three settings: the Heart Centre at Copenhagen University Hospital, patients' homes, and local hospitals. The ICD patients from Denmark, Greenland, and the Faeroe Islands that are connected to the Heart Centre have the implantation and the device follow-ups conducted in Copenhagen even though some of these patients live far away. Patients not on the telemonitoring system travel quite far to get a device follow-up. It takes place every three months and consists of monitoring the ICD and taking action when it does not work correctly, or when it has to be reprogrammed according to the patient's changing condition. An increasing number of ICD patients have a telemonitoring set up at home that is able to read and send the status of the ICD to the Heart Centre. The local hospital's responsibility is to stabilize the patient by checking and adjusting the medical treatment. This takes place during ambulatory visits every three months. However, the part of the CITH project presented here concentrates on the collaborative interpretation work performed by the healthcare professionals at the Heart Centre and by the patients.

## Method

### Action Research

The relevance of expanding the medical informatics field toward a multi-disciplinary approach has been put forward convincingly [26]. Qualitative methodologies for the design and evaluation of technologies in healthcare are entering the field of healthcare informatics [22]. The methodology applied in this paper follows this tradition, emphasizing user-centric designs, and, in particular, we apply the action research method [6]. Action research comprises two iterative interrelated stages: diagnostics and therapeutics. The diagnostic stage involves a joint analysis between the practitioners and the researchers of an experienced problematic situation, while the therapeutic stage involves the introduction of changes combined with an analysis of the effects of these changes [5]. In our case, the starting point was the clinicians' statement that during ICD data interpretation practices they experienced that the absent patient was problematic; thus we initiated an in-depth qualitative investigation of the ICD interpretation practices. These investigations formed the diagnostic stage. Understanding why the absent patient was experienced as problematic, we then initiated the therapeutic stage of the research. Here we investigated, in joint collaboration with both the clinicians and patients, how it might be possible to re-introduce the patient into the socio-technical setup of telemonitored interpretation practices. This intervention took form as a combined design of both changed work practices and a new add-on technical application. Finally, we evaluated the intervention and the possible effect and consequences of such as transformed socio-technical setup-up for telemonitoring practices of ICD interpretation. Action research seeks to contribute both to the practical concerns of a particular problem (the absent patient) and to the goals of scientific research (understanding the collaborative practices of ICD interpretation while designing collaborative technologies) by taking initiatives toward a joint venture between researchers and practitioners [27]. The joint effort was thus guided by the joint research question: Why do clinicians experience problems interpreting ICD data when the patient is absent, and how can patients be re-introduced into the socio-technical setup of telemonitored interpretation practices?

Action research within information systems and CSCW is well established, and even though there are multiple action research approaches, the fundamental activities and issues are similar [28-30]. In our work, the action cycle is divided into three main activities: 1) understanding interpretation work, 2) intervening through design, and 3) evaluating the intervention (see Figure 1).

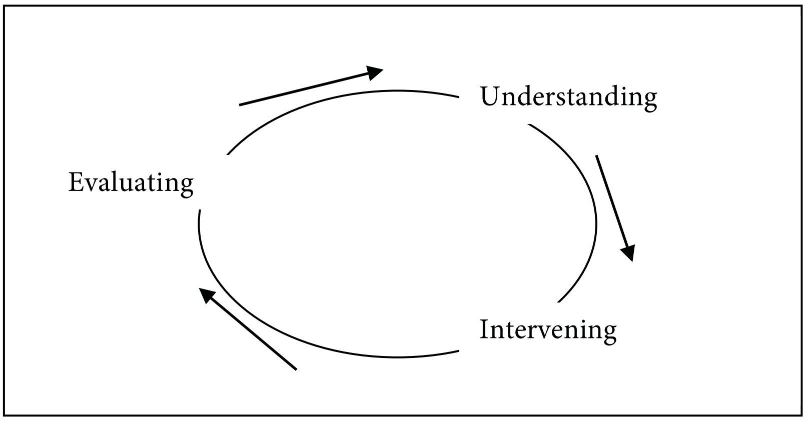


Figure 1: Action research cycle activities

*Understanding interpretation work* is the part of our study that focuses on diagnosing the problematic issues experienced by the healthcare practitioners during ICD data interpretation in the telemonitoring setup. This process includes qualitative data collection, where we combine observations of work practices with interviews, identify the use of coordinative artefacts by various participants in particular situations, and reflect upon these findings together with our empirical partners.

*Intervening through design* is the second part of our study, where, based on the understanding achieved in the first part of the study, we initiate design activities together with the empirical partners. These activities include workshops with both patients and clinicians where together we develop mock-ups that are then turned into a web-based prototype. *Evaluating* is the third and final part of our study, where the designed prototype is placed within the actual practical situation of telemonitoring along with newly designed organizational practices. Evaluation includes activities such as educating the patients and clinicians about the transformed practices, as well as collecting data about the intervention and the consequences of the intervention. Because of the cyclic nature of action research, data analysis was continuously conducted in an iterative manner throughout the entire project. Results from, for example, observations and interview activities (understanding) were used in the initial prototype design (intervening), and then evaluated and discussed with patients and clinicians during workshops (evaluating). Thus, while the whole project enters one main action cycle guided by the research question, the main action cycle consisted of a large number of small action cycles, each entering the ring of understanding, intervening, and evaluating. Considering the criteria for action research, it is essential to understand that an action researcher cannot be a disinterested observer, but must act in practice to solve the experienced problematic situation while simultaneously observing oneself acting [32]. Thus, one of the key aspects of action research is intervention while collecting data about the intervention.

| Type | Description | Proportion |
|---|---|---|
| **Included in the study** | Involved in the co-construction of myRecord | 4 Cardiologists<br>7 Bioanalysts<br>2 Secretaries<br>23 Patients (myRecord users) |
| **Observations of work practices** | Heart Centre: Collocated ICD interpretation | 8 patients<br>(1 video documented) |
| | Heart Centre: Distributed ICD Interpretation | 9 x 4 hours observations<br>(126 telemonitored patients) |
| | Patients' homes: Daily practices | 7 patients |
| | Heart Centre: Use of computer systems (lab systems, research applications, ICD Registry, patients records, ICD data) | 5 x 4 hours observations |
| | Local hospital: Use of computer systems (lab systems, research applications, ICD Registry, patient records) | 2 x 4 hours observations |
| | Local hospital: Patient follow-up | 12 patients<br>(video documented) |
| **Formal interviews** | Clinician interviews | 8 w/ cardiologists<br>2 w/ bioanalysts<br>2 w/ secretaries<br>1 Group interview w/Vendor |
| | Patient interviews | 12 w/ patient and relative |
| **Informal interviews** | During observations | 1 w/ vendor consultant<br>5 w/ bioanalysts<br>6 w/ cardiologists<br>26 w/ patients<br>3 w/ secretaries |
| **Workshops** | Patient workshops | 4 x 3 hours workshops<br>(3 video documented) |
| | Bioanalyst workshop | 1 x 2 hours<br>5 Bioanalysts<br>2 Researchers<br>(video documented) |
| | Clinician workshops<br>(Heart Centre and local hospital cardiologists) | 4 x 2 hours<br>2 - 4 Cardiologists<br>3 - 5 Researchers |
| | Demonstration of prototype for vendor | 2 hours<br>2 IT vendor consultants |
| | Internal design workshops | 3 x 8 hours workshops |
| **Document and artefact analysis** | Heart Centre and local hospital | Collection of all types of documents: lists, plans, letters, forms, etc. |
| **Prototyping** | Sketching, prototyping and building new designs | 7 months – 4 iterations<br>1 part-time developer<br>(387 hours) |
| **Intervention** | Heart Centre: Action Research Interventions | 2 days of 3 hours<br>1 Bioanalyst<br>1 Cardiologist<br>myRecord used by 23 patients in 4 weeks<br>(video documented) |

Table 1: Overview of data collection and activities forming the action research study.

## Results

### Understanding Interpretation Work

Interpretation work of is the work done by participants when exploring and explaining the meaning of particular observations while presenting the results in understandable terms. Interpretation work of ICD data is thus the work where clinicians explore the numbers and graphs collected by the ICD device implanted in the patient. These numbers and graphs are represented by the ICD monitoring system, and clinicians explain these data in understandable terms for both the patient and other healthcare professionals. In this context, understandable terms refer to what kind of action the patient and the clinicians should take based on the ICD data. Basically, the interpretation work can have six different outcomes: 1) re-programming the ICD device, 2) changes to the medication, 3) additional heart surgery (e.g., ablation), 4) replacement of the ICD device (e.g., battery replacement), 5) instructing patients (e.g., on how to act as an ICD patient), 6) no actions. Thus, the main purpose of ICD data interpretation is to determine the appropriate action. Depending on which type of ICD implant a particular patient has, the data available for interpretation differs. However, all bursts, irregular heart rhythms, etc. are captured with date and time, making it possible to draw a detailed, time-accurate graph of the physiological state of the heart.

In the organizational setup we have investigated, the ICD data are available only at the Heart Centre. The interpretation work at the Heart Centre exists as two practices: collocated collaboration and distributed collaboration. In the collocated collaborative setting, the patient, the bioanalyst, and the cardiologist are all located at the Heart Centre, whereas in the distributed collaborative setting, the patient becomes geographically distant because of the telemonitoring setup.

### Collocation: Interpretation of ICD data

We are located in the Heart Centre, and an older lady is being examined. The bioanalyst asks the patient: "How are you feeling, and what kind of medication do you take?" The patient and the bioanalyst talk about the medication—the lady takes four different types of medication. Another bioanalyst reads the screen of the ICD monitoring device while the patient holds the 'stick' (reader) near the heart. "What time is this? There are marks—February 9th, April 20th, and April 29th." The patient says that she had not felt anything. She cannot remember these dates. Then the patient remembers: "Oh…by the way, I did wake up screaming a few weeks ago, but I did not feel it." The bioanalyst says to the other bioanalyst: "How many ATPs[i]—one on three and then electric charge, VTs[ii] all of them—we need to call a cardiologist.” The bioanalyst turns to the patient and explains: “You had 3 VFs[iii] with ATP and electric charge on all of them. They were all during night time, maybe that’s why you did not notice. Maybe you had some bad dreams?” […] After many examinations and discussions they summarize: “Well, we can say that the machine works as supposed to; however, the question remains: should we do anything?” To the patient they say: “Our cardiologist needs to check your medication.” The cardiologist leaves to consult another cardiologist concerning the medication. Just before the patient leaves the Heart Centre, one of the bioanalysts tells the lady that if she experiences anything again (such as nightmares) she should call them up. (Observation notes, May, 2009)

The above snapshot illustrates the crucial activities that are part of the collocated interpretation practice. Firstly, it is evident that although the Heart Centre’s label for the interpretation practice is device follow-up and thus focuses on the device, the engagement with the patient is not solely concentrated on the ICD data (i.e., the numbers, tables, graphs, and percentages read by the ICD monitoring machine). The ICD data, as represented on the screen on the device, is interpreted by the two bioanalysts. However, this interpretation of the ICD data is highly supported by the bioanalyst’s interpretation of the general condition of the patient, which, in many cases, is related to the medication list. The bioanalyst does not have electronic access to the medication lists, so this information is carried by the patient, who typically would bring out a piece of printed paper with the medication information. In all cases observed in the Heart Centre during device follow-up, the patient is asked: “How are you, and what medication do you take?” and the answer to these two questions provides the healthcare professionals essential and valuable information about how they should interpret the ICD data. It should be noted that the way patients answer these questions also affects the interpretation. For instance, if the patient is short of breath while answering, this is taken into account. During an informal interview with two bioanalysts, they explained that the patient’s overall condition highly influenced their interpretation:

In cases where a patient expressed his or her overall condition as feeling good, then even “bad” data is taken less seriously, while in cases where the patients respond they feel bad, the healthcare professionals will take “good” data more seriously and go deeper into the interpretation. (Informal interview with two bioanalysts, October 2009)

Thus, in cases where it seems that the heart rhythms and the device are functioning perfectly together but the patient expresses feeling bad, lack of sleep, lack of breath etc., the bioanalyst will not simply turn the patient away as healthy. Instead, they will take the complaints of the patient seriously and take action.

Secondly, the snapshot also points to another essential activity providing crucial information important for the practice of interpreting ICD data, namely the patient's own interpretation of the ICD data. In the example, the healthcare professionals ask the patient about specific dates where the ICD had reported events. First, the patient cannot remember these dates, but then suddenly she remembers waking up screaming in the middle of the night. This explanation helps to make sense of the data, and the healthcare professionals interpret the experience of screaming as "bad dreams" related to the events marked in the ICD data, reading that the device had calculated risks of heart failure and then delivered a jolt of electricity to the heart a number of times.

So while device follow-up in collocated settings is about 1) interpreting the ICD data read by the ICD monitoring machine and represented on the screen and print-outs, the process of interpretation also includes information about the 2) patient's general condition as well as 3) the patient's interpretation of his or her own condition and ICD data. These interlinked processes of interpretation all together form the foundation for what actions would be appropriate in particular situations. Should they change the medication, should they re-program the device, or is the existing treatment accurate?

Summarizing, there are three main processes of interpretation going on during device follow-up in collocated settings: the interpretation of numbers provided by ICD device data (as in graphs, diagrams, and percentages); the conversation with the patient about the general condition; and the patient's own experiences and thus interpretation of his or her own condition and ICD data.

### Distribution: Interpretation of ICD data

The system has detected two patients "with events"; however, the bioanalyst quickly browses through the information provided on these, but there is nothing of note. The browsing consists of opening the information on the screen, examining the values of certain data while examining the curves and graphs— is it stable or not? (Observation May 2009)

The bioanalyst prints out the schedule for the day and sits by the computer screen logging onto the telemonitoring system to access all the data. The telemonitoring system has pre-sorted the patients according to the system's algorithm. Thus, all of the patients that the algorithm has sorted as possible candidates for further examinations will be labelled as patients with "events." However, all of the patients with an event are quickly dismissed as "no action needed" by the bioanalyst, and, interestingly, it is among the remaining patients that the bioanalyst identifies the patients that need further examinations.

The main interesting observation here is the issue of sorting the patients. The telemonitoring system has done a pre-assessment of the data automatically and has placed the patients with registered events at the top of the list of patients. Here it is essential that the healthcare professional, after quickly browsing the ICD data from these particular patients, determines that the ICD data on these patients does not lead to particular concerns. Instead, the observation shows that investigating the ICD data sent by the telemonitoring system when sorting and selecting requires professional evaluation by a healthcare professional.

More patients have sent their ICD data, and the bioanalyst has sorted the patients, finding two that she decides to discuss with a cardiologist. The cardiologist sits next to the bioanalyst and they investigate the computer screen in front of them. "Look here [pointing to the screen]—it falls. It looks irregular and there are long periods. Then it becomes faster… 320… then back." They discuss back and forth while trying to interpret the data. They are interrupted during their interpretation. First the bioanalyst is called away to the examination room, and then the cardiologist is called away to the operating room. The computer is left alone. The cardiologist returns. She browses through all of the data. The bioanalyst returns. "Here is one episode, are there more? It breaks… then the next episode, where it ramps… then it burst." The bioanalyst is supporting the cardiologist in reading the numbers and measurement. They talk about changing the medications. The patient had three incidents since March—they could ask the local hospital. […] The cardiologist decides to telephone the patient, asking him to contact the local hospital." (Observation, May, 2009)

In the above snapshot, we see the processes involved in interpreting ICD data when the patient and the healthcare professionals are geographically distributed and telemonitoring technology is applied. We see that the interpretation of the patient's condition based on the ICD data requires profoundly varying amounts of work from the healthcare professionals. In some situations the condition of the patient is routinely and reliably determined based solely on the incoming data from the ICD. The healthcare professionals need no additional information to take proper action, and therefore no contextual information describing the patient in further detail is called upon. However, in other cases, the bioanalyst selects particular patients, who she decides to discuss with the cardiologist.

In the cases where the ICD data indicate problematic situations influencing the life of the patient, the geographical distance between the healthcare professionals and the patient complicate the interpretation practice. In the snapshot, we see how the bioanalyst and the cardiologist together interpret the ICD data through discussions and arguments. During the selected episode, the two healthcare professionals debate whether to change the medication of the patient; however, they lack access to the existing medication of the patient. The updated information about medication is in the local hospitals treating the patient. Exchange of medication information is clearly an issue for the people involved in the monitoring and treatment of patients with ICDs. In most cases, the exchange of information is done with the patient as a medium, transporting a folded piece of paper with the current medication record between healthcare professionals. In the case of telemonitoring, it is clearly problematic that the healthcare professionals do not have access to medication information, and in the episode reported here, they decide to telephone the local hospital for the information. However, further in the episode, it also becomes clear that they do not have access to change the medication. Changing medication is, in collocated settings, done by the cardiologist writing a prescription for the changed medication and handing this piece of paper to the patient. This is not possible in the telemonitoring situations. Given this complexity, the episode ends with the cardiologist deciding to telephone the patient and asking the patient to contact the local hospital. Here it is clear that the responsibility for taking initiative based on the interpretation of the data is distributed to the patient. In addition, this results in the patient receiving the complex task of explaining to the local hospital why he or she is contacting the local hospital. What was the issue with the ICD data, since the patient is contacting the hospital?

We see here how the entangled interpretation processes become detached from each other in the telemonitoring situation. In the collocated setting there were naturally attached connections between the numbers, the general condition, and the patient's interpretation; the distributed setting is distinctly different in the way that the collaborative effort from the patient is missing, thus the two interpretation processes concerning the general condition and the patient interpretation disappear, increasing the complexity in interpreting the ICD data for the healthcare professionals.

### Implications for Design: Interpretation Involves Three Entangled Processes

In our empirical study, we found three main processes involved in the practice of interpreting ICD data. First, interpreting ICD data involves processes where healthcare professionals direct their attention toward the actual numbers, figures, tables, graphs, percentages, and diagrams represented on a computer screen or printed out on paper. We will label this process *interpretation of numbers*. Second, we found that interpreting ICD data involves processes where healthcare professionals direct their attention toward the patient's general condition by asking the patient questions such as "how are you?" and "what kind of medication do you take?" In this practice, the patient collaborates by presenting the paper version of the medication list in the collocated situation. We will label this process *interpretation of general condition*. Finally, we found that interpreting ICD data involves processes where the healthcare professionals direct their attention toward the patient's own interpretation of both the condition and the interpretation of the ICD data. This process we label *patient's own interpretation of condition and ICD data*.

In the *collocated setting*, these three processes are entangled into one coherent practice of interpretation conducted as a collaborative activity between multiple healthcare professionals and the patient. Moreover, in many of the empirical observations, the patient family—or others accompanying the patient to the Heart Centre—were also included in the practice of interpreting data. Thus, interpreting ICD data is clearly a collaborative activity requiring highly specialized expertise in reading and interpreting the data as well as access to additional information about the patient.

In the *distributed setting*, the three processes of interpretation were not entangled and did not inform each other. Instead, it was clear that the existing telemonitoring system only supported one of the three processes, namely the *interpretation of numbers*. While the interpretation of numbers was adequate in all the cases where no action was required, it proved problematic in more complex cases. To solve these incidents, much detective work was required by the healthcare professionals. It also emerged from our empirical observations that not only did the lack of access to *interpret the general condition* and to the *patient's own interpretation* increase the complexity of the interpretation practices, it also shifted the responsibility for acting on the problematic condition detected by the healthcare professionals' interpretation of the ICD data.

The effort required for interpretation and investigation in the *telemonitoring setting* varies between cases, but in general two types of patient groups were detected. The largest group of patients, Group A, comprises cases where the bioanalyst decides that the ICD data are *sufficient* as information to determine the appropriate action. The smaller group, Group B, are patients where the bioanalyst decides that the ICD data are *deficient* as information to determine the appropriate action, thus additional information is required.

For the Group A patients, telemonitoring seems to work well, and each "visit" takes less time than if the patient were physically present. The more complicated cases, however, take much detective work to solve. Thus, patients in Group B are the group of patients that take by far the most resources in the telemonitoring setting.

Based on the above study of the work practices involved in the interpretation of ICD data, we found that our design should re-introduce the patient into the collaborative interpretation practice in the distributed setting in order to re-convene the two interpretation processes that disappeared with the telemonitoring setup: *patient's general condition* and *patient's interpretation of own condition and ICD data*. Moreover, the design should support the interpretation work, especially in the cases of patients in Group B, which are the most resource-demanding cases of interpretation.

## Intervening Through Design

Informed by the implications for design, myRecord[iv] was designed and built as an add-on, patient-centric web-application with the intention to actively re-engage the patient in the process of interpretation, and, in particular, the processes of *patient's general condition* and *patient's interpretation of own condition and ICD data*.

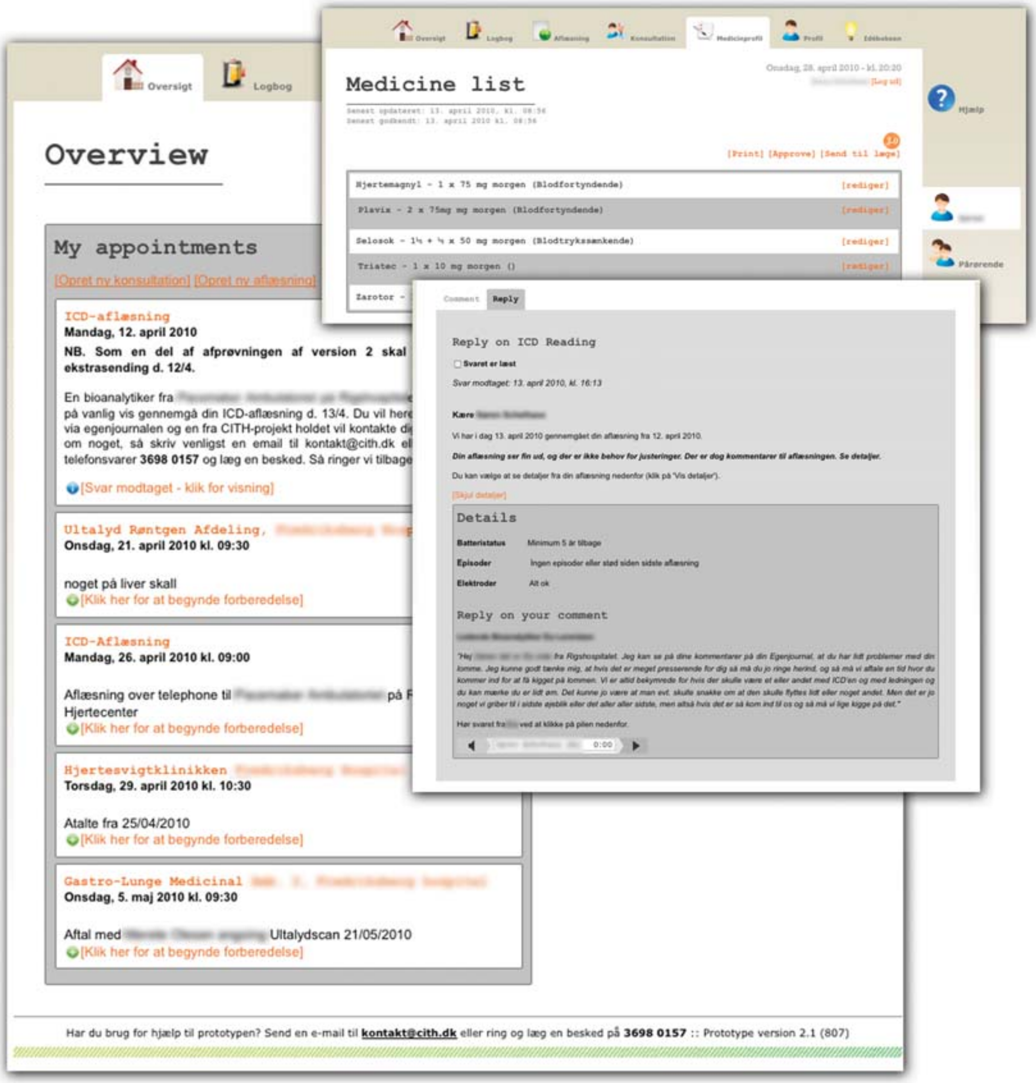
With myRecord, we enable patients to flag attention, write in free text, and select medical categories to communicate their experienced symptoms. Patients can also create and approve their own detailed list of medicine, which then becomes available to the remote healthcare professionals. The bioanalysts and cardiologists can dictate messages and provide additional ICD data as a reply to the patients' comments and ICD transmission. In this way it supports asynchronous dialogue where patients' interpretation gets re-introduced though text and medical categories, while the healthcare professionals can respond by audio and text. With the design, we attempt to transform the current telemonitoring setup into a shared practice of interpretation, which employs the patient's own individual interpretation. By implementing myRecord into to the distributed practice of interpretation, we intervene to explore and experiment with a re-organized telemedicine practice. In the following we present the modules of myRecord that make use of the insights from the process of understanding interpretation work.

## myRecord's Modules

There are two modules of myRecord that support the interpretation of general condition and patient's interpretation of own condition and ICD-data (see Figure 2):

- Medicine List – a module with a patient-generated, detailed, web-based list of medicine, which is editable and approvable by the patient.

- ICD Readings – a module with a list of all scheduled ICD readings. Each reading includes a component where the patient can enter three levels of contextual information: 1) flag attention, 2) describe lived experiences in free text, and 3) communicate symptoms using medical categories. Additionally, each patient can access the healthcare professionals' reply as audio, text, as well as a limited amount of ICD data values.



Overview

My appointments

[Opret ny konsultation] [Opret ny aflæsning]

ICD-aflæsning
**Mandag, 12. april 2010**
**NB. Som en del af afprøvningen af version 2 skal**
**ekstrasending d. 12/4.**

En bioanalytiker fra [redacted]
på vanlig vis gennemgå din ICD-aflæsning d. 13/4. Du vil her
via egenjournalen og en fra CITH-projekt holdet vil kontakte di
om noget, så skriv venligst en email til kontakt@cith.dk el
telefonsvarer **3698 0157** og læg en besked. Så ringer vi tilbage

[Svar modtaget - klik for visning]

Ultalyd Røntgen Afdeling, [redacted]
**Onsdag, 21. april 2010 kl. 09:30**

noget på liver skall
[Klik her for at begynde forberedelse]

ICD-Aflæsning
**Mandag, 26. april 2010 kl. 09:00**

Aflæsning over telephone til [redacted] på
Hjertecenter
[Klik her for at begynde forberedelse]

Hjertesvigtklinikken [redacted]
**Torsdag, 29. april 2010 kl. 10:30**

Atalte fra 25/04/2010
[Klik her for at begynde forberedelse]

Gastro-Lunge Medicinal [redacted]
**Onsdag, 5. maj 2010 kl. 09:30**

Aftal med [redacted] Ultalydscan 21/05/2010
[Klik her for at begynde forberedelse]

Har du brug for hjælp til prototypen? Send en e-mail til **kontakt@cith.dk** eller ring og læg en besked på **3698 0157** :: Prototype version 2.1 (807)

Medicine list

Senest opdateret: 13. april 2010, kl. 08:56
Senest godkendt: 13. april 2010 kl. 08:56

Onsdag, 28. april 2010 - kl. 20:20
[redacted] [Log ud]

[Print] [Approve] [Send til læge]

| | |
|---|---|
| Hjertemagnyl - 1 x 75 mg morgen (Blodfortyndende) | [rediger] |
| Plavix - 2 x 75mg mg morgen (Blodfortyndende) | [rediger] |
| Selozok - 1½ + ½ x 50 mg morgen (Blodtrykssænkende) | [rediger] |
| Triatec - 1 x 10 mg morgen () | [rediger] |
| Zarotor - | |

Reply on ICD Reading

☐ **Svaret er læst**

*Svar modtaget: 13. april 2010, kl. 16:13*

**Kære** [redacted]

Vi har i dag 13. april 2010 gennemgået din aflæsning fra 12. april 2010.

***Din aflæsning ser fin ud, og der er ikke behov for justeringer. Der er dog kommentarer til aflæsningen. Se detaljer.***

Du kan vælge at se detaljer fra din aflæsning nedenfor (klik på "Vis detaljer").

[Skjul detaljer]

Details

| | |
|---|---|
| **Batteristatus** | Minimum 5 år tilbage |
| **Episoder** | Ingen episoder eller stød siden sidste aflæsning |
| **Elektroder** | Alt ok |

Reply on your comment

[redacted]

*"Hej [redacted] fra Rigshospitalet. Jeg kan se på dine kommentarer på din Egenjournal, at du har lidt problemer med din lomme. Jeg kunne godt tænke mig, at hvis det er meget presserende for dig så må du jo ringe herind, og så må vi aftale en tid hvor du kommer ind for at få kigget på lommen. Vi er altid bekymrede for hvis der skulle være et eller andet med ICD'en og med ledningen og du kan mærke du er lidt øm. Det kunne jo være at man evt. skulle snakke om at den skulle flyttes lidt eller noget andet. Men det er jo noget vi griber til i sidste øjeblik eller det aller aller sidste, men altså hvis det er så kom ind til os og så må vi lige kigge på det."*

Hør svaret fra [redacted] ved at klikke på pilen nedenfor.

[redacted] 0:00

Figure 2: Illustration of myRecord's modules. Overview (home screen), Medicine List and ICD Readings are shown.

### The Medicine List

With the Medicine List, patients can create a digital version of their medicine list, which most patients already have in memory or carry around on a piece of paper. It is designed to function as an up-to-date, online, shareable version of the patient's medicine list, thereby providing healthcare professionals as well as patients themselves with an overview of what medication they currently take. It is a simple, web-based list, which the patient can manually update by typing in information on each drug: name, strength, reason for prescription, amount, etc. For each drug, the patient can also record experienced side effects and discrepancies. The whole list is printable and has an "Approve" button, which timestamps the list to indicate when the patient has reviewed and approved the list. For reasons of supporting a shared practice of interpretation, distant patients can use the list to communicate important information concerning their status of medication to the healthcare professionals, which, in the collocated setting, was done through the patient's own paper list of medication.

### ICD Readings –Three Levels of Contextual Information

ICD Readings is a module of myRecord that is designed specifically to support a collaborative interpretation process for both patients and healthcare professionals. It holds a list of all previous and future scheduled ICD readings where each reading links to a page that has two components. One component, "Comment Your Reading," is designed to let the patient enter contextual information on three levels after having made the transmission, whereas the other component, "See Reply," is designed to let patients access the healthcare professionals' reply as audio, text, as well as a few selected ICD data values. The "Comment Your Reading" component consists of three nested levels of contextual information. Initially, the patient is asked: *"Has your situation worsened or are there significant changes since the last reading?"* The patient then chooses either to click the button "Save and Send" (thereby communicating that everything is OK) or to mark that the situation has changed, wherein expanded possibilities for explanation are revealed. We title this the "first level of contextual information" since the patient has the option to "Flag Attention" and thereby, with little effort, express that he or she is aware of something in relation to the ICD reading that needs the attention of a healthcare professional. At the second level of contextual information, the patient can describe their experience in free text. This option provides patients with the opportunity to use individual wording, expressions, and ways of formulating their interpretation of own condition and ICD data. The last step is the third level of contextual information. It consists of three text fields where the patient can enter their morning weight, blood pressure, and heart rate. It also includes nine sets of checkboxes where the patient can select medical symptom categories such as “chest pains,” “shortness of breath,” or “fainting” and whether it appears during heavy or light physical exercise, under no physical exercise, etc.

The final component presents the healthcare professionals’ reply to the reading, i.e., the result of the interpretation. The component is two-fold, showing both a standard reply on the reading (i.e., everything is fine, please contact us, etc.) and selected values from the ICD reading. The selected values are “battery level,” “detailed information on episodes” (if any), including date, time, and type (pacing or shock), and a statement on the “status of the electrodes.” The statement on battery level falls into three categories: at least five years left, at least two years left, and at least three months left. The last category indicates that a replacement of the battery should be scheduled within the following couple of months (the battery is replaced by renewing the whole ICD). Moreover, the healthcare professionals can, as mentioned, dictate a personal audio reply that is automatically transcribed and presented textually within this component.

## Evaluating the Intervention

The intervention was carried out over a period of four weeks and included 23 ICD patients. All patients were scheduled for an extra ICD transmission with the telemedicine setup, and 21 managed to use myRecord to engage in the new collaborative practice of interpretation. One patient was unable to carry out the task because of a re-scheduled vacation and another excluded himself from the study by neither making a transmission nor using myRecord. We tested myRecord at the Heart Centre by observing transformations of the current distributed interpretation practice by requiring the healthcare professionals to take the patients' recordings into account *after* their initial interpretation of the ICD data. In this way we were able to observe how the patients' recordings changed the current telemonitoring practice. The observations of the healthcare professionals' use of myRecord took place over two days at the Heart Centre.

### Hidden Group B Patients Revealed

Nearly half of all patients from the experiment (10 of 21) were classified by the bioanalyst as Group A patients ("nothing to note" or "everything looks fine" and therefore resulting in a "no action is needed" reply). In these cases, the bioanalyst based her interpretation solely on the transmitted device data, thus only on the *interpretation of numbers process*. Every patient in this group also used myRecord to signal whether or not their situation had changed. They therefore completed the use of myRecord with no messages and no pre-answered questions for the healthcare professionals. During the experiment, this relatively small piece of patient-produced information (flagging no attention) proved to work as an additional confirming statement that reassured the bioanalyst of her original conclusion. Thus the patients' statement on their own condition (no news to report) together with the bioanalyst's original interpretation based on the numbers formed a simple collaborative interpretation practice. The bioanalyst could, with added confidence, continue her work based on a more informed and qualified decision.

In the cases where the patient "flagged attention," it also impacted the work of the bioanalyst. In cases where the bioanalyst initially concludes "no action needed" based on the device data alone, she immediately decides differently when confronted with the patient's written remarks in myRecord. One example is a patient who writes: "*I sometimes feel tender in the area where the ICD sits. It might just be me whining, but it feels as if it's the electrode* [the lead connecting the ICD to the ventricle of the heart] *that's attached to the vein. It pinches me*" (man, age 56). The patient's remarks and the indication that it might have to do with the lead causes the bioanalyst to respond by dictating a message to him, where she explains, "*from your comment I can see you are having some problems with your pocket* [the implanted ICD is hidden in a little pocket-like breach in the chest]. *We are always concerned about the condition of the ICD and the leads, and you feel a little sore. We might talk about moving it a little*" (bioanalyst's dictation, April 2010). This scenario illustrates how information from the patient describing an aspect of his own condition triggers and helps the healthcare professional to provide the patient with a calming answer, and it also provides an opportunity to teach the patient how to manage and react to important symptoms. Moreover, we see that the use of myRecord spurs a collaborative effort between the patients and the healthcare professionals.

In another case the bioanalyst initially classifies a woman (age 62) into Group A, but changes her mind based on the patient's information from myRecord. The patient documented in myRecord that she had experienced a "fluid alarm" on two specific dates. The bioanalyst quickly locates the date within the numbers and graphs and reiterates the values in her system to conclude the patient is right. As a reply to the woman's experience, the bioanalyst makes an elaborate dictation, explaining how the patient should stay alert the coming week by tracking her weight and contact her GP if the situation changes.

The three examples illustrate how the patient's own interpretation of condition and ICD data mediated by myRecord can have important consequences for the practice of interpretation. The patients' decision-making and ability to formulate their experiences provide the basis for establishing a remote collaborative process of interpretation.

### Sufficient Contextual Information

In the evaluation of myRecord, we found that several patients made use of the healthcare professionals' pre-made symptom categories as a means of communicating their experienced symptoms. When patients use the symptom categories they collaborate by making sufficient contextual information available for the bioanalyst and the cardiologist so they can make an informed decision.

In one case the bioanalyst classifies a patient into Group A based on device data. The patient writes: "*under physical training at RH Monday [date] in the period around 3.15pm-3.45pm – several near-syncopes and palpitation*" (man, age 61). Here the patient describes loss of consciousness and abnormal heartbeats. The patient also asks questions about the ICD data at particular times. This information makes the bioanalyst re-examine the device data, conclude that nothing is recorded, and explain that the patient's experience is not visible in the transmitted data. She then revisits his recordings in myRecord and finds the patient's selection of two medical categories (level 3): *"Heartbeats – Yes, under high physical activity" and "Near faint – Yes, under high physical activity"* (man, age 61).

This information changes the bioanalyst's previous decision. She navigates to the values in the patient's device data, which describe what zones the patient's ICD is programmed to monitor. She uses the patient's textual description and selected categories to conclude that the monitor zone is not set up to record the patient's experienced event. She calls a physician for support and collects the device paper record. When the physician arrives, they use both levels of the patient's contextual information and compare it with the device data and information from the device paper record. They conclude and dictate two messages where they explain that his device is not programmed to monitor what he experiences, and they recommend that he make an appointment at the Heart Centre in order to adjust the monitor zone. As such, the patient's work of questioning and informing the bioanalyst and the cardiologist rightly impact the result of the interpretation process. The patient succeeded in providing sufficient contextual information to support the healthcare professionals' work of re-interpreting the device data.

### ICD Data Made Understandable

In the case of a woman (age 56) classified by the bioanalyst into Group A, the bioanalyst selects the device data to be presented in myRecord and notes that a replacement of the battery might soon be required. She therefore chooses the label "minimum 3 months left" in myRecord. The bioanalyst decides to use myRecord to dictate a message where she explains in more detail the reason behind the label and how the patient is to manage the situation "when the device starts beeping." The bioanalyst dictates, *"We can tell from your ICD that you'll soon start beeping. It may be within the next six months to a year or even 1.5 years. But because the value of the battery decreases in stages, we cannot say exactly when it will be. You should just be aware that when it 'beeps,' you should call us. Then there are three months left on the battery before we need it changed"* (bioanalyst's dictation, April 2010). The situation is interesting for two reasons. Prior to the introduction of the new telemonitoring practice, patients were (in the collocated setup) informed about the level of battery left on their device, and, in the case of "3 months left," they were given guidance and explanation similar to the above example. However, upon the switch to the new practice, the Heart Centre decided not to inform patients on their battery level because, as the bioanalyst explains, *"it's simply not doable for us if we were to phone every patient upon every ICD scan, just to inform them on their level of battery. They already know that* *they should call us if their device starts beeping*" (bioanalyst's dictation, April 2010). The healthcare practitioner knows from previous experience that labelling batteries "at least three months left" often causes anxiety and confusion for some patients. But the distributed nature of the telemonitoring practice has forced them to skip informing patients about batteries to avoid overhead work. The case illustrates how the new design holds the opportunity to re-introduce important but otherwise disregarded elements of the interpretation process. Specifically we see how the dictation feature in myRecord serves additional purposes, for example, as a feasible and convenient way to communicate important messages while still preserving the benefits of asynchronous verbal communication. Patients are thereby helped in interpreting their own condition by ICD data being made (more) understandable.

### Support for Patient's Own Interpretation

During the evaluation we found that some patients used myRecord to support their own work of interpretation and self-diagnosis. Instead of simply commenting on experiences to aid the bioanalyst's reading of device data, some patients used myRecord to ask the bioanalyst to provide device data to them.

In one case a man (age 60) flags attention and asks how much his ICD has paced since last transmission. The bioanalyst responds by dictating an answer where she includes the value and that it is her interpretation that the ICD probably paces at night. Another patient writes: *"Have NOT heard ALARM the last two mornings (after continuous alarm in 51 days) – is it correct? (Or have I become more deaf and/or battery flat?)"* (man, age 62). The bioanalyst revisits the ICD data and responds by dictating a message where she confirms that the alarm has been off the past two days and calms him by telling him not to worry.

In another situation the bioanalyst found an episode in the ICD data. The patient (man, age 65) also flagged attention and described his experience and the date of the episode (using both the free text and the medical symptom categories). However, the event in the ICD data is different, and the bioanalyst decides to record a message where she recommends that he make an appointment with the Heart Centre to get his ICD re-programmed with an extra feature. The reply included the date and time of the recorded episode. We later learned that the patient himself correlated the time of the recorded episode with an incident where he was asked to "give it all you got" in a cardiac stress test in another research project. He later informed us: *"This is therefore a situation where I gave myself physically to the fullest. [The physician] said that I could safely engage in physical exercise. The question now is: Can I?"* (man, age 65's logbook entry in myRecord, April 2010). In this way the bioanalyst's reply supports his own interpretation and makes him actively question his treatment and the advice of the physician.

### Use of Medicine List

The paper-based medication list was an intricate part of the interpretation practice in the collocated setup. The patient would carry the folded piece of paper with the medicine information to the Heart Center and this information would be included in the interpretation process. In the telemonitoring setup the healthcare professionals lack access to the medication list. In myRecord we designed for patients to create, update, and approve an online shareable Medicine List with the ambition to test whether this list could support the healthcare professionals in their interpretation practices. Surprisingly, we found that bioanalyst purposefully disregarded the Medicine List doing the evaluation. In one case, a patient (woman, age 60) was initially classified in Group A by but in myRecord she flagged attention. In the free text field she explains that her medicine was changed by her local physician. She also provides a full list of her current medication. The bioanalyst does not even glance at the Medicine List but immediately records a audio message: *"[…] Hi [ the woman's name], it's about the comment you wrote in myRecord about your medication. I can only say yes / OK for it, since we do not interfere with what they do in research [another medical research project]."* (bioanalyst, dictation in myRecord, April 2010). In this way, the bioanalyst explains the responsibility related to medication changes and does not use the information in the list. During the intervention the bioanalyst explains about the use of medication informations:

*"So, our problem right here is that, we type all [medication information from the patient's medication list] into [a medicine management system] and then we go to the ICD Registry [national online ICD/pacemaker information] and type it again. (…) If the patient is physically present we always ask: 'what medication do you take?' The problem is that we don't [type in medication information] in the [telemonitoring setup], because we can't telephone each patient and ask about their medication. We [bioanalysts in the telemonitoring setup] don't use [medication information] for anything; it is only for physicians that might need [the information]"* (bioanalyst, observation, April 2010).

In this quotation the bioanalyst explains how the telemonitoring setup changed the practice surrounding medication, by re-organizing practices to disregard medication information because of the lack of access to this type of information. The absent patient caused absent medication information, thus forced the bioanalysts to skip the task of updating the national ICD registry. We found that in the telemonitoring setup, it was only the cardiologists who were interested in medication information, where in the collocated setup it included the bioanalytists. However, during the small sample of where the healthcare professionals had access to medication information using myRecord, we did not see any cases where the cardiologist asked for the medication list. However, this might be due to the previously changed practices caused by the telemonitoring setup, where the cardiologist had learned to do without such information, since these were not available. More studies are required to determine whether medication information is essential or not during telemonitored interpretation practices.

## Discussion

In our study, in the same way as Bardram et al. [15], we investigate the transformed practices caused by telemonitoring, and as Bardram et al., we see how the rich collocated conversations between the patient and the healthcare practitioners were reduced – not to asynchronous messaging as Bardram et al. found – but to one-way communication of sending bodily device data and getting a short reply. The previous collaborative process of interpretation in collocated settings was reduced to data transmission. However, whereas the latter study [15] found that the patient became more involved in the interpretation of the data, our study showed the opposite. Namely, our study showed that the patient became passively disengaged and more distant from the data interpretation process. This disengagement due to the socio-technical setup of telemonitoring affected the ICD data interpretation practice by neglecting the patient’s vital role in general, and in particular, the patient’s own interpretation of the general condition and the ICD data. Interestingly, we found that that disengaged patient was problematic for the healthcare practitioners because they lacked essential information for interpreting the data, in particular, for the Group B patients, where the available device data was not sufficient to determine the appropriate action. Our design intervention was designed specifically to deal with this problem, bringing additional contextual information to the healthcare practitioners supporting the ICD data interpretation and re-introducing the patient as a collaborative partner. In the evaluation of the design intervention, we found that myRecord did provide additional useful contextual information enabling the decision for appropriate action for the Group B patients. In this way our design did make the work of interpretation more collaborative; however, we question if this re-designed practice (where the patient contributes with additional information) can be labelled as collaboration or as mere transmission of more data?

If we look at the three different levels in which the patient can provide the additional contextual information within myRecord, one could argue that simply flagging attention or filling out the medical categories are practices where the patient simply delivers more data and not an act of collaboration. Collaboration requires that the actors are mutually dependent in their work [1], thus the question is whether the patients and the healthcare practitioners are mutually dependent on each others’ actions? Given that the healthcare practitioners were able to conduct their work before the introduction of myRecord without any involvement of the patient beyond providing the bodily data, one could argue that the patient and the healthcare practitioner were not mutually dependent in their work prior to myRecord. However, with the introduction of myRecord, when the patients flag attention, they change the state of their individual work (their involvement in the data interpretation is not simply providing bodily data). The question, then, is whether this individual activity (flagging attention) also changes the state of the work for the healthcare practitioners and thus the common field of work? During the evaluation of myRecord we saw how patients originally categorized as belonging to Group A (sufficient information) where moved to patient Group B (deficient information) by the bioanalyst as a result of the flagging attention, as was the case with the ten patients who chose not to flag attention. This points to how even a small amount of information can change the state of the common field of work. The collaborative aspect of the common field of work (the ICD data interpretation) is thus re-introduced by our design intervention. However, it was also clear that the patient's active role in the new transformed collaboration practice comes in different forms depending on the level of involvement the patient chooses.

At the lowest level of involvement the patient simply flags attention, which is used by the healthcare practitioners to re-evaluate whether their initial categorization of the patient is accurate. Then, at the second level, the patients have the opportunity to express, using their own language, what they think might be relevant for the ICD data interpretation practice, and at the third level, the patients volunteer their own diagnosis of their condition, applying the professional medical language of the healthcare practitioners. There is no question that all of these levels of involvement change the state of the common field of work, therefore they are all part of the collaborative practice. However, we saw how the collaborative practice took different forms.

We saw that, in the case of Group B patients (where the ICD device data are insufficient to make a decision), the additional contextual information provided by the third level of information (the standardized medical language) was sufficient for the healthcare practitioners to make a decision, as in the case of the patient (man, age 61) who used the medical symptom categories. In this way, the collaborative interpretation practice ends quickly with a decision of appropriate action. While this form of collaboration was intended by our design, we also detected two other intriguing forms of collaborative activities caused by our design: inclusion work and self-diagnostic work.

*Inclusion work* is work that healthcare professionals do when educating the patient outside of training sessions, such as comforting and reassuring patients about their abilities to master new technology, thus turning potential non-users into users [18, p. 280]. Inclusion work for ICD patients includes telling the patients how to react to different alarms set off by the ICD, for example, fluid or battery alarms. In the collocated setting, inclusion work is an embedded part of the collaborative interpretation that unfolds in joined conversations with the patients at the Heart Centre. However, in the distributed telemonitoring setting prior to the introduction of myRecord, inclusion work disappeared from the ordinary activities. With the introduction of myRecord, we unexpectedly found that inclusion work was re-introduced, for example, in terms of explaining ICD battery state. Here, based on her experiences with patients' misunderstandings, the healthcare practitioner translated the ICD battery state, "at least three months," into understandable language for the patient within an audio recording using myRecord.

*Self-diagnostic work* is the work involved when the patient is actively engaged with the diagnostic work usually done primarily by the physicians. This type of work serves to distinguish and identify how particular bodily experiences can be interpreted. When the patients were asked to apply the standardized medical categories within myRecord to determine the current condition of their health, they were asked to be a part of the diagnostic work. We saw that patients took this task seriously. Besides providing additional contextual information, they also took an active role using myRecord and asked the healthcare practitioners direct questions, for example, to confirm their own interpretation of a stopped alarm or to use the ICD data to question physicians' recommendations.

We argue that the socio-technical setup of myRecord re-introduces the critical role of the patient, thus bringing back the collaborative aspect of ICD data interpretation practices. The consequence of this re-introduction is that the patient is situated as a diagnostic agent and the two processes, interpretation of general condition and patient's own interpretation of condition and ICD data, which were otherwise lost in the distributed setting, reappear in the telemonitoring setting through the design intervention myRecord. By intervening, we probe into ways of re-positioning the patient as a reliable and valuable diagnostic agent, thereby challenging the dominant logic of care [33] while still maintaining the benefits of remote monitoring in terms of saving time for patients and healthcare professionals. Patients are re-introduced as technologically empowered actors with increased expectations toward taking part in their own treatment. The patients become actively engaged and are expected to take on an increased workload to realize the full potential of the new design. The evaluation showed that the majority of the patients were willing to take on that workload, especially in situations where they saw that as a strategy for receiving more elaborate feedback from the healthcare professionals' interpretation. Patient-generated content makes for a new practice that renders patients more responsible, and consequently more disciplined actors [34], with increased expectations of active membership attached. At the same time, however, it raises questions still not fully answered, neither in our study nor in the literature, about the responsibility and pragmatics of healthcare practitioners to act upon critical symptoms provided through designs like myRecord in a timely manner.

## Conclusion

Earlier studies [18] show that including the patient in telemonitoring practices is vital; however, the patient needs time and effort to become a skilled, active, and responsible participant able to engage in the interpretation process. When the patient is reduced to representations such as images and graphs, the essential cooperative potential between the healthcare practitioner and patient when interpreting the ICD data collocated disappears. The invisible work of the patient involved in interpreting practices is missing. While the reduced representation might be adequate in some situations, it seriously "disables" the data interpretation process in situations of uncertainty. Here the patient's active role as diagnostic agent is needed so that the representation becomes adequate "to speak" for the patient [19]. We designed myRecord to re-involve the patient in the interpretation process by providing the patient with the opportunity to add contextual information to the partial representations captured and measured by the ICD-monitoring system.

New technologies involved in the monitoring and treatment of chronic heart failure patients with ICDs make it possible to transform the previously local practices of interpreting ICD data into a globally distributed activity where the patient and healthcare professionals are geographically distributed. However, before embracing these new opportunities, we must examine the existing local practices of interpreting ICD data, ensuring that the new technologies enable rather than constrain these practices. Based on our observational study, we conceptualize the ICD data interpretation practice as three entangled processes: *1) interpretation of numbers, 2) interpretation of patient's general condition, and 3) the patient's own interpretation of general condition and ICD data.* Moreover, we found that the current telemonitoring system only supports the first process of interpretation, leaving out the two others.

Our socio-technical design intervention re-introduces the patient and takes the collaborative aspect of the interpretation practice seriously. We saw how our design intervention managed to include the two otherwise lost processes of ICD data interpretation, as well as how the patients went from passive bodily device data sources to active diagnostic agents. We believe that this approach to increase the participation of the patients in telemonitoring situations forms the future for improving telemonitoring practices. Previous studies of what gets lost in the design of telemedicine point to the invisible, however essential, work of combining various information artefacts into a coherent whole [18, 19]. In our design intervention, we try to bring back the invisible work done by the patients during ICD data interpretation, thus taking seriously what was otherwise lost in telemonitoring.

## Acknowledgments

Co-constructing IT and Healthcare (CITH-project) is a 4-year project funded by a grant from The Danish Council for Strategic Research #2106-07-0017" and involve partners from IT-University of Copenhagen, Danish Technical University, Copenhagen Business School, Copenhagen University, and Copenhagen University Hospital.

### Conflict Of Interest Statement

Authors and participants in this study took part by they own free will. There were no financial or personal relationships involved. It should be noted that due to the nature of this study the evaluators are also the designers of the IT application as well as the changed work practices.

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## Notes

[1] Action research typically involves cycles: problem identification, planning interventions, executing actions, observing the outcome, reflecting upon the results, while simultaneously collecting data about the situations and the interventions [31].

[1] Anti-Tachycardia Pacing (ATP) is a fast-pacing treatment for ventricular tachycardia (VT).

[1] Ventricular Tachycardia (VT) means fast heart rhythm and is potentially life-threatening because it may lead to sudden death.

[1] Ventricular fibrillation (VF) is an uncoordinated contraction of the cardiac muscle of the ventricles in the heart. It is a medical emergency requiring immediate interventions due to high risk of sudden cardiac death.

[1] myRecord is a prototype of a patient-centric web-application that includes multiple features. To mention some, there is a module entitled 'LogBook,' which is designed for patients to keep an online diary, record symptoms, and write and organize their anamnesis. Another module, 'Profile,' enables patients to manage contacts, preferences, and personal information. A third module, 'Consultations,' is designed for patients to prepare for consultations, thereby qualifying both cardiologist and patients for a better dialogue.

# Paper IV

# The Patient as Co-Creator

Moll, J. (2010). ***The Patient as Service Co-Creator***. Participatory Design Conference 2010 – Participation :: The Challenge (PDC2010), Sydney, Australia, November 29, 2010 – December 3, 2010. pp. 163-166.

## Abstract

This paper reports on insights from designing support for patients as participants in their own treatment and care. Informed by the notion of *service*, the paper illustrates how the new design reconfigures the role of patients to stage a more participatory and co-created practice of care. By conceptualizing the *patient as service co-creator*, the paper then explores the consequences and opportunities of this reconfigured role.

## Introduction

To actively involve patients in their own treatment and care and to design for increased participation in decision-making activities are today considered imperatives of future health care research and design (Pilnick et al., 2009; Pritchard & Hughes, 1995). This is not least driven by a political and economic call for better use of resources and the desire to reduce costs (Berg, 2002). Central to the discourse are the promotion of the patient as a potential collaborating and resourceful partner in own disease management. Often referred to as the *active patient* (Swan, 2009). Participation, in the sense argued for by Kensing and Blomberg (1998), thus becomes a central concept to work with when (re)designing health care services (Thompson, 2007).

As we query into ways of redesigning modern health care, we simultaneously query into ways of reconfiguring the role of patients. Roles and responsibilities that are reconfigured in significant ways, when designing for increased participation. The paper illustrates how the role of the patient is changed in significant ways when the patient is staged as an important and collaborating actor. Informed by recent research on service-oriented design and organization of resources (Bryson et al., 2004; Kimbell & Seidel, 2008; Miettinen & Koivisto, 2009) this paper explores the consequences and opportunities of designing for increased patient participation. Thinking through the lens of *service* the paper offers an understanding of this re-configured role by conceptualizing the *patient as service co-creator*. The changed role is then analyzed through the lens of service, whereby the changed and restructured work of patients can be recognized as activities of *value co-creation*.

The central argument of the paper is that thinking through the lens of service invites novel analytical insights on designing for increased patient participation. Through an empirical case the paper reflects on how support for patients to act as participants can be designed and brought into being in ways that brings forth interesting aspects of a more collaborative practice of care.

## Background and Research setting

The paper reports on a participatory design research project[6] in which a patient-centric personal health record (PHR) is designed (Kaelber et al., 2008). The research project explores the collaborative practices involved in disease management of remote monitored heart patients living with implanted advanced pacemakers. Essentially, the PHR in our project is a prototype of a patient-centric, collaborative, web-based tool, that enable patients to produce, collect, exchange and share their health related information. The prototype aims to support chronic heart patients in being actively involved in their own treatment and care by structuring and mediating collaboration between patients and their health professionals. Driven by our wish to explore and experiment with a reorganized practice, we intervene into the distributed health care settings with the prototype. The interventions have spanned a period of nearly two years, in which, patients, health professionals and researchers have been co-designing and trying out different evolving versions.

## Designing for Service

Before we explore the ways in which the prototype supports and configures patients as co-creators of the health care service, this section briefly presents the basic points of the service notion and the concept of *value co-creation*, which is central to the service discourse.

As argued by Swan, an important implication “of emerging patient-driven health care models are that a collaborative co-care model is starting to evolve for health care delivery”. A model in which the role of patients may “become one of active participant, information sharer, peer leader and self-tracker, while the physician’s role may become one of care consultant, co- creator and health collaborator.” (2009, p. 520).

Drawing on work in economics, sociology and marketing Vargo and Lusch (2004) point to a shift in the models of economic exchange. A shift away from a goods-oriented, output-based model, “away from tangibles and toward intangibles, such as skills, information, and knowledge, and toward interactivity and connectivity and ongoing relationships” (2004, p. 15). They conclude their work by proposing “a more appropriate unit of exchange” which emphasize “the application of specialized knowledge and skills” as the fundamental unit of exchange. Vargo and Lusch refer to this shift in perspective as a “service-dominant logic” (2008) and argue for a different mode of thinking about how value is created in modern, dynamic relations between customer and supplier, or

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[6] More information on the project website www.cith.dk.

in this case between the patient and the health professional. In other words they argue for an understanding of value being created in use.

Building on the work of Vargo and Lusch (2004; 2008), Kimbell (2009) points out that the concept of service “foregrounds the application of one’s resources for the benefit of another”, but the “fundamental exchange is service for service in a dynamic process. Instead of value being embedded in objects through a value chain, value is created through exchanges of service in value constellations or value-co-creation systems” (Kimbell, 2009). The co-creation of service then happens through interactions between service providers and recipients, often these interactions are mediated by technology (Blomberg, 2009).

Gutek (1995) illustrates how we can apply the service notion as a lens to make sense of health care activities. Think of the common relationship between a physician and a patient. The physician provides advice and treatment in service of the patient and the patient makes use of the physician’s service. Without the interaction between the patient and the physician there would be no service. Service is then only rendered in use, when both parties perform their roles and actions. An aspect, which foregrounds a central element of the service notion. Namely, as services are rendered in use the consumers of service are often themselves actively involved in the process of creating and maintaining the same service (Gutek, 1995). An implication of the service mindset is therefore that service is co-created, it is created and used simultaneously (Hollins & Hollins, 1991).

Drawing on Payne et al. (2008) Kimbell (2009) emphasize how the service definition “highlights the role played by customers in co-creating value in the exchange of service. [The] service-dominant logic sees customers, end users, and other stakeholders as always involved in co-creating value”. Services are thus co-created “in practice through the embodied doings and sayings of end users” (Kimbell, 2009). Finally, Blomberg (2009) points to the relation between the core principles of participatory design and the co-creation aspects of service thinking. Hereby, Blomberg (2009) adds to the literature by emphasizing the blurred relationship between participating in activities of design and use.

## Case – The NYHA Preparation Module

The following empirical case summarizes a series of interventions to try out a particular component of the prototype. The case is meant to illustrate how the designed prototype holds the potential to change the work practice and thereby reconfigure the role of patients. The component illustrated here is designed to support patients in communicating symptoms remotely from home. Prior to a consultation with their cardiologist, the patients in our study can use the prototype to prepare for the consultation from home. Upon completion the preparation is digitally send to the health professionals prior to the consultation with the patient. The case here will focus on a specific questionnaire. Informed by our fieldwork we co-designed this together with patients and health professionals.

From our fieldwork on consultations we learned that cardiologists, in order to determine the best course of therapy, use what is called the NYHA[7] classification scheme to determine and assess the stage of heart failure for the patient. The NYHA classification scheme relates everyday activities to specific symptoms, which cardiologists then use to determine if they should change or intervene with the current treatment. The NYHA scheme consists of four levels (NYHA I-IV), ranging from indications of mild, over moderate to severe heart failure. The assessment of each patient in relation to the NYHA classification plays a central part in each consultation, where the cardiologist tries to get an overview of the patient's condition in relation to these classifications.

Guided by our wish to explore how to design support for patients as collaborative participants we co-designed and transformed the classification scheme into a specific set of questions, which each patient would be presented with during their remote preparation. The questions to be presented were developed through a series of workshops, where health professionals from two different hospitals collaboratively worked out the wording and form of the final questions.

In practice this translated into nine sets of check boxes, where the patient can select symptoms such as 'chest pains', 'shortness of breath', or 'fainting' and whether the symptom appears during heavy or light physical activity, during no physical activity, and so on. For each question the patient has to choose one of the four possible categories. Each of which corresponds to a NYHA classification category. The module thereby becomes a way for patients to communicate symptoms using the NYHA-informed categories.

Having introduced the backdrop for case the following will present a situation from the evaluation.

(Evaluation from April 2010)

We are located at the hospitals Heart Centre. The leading bioanalyst is going through the day's telemonitored patients. She (the bioanalyst) initially classifies one patient (a man, aged 61) as "no action needed" based on the available data in

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[7] The New York Heart Association (NYHA) Classification of Functional Capacity and Objective Assessment of Patients With Diseases of the Heart, 1994.

her system about the patient's ICD. Bringing up the prototype she notes that the patient has left a message for her. The message reads:

"*During physical exercise last Monday [date] in the period around 3.15pm - 3.45pm several near-syncopes and palpitation*". (Entry in digital logbook, April 2010)

The patient is describing loss of consciousness and abnormal heartbeats. Reading this the bioanalyst re-examine the device data. She concludes that nothing is recorded in her system and explains that what the patient experiences is not visible in the transmitted device data. She then revisits his recordings in the prototype and finds that the patient has selected two of the NYHA categories:

*"1. Heartbeats – Yes, under high physical activity and*

*2. Near faint – Yes, under high physical activity"*

(Entry in prototype module, April 2010)

This information changes the bioanalyst's former decision. She decides to call a cardiologist for support and arrange for the paper record to be brought to them. When the cardiologist arrives, they together use the information provided by the patient and compare it with the device data and information from the paper record. They conclude and end by dictating two messages, where they explain that the patient's device is not programmed to monitor what he experiences. They therefore recommend that he make an appointment at the Heart Centre in the near future, in order to get his device adjusted.

## Patients Become Service Co-creators

As illustrated through the case, the prototype serves new functions. It serves as a way for patients to communicate symptoms using the classification-informed categories. Important parts of the work that previously took place solely during consultations are now delegated to the patient and the prototype. Thereby, central elements of the NYHA classification work are now done remotely from home by the patient. As the case also illustrates the patient's work of informing the health professionals significantly impact the result of the remote care process. The patient succeeded in providing sufficient information to support the healthcare professionals' work of re-interpreting the device data. This was done by way of the NYHA classification categories. Thereby, the classification categories act as a way for patients to provide information about their own condition in ways that are manageable (Berg, 1997) and ready-to-hand for the health professionals. The patient depicted in the case become co-creator of the health care service. Thus, the work done by patients through the NYHA module becomes a vital part of rendering the service of care. Using the module the patients co-create value for the service. Drawing on the service mindset we can thus reconceptualize the role of patients to that of *service co-creators*, hereby illustrating the analytical advantage that this perspective offers. The reconceptualization allows us to see the relationship between the health professionals and the patients in a new perspective. Namely, as both being co-creators of the same health care service, which acts as a mediator and infrastructure for the collaborative creation of important information for the patient as well as the health professionals. This is achieved by empowering the patient to communicate and express her own condition through the selection of the pre-defined NYHA-informed categories. The information produced and supplied by the patient feeds into the service.

As illustrated with the case a view through the lens of service invites new perspectives on the work of health professionals and patients. Opposed to traditional views on roles and responsibilities, where health care offerings are thought of as being available to the patient upon request. In the traditional view the patient is the passive consuming part, who requests and taps into the knowledge of the health professionals, whereas the professional is the only active and producing part. By employing the service mindset we are encouraged to understand the network of health professionals as a coherent service, which in turn invites a repositioning of the patient as a contributing actor and service co-creator. From being perceived as a somewhat passive receiver of care the patient is then re-positioned as an important source and creator of useful and important information, thus becoming an essential part of the collaborative practice, as also pointed to by other researchers (see e.g. Oudshoorn, 2008). By using the NYHA-informed categories patients collaborate with the health professionals by producing information that enable the health professionals to make informed decisions. By using the prototype important responsibility is delegated to the patient, which in their reconfigured role have to make significant decisions that may have direct impact on their own disease management.

## Conclusion

This paper has argued for the insights gained by adopting a view through the lens of service. It has illustrated how support for patients to act as collaborating participants can be designed and brought into being. The patient as important actor in own treatment and care was then explored through the lens of service, which allowed for a re-conceptualization of the work of patients to be recognized as activities of *value co-creation.* Thereby appreciating the relation between designing the active patient and designing for value co-creation.

## Acknowledgments

The work presented here is part of the larger research project ‘Co-constructing IT and Healthcare’ (CITH) supported by The Danish Council for Strategic Research through grant #2106-07-0017. CITH engages partners from the IT University of Copenhagen, the Technical University of Denmark, Copenhagen Business School, University of Copenhagen, and the Heart Centre at Copenhagen University Hospital. I am grateful to Tariq Andersen, Jeanette Blomberg, and Finn Kensing for comments on early drafts.

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