

Patient-oriented ICT: Policy and practice



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Forord

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Summary

The development of ICT aiming at patient users is a prioritised area in health care. This thesis investigates the policy background for this development, and on the changes that take place when health ICT is introduced to patients. The research draws on a document study from the European health ICT sector and on two case studies where an electronic communication tool was introduced in doctor – patient communication. The findings indicate a discrepancy between expected and actual changes: patients' use of ICT in everyday practice is more varied than the dominant conceptual models of the patient – ICT relationship take into account. The policies express expectations of health ICTs to function as riverbeds of information and thus contribute to realise contemporary ideals of patient involvement and new public management. In everyday practice, however, patients also relate to technology as security alarms, as shields to the pathologising of everyday life, as tokens of competence, and as symbolic attention from the health care system. Patient-oriented ICT does more than is expected of it, and opens for a new flexibility in patients' relationship to health professional advice and care. In some situations patient-oriented ICT seems to matter more for patients feelings of everyday security and for their ability to distance themselves from their illness in everyday life, than for patient involvement in professional care. New patient-oriented ICT might matter on micro, conceptual and structural levels. Studies of how patient-oriented ICT matters require a perspective that is attentive to the active role of users and technologies in micro level practice, but that remains open to discuss the importance of technology to patients on conceptual and structural levels.

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Introduction

The use of ICT in health care has increased steadily since the early 90's/ mid 80's. The background for this increase is complex. ICT is diffusing into all sectors of society, and into the everyday lives of each and every one of us. In the social sciences the significance of ICT in contemporary society is discussed and highlighted through the use of terms such as “the network society” (Castells, 1996), “The information society” (Webster, 1995) and “knowledge societies” (Stehr, 2001). Although the pace might vary, the general use of ICT such as the Internet and mobile phone services are on the rise around the world. This development also has implications for health and health care.

While the early years of health ICT development and policies concentrated on technologies to be used by health professionals, home based health ICT aiming at patient users is now a prioritized area (eHealthNews.eu, 2010). More and more technologies intended for use in patients' homes are being designed. The widespread private use of the Internet for health purposes in western populations has been taken as an indication of a new grass roots phenomenon in health care, indicating a democratic development where lay patients gain power and control on behalf of professional power (Hardey, 1999). However, the growth of patient-oriented ICT is not only a grass roots phenomenon deriving from patient needs. When outlining the background for this development, the health care system's struggle to cope with demand is also highly relevant. In spite of large economic investments the pressure on the health care sector continues to grow. Demographic changes lead to larger elderly populations and hence also more (elderly) health care users. Improved and increasingly differentiated medical treatment opportunities allow people to live longer with chronic diseases. More and more human conditions are being considered relevant for professional medicine, a process often described as medicalisation (Conrad & Schneider, 1980). In this historical context, ICT

is investigated as a means to develop more effective health care systems, where less money is spent but tasks are being performed with undisturbed or even improved quality. The Internet has been suggested a suited channel for health promotion campaigns, as it can reach a large number of people at high speed and low costs (Korp, 2006). The phenomenon of patient-oriented health ICT is thus a complex matter. The relations between patients, ICT and health can be highlighted from different angles.

Through empirical analyses this thesis reflects on how ICT for patients gets involved in negotiations of patientness and health. The implementation of patient-oriented ICT brings with it moral discussions on how patients should relate to technology, health expertise, and healthy living as a standard for everyday life. The studies illuminate how co-constructions of ICT, patients and health in everyday patient practice sometimes differ from what is expressed as the expectation from health professional-, policy-, and political spheres. To explore the phenomenon of ICT and patients we need an approach that opens for investigations of how technology matters on different levels; from local micro practices, across conceptual explanation models and to the social structures where health and illness is distributed in and among populations.

Research questions

In this thesis the overarching research question is; *how does patient-oriented ICT matter to performances of health and of the patient?* The question has been operationalised in five sub questions. These were developed as the research progressed. My search for answers to the overarching research question thus guided me through several slices of data. In sum, the research addresses how ICT for patient users matters to the performance of health and patients on three levels:

| Level | Empirical setting | Research Question |
|----------------|--|---|
| Micro-practice | Patients' homes | How is professionally initiated ICT integrated in patients' and their family caregivers' everyday performance of health and illness? |
| | Patient – doctor encounters | Will the “effect” of introducing solutions for electronic communication with health professionals be patient involvement? And will this ensure the patient a stronger position in relation to her/his doctor? |
| Conceptual | Policy-language | What is the patients' problem(s) presented to be in European e-health policies? |
| | Research/ scientific language | What aspects of health and illness in contemporary society can be illuminated through the notion of “the empowered patient”? |
| Structural | Distributions of health, patientness and health ICT in social structures | Can ICT for patients matter to social inequalities in health? How? |

The growth of health ICT; Telemedicine and e-health

Telemedicine, telehealth, telecare; e-health, p-health and m-health. These are all concepts that are currently in use in academic debate, policy and political discussions as well as in everyday medical and health professional practice. They all point to the phenomena of using ICT in health and medicine. Whilst unknown concepts up until the 80's/ 90's, both telemedicine and e-health can now be considered sub-disciplines within medicine and health sciences as well as important areas in public policy. As sub-disciplines they operate with their own journals and education programs. The terminology, including these two most used concepts; telemedicine and e-health, are constantly being contested, challenged and re-defined. A review paper from

2007 found 104 definitions of telemedicine (Sood, et al., 2007). A similar search for definitions of e-health (Oh, Rizo, Enkin, & Jadad, 2005) was able to identify 51 different definitions. Medicine and health sciences are not the only academic disciplines interested in health ICT. Considerable bodies of literature are emerging within new fields such as medical informatics, medical internet research and health technology assessment. Conferences in the sector are often targeting multiple stakeholders such as researchers, health professionals, policy makers, technology developers, industry and politicians at the same time. The variation in definitions and concepts to describe the use of ICT in health and medicine mirrors the fluidity and the complexity of the phenomenon. In the papers I have used the terms telemedicine and e-health. In this executive summary however, I speak of health- and patient-oriented ICT. These concepts can include the different technologies that have been studied, and contribute to distance this sociological discussion from the rivalling over concepts within the field of practice. Health ICT serves as a joint category that includes all kinds of ICT that are used in the health care sector. Patient-oriented ICT points to ICT's that are used in electronic services offered to patients, that is; ICT solutions that have been developed for electronic interaction between health care professionals and patients.

Motivation and purpose for the research project

Prior to enrolling for the PhD programme at the University of Tromsø, I worked for five years as a chief consultant and research fellow at the Norwegian Centre for Integrated Care and Telemedicine (NST). At the time, technologies designed for use in patients' homes and by patients on the move were emerging as a new field within telemedicine and e-health. While the early years of health ICT development and policies concentrated on technologies to be used by health professionals, ICT aiming at patient users is now a prioritized area (eHealthNews.eu, 2010). The initial idea to studying how patient-oriented ICT matters in

performances of health and of patients was rooted in an observation from the field; the presentation of the patient and the patient's voice in telemedicine and e-health was seldom done by patients who had experience from using health ICT. Most often, potential patient expectations and benefits of such technologies were presented by health professionals, and sometimes by patient organisations. At the same time, interesting patterns were beginning to emerge in patient user statistics; a study from 2001 concluded that 45 % of Norwegians wanted to communicate with their doctor by using e-mail (Andreassen, Sandaune, Gammon, & Hjortdahl, 2002). In the same study, 48 % claimed they felt relief after going online for health information whilst 13 % had answered they experienced anxiety after such activities. Still, little research was based on in-depth studies where the patients had been included as informants. The background for lay experiences of relief and anxiety or for wanting e-mail access to the doctor had not been investigated. I was curious about the patient version(s) of how patient-oriented ICT mattered, and of how this would relate to professional and policy versions.

Haraway (1988) discusses the situatedness of knowledge. In her view all knowledge, including scientific knowledge, is (and should be) partial and context dependent. Haraway wants more voices integrated into scientific accounts of the world (Rustad, 1998). In this project it was an ambition to identify and bring forward potential lay/patient voices from the field of health ICT and give room to these. It was also my aim to investigate and reflect on those voices and stories that were already strong and influential in the health ICT discourses and that I had encountered through my affiliation at the NST.

When this PhD study was initiated, a debate on the normative assumptions about patients' need for information and information technology had been introduced in sociology (Fox,

Ward, & O'Rourke, 2005; Henwood, Wyatt, Hart, & Smith, 2003). This debate concentrated on private use of the Internet to gather health information. The topic of patients' reception of professionally initiated ICT was far less studied. During the project period, interesting sociological contributions to the literature on patients' use of health ICT have been made; e.g. Oudshoorn (2008) have introduced the concept of "diagnostic agent". The concept suggests the telemedicine-patient as a doctor-assistant whose role is to operate technological devices to ensure the doctor obtains clinically relevant information. Further, a study on "Telemedicine and the "future patient" – "Risk, governance and Innovation" was conducted in the UK (Finch, Mort, Mair, & May, 2008; Mort, Finch, & May, 2009). Mort, Finch and May (op.cit) examine how telehealthcare technologies assume "telepatients" and that the making and unmaking of these interfere in processes of governance and participation. Their study did not, however, include patient informants with experiences from using ICT in health. In Norway Tjora and Sandaunet (2010) have edited an anthology on "Digital patients". This collection of 12 texts on the topic reflects the growing interest for it in Norwegian health sociology. The role of the Internet in individuals' everyday health management and the importance of online self-help groups to patients have also been further explored since the start of this project (Kivits, 2009; Sandaunet, 2007).

The thesis aims to contribute to sociological research on health ICT, both empirically and theoretically. Empirically, the inclusion of patient informants in a sociological exploration of professionally (and politically) initiated health ICT is relatively new. The empirical material makes the studies presented in this thesis newsworthy and gives the research an applied dimension. Knowledge on patients' reception of home based health ICT and the co-construction of such technologies and lay people's everyday lives might enlighten and influence future developments and implementations of home based health technology tools.

Further, through the empirical reflections and analysis presented in the papers, this work makes theoretical suggestions on how to study the diffusion (and non-diffusion) of patient-oriented ICT: the phenomenon can be understood as processes happening on three different levels. Processes at different levels are simultaneous and interfere with each other.

In sociology, the diffusion of ICT into medicine and health care have brought two traditions to the same empirical case; researchers from medical sociology and sociology concerned with technology have a joint interest in studying the implementation of ICT in health care. This thesis draws on elements from both these traditions in the analysis. The work presented confirms to what Timmermans and Berg (2003) have labelled a “technology-in-practice” strand in the sociological literature on medical technology. Medical sociologist Simon Williams defines health as a set of “ritualized practices by which one, literally and metaphorically, becomes ‘viable’ at all; both materially and socially, culturally and morally, individually and collectively” (Williams, 1998, p. 450). In my analysis I have coupled with the relational understanding of technology expressed in science technology studies (STS) (Law, 2004; Mol, 2002; Timmermans & Berg, 2003), with the interest in health as practice (Williams, op.cit). The combination of these perspectives has allowed for some new aspects of patient-oriented ICT to be highlighted that I have not seen thoroughly discussed in previous studies.

The historical background for patient-oriented ICT: Patients, politics and conceptualisations of health in contemporary health care

Political priorities in the health sector are historically situated. The growth in funding for patient-oriented ICT resonates with general trends in health politics, where the rhetoric on

patient centeredness and expectations of individual responsibility are increasingly important (Michailakis & Schirmer, 2010).

Ideals of patient involvement, patient centdness and patient empowerment are applauded in contemporary health care; among professionals, politicians, policy makers and patient organisations alike. It signals changes in the circumstances of patients that will lead to patients gaining more power and influence. Many patients want and welcome change; often patients are persons who want nothing more than to change the very fact that they are patients. Giving them power and influence then, appears a good idea. In practice however, this political and clinical shift might end up loading ill people with new responsibilities. Petersen and Lupton (1996) have discussed how 'the new public health', the expressions of the new public management paradigm within the field of public health care, ends up transferring responsibility for the distribution of illness from larger institutions - like the health care system, downwards in the system and finally place it on the shoulders of individual patients.

The responsibilities of patients have been a central topic in sociology since Parsons' (1951) presentation of the sick role as an important element in society's handling of illness. What are the social obligations and rights of those who are ill? This discussion is relevant for all of us. We are all patients or potential patients. The context where the patient role is defined and shaped has however changed since the 50's.

New technologies, the topic of this study, are one of the elements in a development leading towards more home based professional care. Home based telemedicine and e-health solutions, as well as mobile health technologies (m-health) are on the rise, opening for the patient status to be made relevant practically anywhere and anytime. According to the EU

eHealthNewsletter (2010) the aim of the European Commission's e-health policy since 1999 has been to develop and "show the benefits of" technologies that "cover the whole system of patient monitoring at home or on the move – from medical sensors to intelligent processing of the bio-signals, alerts and medical (tele) services back to patients" in order to "support health monitoring (homecare), chronic disease management and disease prevention." (op.cit). Hence ICT is involved when the development in the west today goes towards further expansion of the 'where and when' of the patient role.

Since the World Health Organisation (WHO) was established after end of World War II, the international trends in health care have been to focus more on public health, health promotion and preventive medicine, in addition to ensuring treatment for already ill patients. After "the Ottawa charter" (WHO, 1986) health promotion was established as an area entitled to its own strategies and programmes in the health care sector. The development has consequences for our conceptualisations of the recipients of health services. When looking for the handling of illness in contemporary society, we need not only to ask of the rights and obligations of those who are already ill, but also of those who might become ill, as they too are the concern of public health care systems.

Along with the redefinition of the target area for publicly funded health care systems described above, we have seen a shift in the definitions of health. As part of the WHO aim to improve world health through the means of health promotion and illness prevention, a new definition of health was launched. It stated that "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1948, p. 100). In health promotion literature it is common to distinguish between negative and positive definitions of health (Green & Tones, 2010). The WHO post-war definition is a positive

definition, concentrating on what should be included in good health, rather than on those elements that should be excluded in order to reach the status “healthy”. A change in health politics to a stronger focus on health promotion, prevention and public health thus came together with a change in the understanding of how health should be defined. The WHO’s definition of health from 1948 and their underlining of health promotion as a new orientation for the health care sector illustrate in broad outline two major traits in post war western health politics: health is defined as a positive state that all humans are to strive for, and the public health care sector has a mandate to organise for individuals to do so, also when they are not officially enrolled as patients in a health institution.

Nettleton (2006) has suggested the change from addressing “patients” to now talking of “persons” as one of the central transformations in contemporary health and medicine. This overall transformation is also reflected within the field of health ICT where the use of the term patient is debated. It has been claimed that ICT is one of the elements contributing to a development where the patient diffuses into other roles and statuses: “With its capacity for inexpensively retrieving information when, where, and how it is needed, the Internet is already transforming physician: patient encounters. In fact, the word ‘patient’ is being slowly replaced, at least implicitly, by ‘consumer’” (Ball & Lillis, 2001, p. 2). Nevertheless, in the research question as well as in the analysis and discussions presented in this thesis, I will stick to the term patients. Empirically, the project draws on in-depth interviews with patients who were recruited to participate in technology R&D projects by medical professionals. The patient status was the explicit premise for their participation. Both the informants themselves and the others who were involved in the ICT projects used this term actively. Further, the patient concept continues to be important in discourses on health and illness, in spite of the critical discussions and alternatives suggested. Mort, Finch and May (2008, p. 13) have

pointed out that “defining the patient has long been at the centre of ideological and economic contests in state-funded health care systems”.

Health professional literature, the media coverage of health care and the many patient laws that have emerged in western European countries over the last decade might give an impression of a “patient era” in health and medical work (Mol, 2008). The focus on patients’ judicial rights, as well as on how to achieve patient involvement and patient centeredness give the impression of a health care system that lifts forward the patient and his or her perspectives. In line with this general development, the term “patient empowerment” has been central and influential within e-health and telemedicine. These changes in patient rhetoric need to be understood in relation to the health political changes in the post war period, as described above. When there has been an increased interest in health promotion and preventive medicine this also implies new definitions of health; health needs to be more than the absence of disease if it is something the whole population can strive for. And that is how the WHO positive definition of health not only enables, but actually imposes patient involvement in health care. “A state of complete physical, mental and social well-being” (WHO, 1948, p.100) cannot possibly be established and recognized by anyone else than the person who’s health is in question, and within the system of professional health care that person is the patient.

The study presented contributes to identifying and describing co-constructions of health ICT and patients. The research topic on policy and practice in patient-oriented ICT is thus an entrance to highlight aspects of more general changes in the handling of health and illness in contemporary society. An underlying question is whether ICT - patient co-constructions contribute to alter the limits of the categories “health” and “patient”. When ICT is introduced

to patient users, the technology might get involved in practices where the understanding and content of these categories are negotiated.

Theoretical inspirations

This chapter will elaborate on the sociological background for the research conducted; the literature, theoretical perspectives and concepts that have been important for the analytic encounter with the data.

As already mentioned in the introduction, within sociology the phenomenon of ICT in health care is approached both from medical sociology/ sociology of health and illness, and from the branches of sociology concentrating on technology, in particular science technology studies (STS). Both medical sociology and STS are in themselves multifaceted disciplines and cannot be seen as coherent entities. For the purpose of describing the background for a sociologic interest in health ICT however, describing these as two approaches complimenting each other might be illustrative. Both Norwegian and British sociological authors on ICT in health care such as Carl May (2006) and Aksel Tjora (2003) include an interest in socio-technical change and science studies in their research within medical sociology. This thesis follows up on this dualistic approach when describing patients' relations to ICT in their everyday lives. Below I aim to unpack the theoretical inspirations from medical sociology and STS and show how they have informed my research.

Everyday life

As already described, part of the motivation and purpose of the project was to look for stories of health ICT and patients from outside the professional health care sector, in order to enable a comparison with the stories I had already encountered as an employee in the Norwegian health care system. This implied I was interested in the everyday aspects of patients meetings with health ICT.

Since the 60's there has been increasing interest in studies of everyday life across the social sciences (Löfgren, 2004). Löfgren interpret the interdisciplinary research orientation towards everyday life as an anthropologisation of approaches and frameworks in sociology. In this thesis a qualitative approach to the seemingly trivial or invisible routines of the everyday is followed up on in one particular setting: the patient's everyday life outside of the doctor's office or other health institutions. As underlined by Löfgren (op.cit), what is interesting about everyday life is that it is ever-present. Encounters with health professionals and health care institutions are on the contrary rather special incidents in the patients' lives, as they represent moments where daily routines are disrupted. The interest in patients' everyday life allowed this sociological study to expand the empirical focus from humans' relation to technology in the performance of a particular illness or diagnosis. The latter is a topic that has been addressed in previous research (Mol, 2002; Moser, 2008; Willems, 1998).

Crawford's (1980) paper on "Healthism and the medicalization of everyday life" and Kleiman's (1980) model of three sectors in health care (a professional, a folk- and a popular (lay) sector) exemplify how the interest in everyday life has influenced social science studies of health and illness. Through their interest in health as an important social phenomenon in

lay peoples' everyday lives, these works have influenced the approach to patients that underpins this thesis. In an overview paper on more recent approaches, Pierret (2003) stresses that studies of everyday life and related coping strategies is one of three main themes in sociological literature on the illness experience¹. From the patient's viewpoint, she claims, this perspective typically focuses on the diversity of experiences of living with an illness; how patients are active in everyday life; how their lives are shaped by the social context and how they help change this context (Pierret 2003, p. 11). Diversity in the use of technology in everyday life is a main finding in my studies. Some of the analyses aim to highlight exactly the aspects that Pierret mentions here; namely, how patients' and their families' lives are shaped by their local social context and how they relate to technology in their coping with health and illness in this context.

The notion of everyday life is also a basis for studies in the STS tradition. Latour's (1979) book "laboratory life" might serve as an example. In this foundational work, he outlines science as everyday activity. The social science research orientation towards everyday life has thus been a strong theoretical influence in this project. The analysis have exposed patient – ICT relationships in everyday activities.

Performativity

The research question - on how patient-oriented ICT matter to performances of health and of the patient, gives away that this work has relied on a performative approach to studying health and technology. In sociology Erving Goffman's (1959) pioneering work "The presentation of self in everyday life" has been given credit for introducing performance as a central concept

¹ The other two mentioned in Pierret's (2003) paper are subjectivity and social structure.

for sociology (Mol, 2002). Goffman described how people perform their identity through the role play of everyday life. He used the theatre metaphor to illustrate how this *performance* happened at a social front stage, whilst drawing on another reality; an *identity* that existed on a backstage. Goffman thus defined identity as an interesting topic for sociology through differentiating it from the aspects of identity that was studied by psychologists; their topic would be the backstage.

Since Goffman's studies the performative perspective have evolved. Later notions of performance includes Butler's (1990) version of doing gender. Her understanding of performing the social goes further in a constructivist direction than Goffman's original notion. It ignores the idea of a border between a back- and a front stage; "there need not be a 'doer behind the deed', but the 'doer' is variably constructed in and through the deed" (Butler, 1990, p. 142). From medical sociology I have interpreted Simon Williams (1998) definition to exemplify a constructivist performative notion of health: "health ...is not simply something one has, or is, rather it constitutes a reiterative set of ritualized practices by which one, literally and metaphorically, becomes 'viable' at all; both materially and socially, culturally and morally, individually and collectively" (Williams, 1998, p. 450). From this perspective the interesting question is not what health humans have, but what health they perform.

I have rested my approach to performativity on Mol's (2002) outline of the perspective. She claims "performances are not only social, but material as well", and underlines that objects "take part in the way people stage their identities. But once objects are on stage we can investigate their identities, too" (Mol, 2002, p. 40). Evidently though; I have not followed Mol in "banning" the word performance from her newer texts. She claims the word (not the perspective) is burdened with resonances to intentionality and causality, and suggests is

exchanged in a verb fresher to social science theory; namely “enact” (Mol, 2002, p. 41). I will not pursue this discussion here, but stick to the verb “perform” that I have used in the analysis presented in the papers. I have looked into practices where health ICT is involved in the doing of health in everyday life; co-constructions of patients and technology. Through opening a discussion on how patient-oriented ICT matters to performances of health and of the patient, I have aimed to highlight examples of how the material (technology) is involved in the performance of health as a social and moral phenomenon.

Perspectives on technology

Timmermanns and Berg (2003) give an overview of sociological perspectives on medical technologies. They identify three strands: technology determinism, social essentialism and the technology-in-practice perspective. In short, their argument is that whilst the two prior positions overrate the influence of technology on the social and of the social on technology respectively, the third position opens for a more dialectic approach that is able to avoid both determinism and social essentialism, and thus allow for empirical studies that are sensitive to all the changes (and reproductions) that might happen in an encounter between technology and humans. The technology-in-practice perspective is represented in studies that “apply central ideas from the interdisciplinary field of science studies to medical technologies” (Timmermanns and Berg, 2003, p. 99). In STS, technology is not seen as prior to or as an effect of the social, but as part of it. I have found this perspective to study technology in practice as inspiring in my analyses. Nevertheless, the opposing perspectives of technology determinism and social essentialism were detected in my empirical material; in the analysis of policy documents, and also in the conceptualisations of e-health and patient involvement that to some extent framed the research and development project-cases that I have studied. Sally Wyatt is concerned that we “cannot ignore technological determinism in the hope that it will

disappear and that the world will embrace the indeterminacy and complexity of other types of accounts of the technology-society relationship” (2008, p. 169). This is a problem I have aimed to relate to. I have tried to translate the outcomes of my analysis into some ethical and practical questions that could be of relevance to practitioners from both the health professions and from health politics and policy making.

Studying patient users of health IT

The title of Oudshoorn and Pinch’s (2003) book: “How users matter. The co-construction of users and technology” illustrates how the STS tradition draws attention to the mutual shaping of humans and technologies. Oudshoorn and Pinch’s title also highlights another aspect that has been important for my work; they emphasise the end-users in studies of technology, in contrast to studying how developers and implementers relate to it.

Bijker (1995, pp. 288-289) underlines that “sociotechnical change cannot be understood as the product of one prominent actor, whether an inventor, a product champion, a firm, or a governmental body”, and this, he claims; “is a matter not of post-modern relativism, but of recognizing that there will always be other actors who contribute to the construction of society and technology, actors that cannot be controlled”. Users (in my case, patient users) can be understood as one group of such “other actors”. The question then, is what their contribution is. How do patients and patient – doctor relationships contribute to the construction of society and technology? I found Achrich’s (1992) concept “technological script” and Hutchby’s (2001) concept “affordances” suited to highlight some of the differences between patient and doctor users, as well as between users and implementers’ expectations and performances of health, patients and technology.

Medicalisation, demedicalisation and governmentality

My research questions centre on a curiosity for how health and illness as well as health ICT, are social phenomena; how they are shaped by- and contribute to shape, social realities. In medical sociology, theories of medicalisation have provided some answers to such questions (Conrad, 1992; Conrad & Schneider, 1980; Crawford, 1980; Illich, 1976). Medicalisation explains the process by which human conditions and problems come to be defined and treated as medical conditions and problems, and thus come under the authority of doctors and other health professionals. On a general level, questions on medicalisation have been part of the background when designing this research. A core issue in all discussions of new technologies is their potential to lead to change. The introduction of patient-oriented health ICT, like electronic tools for patient – doctor communication, represents a potential change in the way we administer health issues in our everyday lives. A question then, is whether eventual changes in the wake of such technologies will be examples of medicalisation, or on the contrary are forms of “demedicalisation” (Williams & Calnan, 1996). Will patient-oriented ICT lead to a further “invasion” of medical rationalities in lay people’s everyday lives, or will it enable people to act more independently from such influences? Throughout the research process these are questions that have emerged on several occasions. However, through the empirical readings and analysis some critical questions towards the relevance of the medicalisation critique in studies of technology diffusion have also emerged. The findings on patient - health ICT relationships on a level of micro-practice were hard to classify as either medicalising or demedicalising. The complexity of patients’ everyday health and technology practices as well as the multiple aspects of patient- doctor negotiations are hard to evaluate in light of a singular notion of medicalisation/ demedicalisation. This illustrates how the technology in practice perspective challenges social essentialist notions of technology as governed by social interests only. However, there is theoretical overlap between the notion of

medicalisation and governmentality (Foucault, 1979); both concepts point to how lay people's micro practice and mentalities are governed through professional and state power. In the analysis of how health ICT – patient relationships are conceptualised in official rhetoric (Andreassen, submitted) as well as for the reflection on the relevance of the notion of “the empowered patient” for sociology (Andreassen & Trondsen, 2010) the concept of governmentality opened for some interesting discussions. Further, Foucaults' notion of “the medical gaze” can also be interpreted as a theoretical tool to highlight processes of medicalisation (Tjora, 2003). “The medical gaze” was a useful concept in the analysis and discussion of some of the particular practices that I encountered in the empirical material; where parents used ICT to shield their children from the doctor's language and practices that they themselves labelled as “pathologising” (Andreassen, 2011).

Micro practice and macro structures

A basic challenge to sociology is how to explain the relation between micro-practice; the doings of everyday life, and macro structures; the systematic patterns of resource allocation in and between societies. Within the STS tradition, no differences and distinctions are included in any analyses as a priori facts, but seen as “... effects and outcomes. They are not given in the order of things” (Law & Hassard, 1999, p. 3). One of the critical questions posed towards this stance is that it lacks sensitivity to social structures. It has problems acknowledging asymmetry as a historical structural problem (Haraway, 2004). Through combining an STS approach to technology with elements from medical sociological theory I have aimed to combine an analytical approach to technology as relational with sensitivity to contemporary social structures.

One way to answer to the methodological challenge of balancing the focus on micro level practices with a focus on structural patterns is to develop layered sociological approaches. Turner and Samson (1995) claims that “in order to develop a general theory of health and illness in society” medical sociology needs to concentrate simultaneously on three levels of analysis; an individual level where the topic is illness experiences, a social level focusing on the cultural categories of sickness and a societal level thematising health-care systems and politics of health” (op.cit, pp 4-5). Similarly, within medicalisation theory, Conrad (1992) has suggested medicalisation also occurs on three levels; on an interactional level (in patient-doctor relations) on a conceptual level (when the vocabulary for describing a medical problem is chosen) and on an institutional level (where an organization adopt a medical model for treatment). Rhodes (1991) has underlined the importance of sociology to look into empowerment as a process happening on a community level and not only on an individual level. When working on this part of my thesis, the executive summary, I found it useful to look towards such layered models when describing the totality of this research project.

To round off this chapter on theoretical inspirations I will cite Turner and Samson (1995) on their eclectic approach to theory: “theoretical openness in sociological explanations of illness is not only desirable but necessary” ...“the point is to use theory creatively and constructively, rather than to generate narrow and exclusive positions” (op.cit, pp. 14-15).

Cases and methods

The data production concentrated on two implementation projects at the Norwegian Centre for Telemedicine (NST); “PatientLink” and “Web based eczema counselling”, and one document study that included official documents on health ICT from the European Union. My

participation in the implementation projects gave insight into the process of developing, planning and implementing health related ICT in patient –doctor communication. Interviews with the doctors and the patients who were enrolled to pilot the ICT provided data on how technology is integrated in practice in the patient- doctor relationship, and in the everyday life of patients in their homes. The document study highlights how the patient is represented in official (e-) health policy and political rhetoric. Finally, as a last step in the research process, collaboration with a colleague (and sociologist) allowed for a study including data from a third NST implementation project “Born on broadband”. These data were included in an analysis where they were used to complement and compare the findings from patient settings. This allowed me to explore the general value of the explanations and conclusions developed at prior stages in the project. The procedures for data production from the “Born on broadband” project are described in paper 5 (Andreassen & Dyb, 2010). As I was not involved in the fieldwork, I will not discuss the methods and methodologies for data production from this project any further in this executive summary.

Below I describe the two cases and the documents from the European Council, as well as the methods for producing data from these.

PatientLink

In the project PatientLink, a medical practice with six general practitioners (GPs) was recruited to participate in a trial designed to test a secure web based messaging system for doctor – patient communication. The encrypted communication was asynchronous and text based, much like e-mail, but the patients used the Web browser on their private computer for sending and reading messages. The patients received a user name and password at the doctor’s office. Each time they wanted to get in contact with their doctor through the

PatientLink system, they had to log in with their user name and password, following which they immediately received on their mobile phone an SMS (short message service) with a one-time code. The code had to be used to complete the login process. The GP was notified when a new message had arrived by an icon on the computer, and could store the messages unedited in the patient's electronic record. The patients were informed that they would receive an answer from the doctor within 3 days at the latest. When a response from the doctor arrived they were notified by a SMS. The local Norwegian research ethics committee (REK) approved the project protocol. There was no compulsion on either the GP's or the patients' sides to use the system. PatientLink required that the patients initiate the electronic contact. The doctors could only respond to received messages. The trial lasted over a 12-month period in 2002-2003. Recruitment of patients was conducted in the primary clinic's waiting room where recruitment forms were handed out to adult patients (18 years and older) with a scheduled appointment to see the GP. A total of 201 patients were recruited. PatientLink was organised as a randomised controlled trial (RCT), meaning that these 201 persons were randomly divided into intervention and control groups. While the 100 patients in the intervention group were given access to the PatientLink web address and could send messages to their doctor's inbox, those in the control group were not given such access. PatientLink fulfilled Norway's rigorous data security requirements for communication in health care.

In connection to the PatientLink project, a separate social science study was conducted. The aim was to follow the technology development project, and the technological tool in its user settings; among the GPs in the practice and in some of the patient homes. The interviews and the observations from participating in the PatientLink project became the first slice of data for this PhD research.

All six GPs and the 12 most active patient users were interviewed. The patients had already agreed to be interviewed on the consent form they signed when registering for the RCT study. System logs were used to identify the most active users among the 100 patients allocated to the intervention group. Initial contact with the patients was made through a letter inviting them to take part in an interview addressing their experiences communicating electronically with their doctor. The invitation was followed up through a telephone call, where they were asked if they wanted to participate. All agreed. After interviewing the 9 most active users, we had enough material to start the initial analysis. Later, we added 3 more interviews to confirm that all relevant aspects of the users' experiences were covered. The patient interviews were conducted 3 to 5 months before the 1-year intervention period ended. The doctor interviews were conducted after the end of the trial. The patient interview guide consisted of an index with the following headings: expectations regarding the technology, practical experiences, the content of messages, concerns about data security, experiences and attitudes toward patient roles, experiences and attitudes toward the patient-doctor relationship (subdivided as communication, responsibility and patient participation), experiences related to empowerment, experiences of health-related anxiety, experiences of health concerns in everyday life and everyday life relations, and experiences of writing about health matters. The GP interview guide consisted of the headings: expectations, actual use, topics addressed in the messages, time schedule, the doctor – patient relationship, challenges for the GP, potential drawbacks, attitudes towards making electronic communication a permanent service and suggestions for improvements. The 12 patient informants were interviewed in their homes, and the doctors at their offices. While the patient interviews were conducted in person by the candidate, a research fellow was engaged to do the doctor interviews. The interview guide was produced in close collaboration between the two researchers, and revisited after a few initial interviews. All interviews were recorded and transcribed. The project team from the

NST who were developing and implementing the technical solution were included in discussions on the interview guides' design and the data analysis.

Web based eczema counselling

Later, the technological solution from the PatientLink project was further developed and commercialized by a local company under the name “MyDoctor” (MinDoktor). This company collaborated with the NST and the University Hospital of North Norway (UNN) to set up the project “Web based eczema counselling”. As in the previous case, PatientLink, the project was organised as a RCT. Later in the process a second hospital, Hammerfest, was included to participate in the trial. In this project, the technology developed in the PatientLink project had been adapted to and was tested in a new setting: communication between hospital specialists and parents of patients (children) diagnosed with atopic eczema.

The hospital and the NST had already run a pilot on eczema counselling offering (children) patient families the opportunity of sending digital photos as well as text in 2000 – 2001. The potential for improved coping and health outcomes for the families was considered high; however, the pilot was based on messages communicated via the Norwegian Health Net, a secured network normally restricted to health professionals in Norway. Whilst the inclusion of a limited number of patients into this network had been approved for a pilot, a permanent solution for hospital - patient communication required a secure solution outside the health net. MyDoctor was such a solution. The company offering MyDoctor on the side was interested in developing and testing a new addition to the service; the possibility to attach digital photos to the messages. Hence, collaboration was initiated and a research project was designed. Funding was received from the regional health authorities. Recruitment of patient families started in May 2005 and lasted for 15 months. Patients who had been appointed by their GP

for an ordinary outpatient consultation concerning atopic eczema at the hospital were recruited by the hospital specialist. A total of 98 patients were recruited and randomly divided into an intervention group and a control group. The 50 patients allocated to the intervention group were given the web address leading to the eczema counselling service, and a password to log in.

From the patient side the technological solution was similar to e-mail, and very much like that in the PatientLink project. The system had been adapted to the diagnosis through providing the patients with two new options; a table for ticking out the severity of the eczema on a scale from 1-5, for different areas of the body, and a functionality for attaching digital photos of the skin affected by eczema.

Similar to the previous case, the social science study was conducted as a separate project. The data production for the social science study was not included in the “Web based eczema counselling” project protocol. I participated in selected project meetings, and was present in all phases of the project, from the initial planning, through the recruitment and evaluation phases. The project group provided me access to all written material, including the messages sent between the hospital and the patients – in the cases where the patients had agreed to this through signing a separate consent form. They also gave me access to the lists of participants for recruitment to interviews. Further, I communicated regularly with the project group on the development of the project and their RCT.

The 50 families in the intervention group were all invited to participate as informants in my social science study, through a letter explaining the PhD project and procedures planned. The initial plan was to do a brief interview by telephone with all families, and then make a smaller

sample for face-to-face interviews. The instructions from the regional ethics committee (REK) and the Norwegian Social Science Data service (NSD) required the informants had to agree in writing, by signing a consent form and return this by ordinary postal mail. Reminders were sent to those who had not returned the consent form within a month. A total of 14 answers were received, of these one had marked not wanting to participate on the consent form, and one informant later withdrew. As the number of informants was lower than expected, I decided to ask all who had returned the consent form to participate in a face-to-face interview. Parents from 12 patient families were interviewed.

The interviews were conducted in the period from December 2006 until March 2007. The interview guide was built around three main topics; practical use and integration of the technology in everyday life, electronic services and the boundaries between lay and professional/ public health spheres, and the patient role/ the caregiver role. Out of the 12 interviews, 10 were carried out at the informant's home and two in restaurants; then on the informant's suggestion. This involved travelling across North Norway, as there were families from all the three northernmost counties in Norway: Finnmark, Troms and Nordland. When calling up the informants after receiving the consent form I was explicit on wanting to look at the integration of the technology in the homes of the informants, but also on being flexible and open towards alternative meeting places. The interviews lasted between 45 and 90 minutes. In some cases I stayed longer (up until a few hours) at the families' homes than for the exact interview.

EU document study

The European Union was selected as a source for official documents that could be suitable to study how expectations of the patient- ICT relationship were expressed in policy rhetoric. The

international profile of the field of practice was an important argument for looking towards the EU instead of national health policies. Telemedicine and e-health development and research is a field of extensive international project and policy collaboration, and the EU holds an important role as funder and promoter of health-ICT projects. Through their framework programmes the EU possesses a strong policy tool for technological development in the health care sector in European countries. As a preparation for the document study, a colleague from the NST who had experience from working on international issues in e-health and telemedicine was interviewed. Based on our discussions I decided to include two samples of documents in the study. First, a complete collection of the conclusions and sum-ups from the “European high-level ministerial e-health conferences” that have been arranged annually since 2003. These conclusions represent the joint attitude and are signed by all health ministers from EU, and for some years also by the health ministers from the EFTA states. All conclusions and summaries were available from the European Council web page (EC, conferences). Second, the most recent of the documents returned from a general search for “e-health” on the EC web page were selected as an entrance to the body of policy documents on e-health in the EU. The next step was to follow the footnotes of this document (a press release), and include the referred documents in the sample. Activities in the EU organisation produce and rely on a wide variety of documents. This is reflected in the second sample of documents. However, my analysis focused on the content of the documents and on how they related to each other. Their intended use and origin were not my main interest. The procedure led to a total collection of 20 documents. All the documents were available electronically. After an initial reading of each document, the electronic versions were searched for the terms “patient”, “user” and “consumer”. All paragraphs including these concepts were then subject to a close reading. The analyses were based on Bacchi’s (1999) discourse analytical approach and aimed to study policy documents by asking what problems they set out to solve.

Potentials and limitations of the methods

In this chapter, I will reflect on the potentials and limitations of resting a study of technology in practice on data produced through interviews and document readings.

Interviews

Compared to studies of technology in practice in professional settings, studying the use of health related ICT in a patient's home presents the researcher with additional ethical and practical dilemmas. On the practical side, the rare use of the technology is a problem when observing patients' use of an electronic communication tool to their doctors. Whilst research on the use of ICT, and especially from the STS tradition, often relies on ethnographic approaches to data production (Law, 2004), this was not an option for my two studies including 12 patient users each. An ethnographic study would require me to stay in the patients' home for an extensive time period in order to actually come across active use of the technology. Another practical issue was the travelling that the interview fieldwork required. Initially the idea of observing the patient families' actual, practical use of the technology was central, which implied a need to visit the locality where they usually logged on to their computer and ask them to give a demonstration. The sample included patients living in all the three northernmost Counties of Norway. In retrospect, after the analysis that revealed patients and their family carers relate to the technology also when it is not actively used for communication, it can be added that observation studies will be limited in studies of patients' use of technology at home, as they will not necessarily notice human – technology relations that do not involve active hands-on use of the technology. Even if the observations of such hands-on uses were not the most central findings in the empirical readings, travelling to the

patients' homes was important. It provided a safe atmosphere for conversations where the patients were on their own premises. Further, the travelling was important to my understanding of the geographical circumstances and how they affected on the patients' health and technology practices. This is a topic I have mentioned in the papers (Andreassen & Dyb, 2010; Andreassen, 2011).

Entering the private sphere of a family also requires ethical considerations other than field observations in a health institution. My visits to the patient's homes could, in fact, be interpreted as part of a medicalisation of everyday life in itself. I made initial contact as an employee at the NST. The letters inviting the informants to participate in interviews had the NST/ UNN letterhead. I consider the interview as a social happening and not a neutral source of objective information. Holstein and Gubrium (1995) underline the importance of focusing on the "activeness" of the interview. One of the ways I dealt with this issue was through a rather long introduction when opening the interviews. I underlined my dual position as affiliated to the hospital and the NST, and at the same time leading an independent PhD project as a registered student at the department of Sociology at the University of Tromsø. Further, when interviewing the parents of the young patients I mentioned that I had children myself, when underlining that I was more interested in the topic from a practical everyday point of view than I was in evaluating the necessity of the solution from a medical standpoint. As I aimed to open for the patients and the parents' in-depth reflections, I tried to avoid framing the situation too strictly through the interview guide. This was a skill that improved throughout the project, through the practice the interviews gave me. In the latest interviews I did not bring out my semi-structured interview guide until the interview was close to the end. Then, I would say that I needed to go through my check list to ensure I had remembered all

topics I had planned for, while at the same time asking if the informants had prepared for specific topics that we had not touched upon.

I do not claim to have gathered neutral data on patient experiences. These interviews were particular social situations that allowed for other topics and stories to be told than other social situations would have. This is how these active interviews might have allowed for important alternative versions of the patient – health ICT relationship to be illuminated.

Policy – documents

To study the rhetoric on health ICT and patients in the field of practice, I could have systematised and used my observations from participating in the field. As described earlier, such observations initially made me curious about the patient – health ICT relationship in the first place. I assessed this entrance as problematic. My hesitation was related to questions on validity. As an insider for about 10 years (the document analysis was one of last slices of data to be added), it was likely that I had prejudice both towards the observed models themselves and to the actors who advocated them. There was a possibility that I overrated the importance of some actors and conceptual models over others, based on my own experiences and positions within the field. An entrance through public documents that represented established official attitudes was therefore selected.

Still, it has not been my intention to reveal the accurate truth about the field of health ICT and patients through studying documents. Rather I have aimed to highlight how documents construct their own kinds of reality (Atkinson & Coffey, 2004). From my position within the NST, I had seen how important this reality was in terms of forming a reference-base for the allocation of project resources and development of strategies in the state funded research and

development sector. In the paper “E-health is the solution; what’s the problem” (Andreassen, submitted) I spent time describing how written documents refer to each other. However, these documents do more than merely relate to each other. Health ICT policy documents are also referred to (and refer to) in the realities constructed in oral text; that is in the stories told when designing research proposals, in project meetings, conference presentations, and media covered political accounts of health ICT. This was, in part, what made them interesting for this study. The intertextuality of technology-policy, research and development stories within the health ICT sector could indeed be an interesting topic for future sociological studies of this field.

Situating the researcher and the research project

Here is the true challenge for sociologists studying medical technologies: how to conduct research that is relevant to the users and designers of the devices while maintaining a sociological identity (Timmermanns & Berg, 2003, p.109)

As described elsewhere; the research described in this thesis was set off by the curiosity about an empirical field; the diffusion of health ICT into private spheres, and a motivation to investigate and possibly develop new explanation models and approaches to this phenomenon. Hence, the lack of patient voices in the field of health ICT research and development, as described in the introduction, could be considered the first significant discovery in this process; a point of departure that was established even prior to formalising the project through a project proposal. This discovery was an outcome of the researcher’s participation and integration in the field of telemedicine and e-health. I will discuss the relevance of this particular position to my research in more detail below.

The researchers influence on the data

Alvesson and Sköldbberg (2000) claim the level of qualitative method can be raised by incorporating ideas from the philosophy of science in empirically based social science. A science philosophical question that is of importance to empirical research design is how the researcher influences his or her data and the objective validity of it. Haraway (1988) offers some rather radical answers to these questions in her “version of method-and-politics” (Law, 2004, p. 68). The active participation and influence of the researcher (including his or her theoretical and contextual background) on the research process and the production of empirical facts is acknowledged. Haraway goes further than most social scientists and not only describes this influence as inevitable, but as desirable as well. She argues that, in fact, subjectivity should be considered the only objectivity available; as biological creatures we have no other option than to rely on our own subjective experiences and translations. Instead of aiming for a perspective that in practice is unreachable, a perspective placing the researcher outside of the phenomenon he or she studies, she thus argues for “the privilege of a partial perspective” (Haraway, 1988, p. 575). When aiming to tell true stories of the world through the practice of research, we need to take partiality and situatedness as our point of departure. Her argument is that leaning on a partial perspective will be a preferred position to produce true knowledge, as this is (truly) the only position available to us. Aiming to overcome it is an illusion and can thus only distance us from experiencing and understanding the subject we are studying.

According to Haraway (1988), the partial perspectives of the researcher and the subjects he or she studies must be considered part of their justification. This must not be taken as an argument for the equal validity of all data. Rather, this perspective actually places a huge

responsibility on the individual researcher; particularly, the responsibility to ensure an active, reflexive treatment of the data in all stages of the research process. At no point can it be left to predefined schemes or fixed techniques to ensure reliable, valid data or analysis.

The particular partial perspective of this project allowed for a combination of data from what can be labelled an inside of the health ICT development and implementation sector, and an outside where the ideas and material artefacts of this sector meet with users in everyday contexts. I would argue that my particular situatedness is one of the strengths of this study. It tells the partial truth from a position on the borders between a professional inside and a lay outside of the health care system. My position as a social scientist probably underlined this in-between position when I met with the informants. I was both a professional; as a “researcher / scientist employed in the Norwegian health care sector” and a lay person; as a “non-professional in biomedicine”. This position facilitated the access to different social settings and thus it enabled me to analyse a wide range of aspects of how patient-oriented ICT matters to the performance of health and of patients. Throughout the research process, patient experiences and practices, the scripting of technology, the active role of technology, conceptual constructions of ICT and patients, and health professional and political aspects of health ICT have been explored in order to present an explanation of how patient-oriented ICT matters to contemporary performances of health and of the patient.

This study was designed and conducted as an independent but integrated part of the project portfolio at the Norwegian Centre for Integrated Care and Telemedicine, NST. The work has been independent as it was based on an individual project description. At the same time the work has been integrated into the activities of the research and development projects “Patientlink” and “Web based eczema counselling”. Together with a third NST

implementation project, “Born on broadband”, these have provided the study with empirical cases. I have been affiliated with the institution since before the PhD project was initiated, and also throughout the whole period of the PhD study. My work background and integration in the field of practice has been important to the production of data, and to the development of the research questions.

The NST has been assigned the task of promoting and evaluating health ICT in Norway. This implies there is a need to discuss the relation between the political mission of the host institution and the research presented. As a sociologist and politically interested employee in Norwegian health care, I have been both optimistic and critical towards different policies aimed at achieving technology diffusion in the sector. My research has been coloured by and is contributing to a growing acknowledgment in the field of health ICT; that technology is diffusing at a slower pace than originally anticipated. When I first entered the field at the beginning of the millennium, the sector itself, as well as the sociological accounts of it (Hardey, 1999, 2001) were influenced by technology-optimism and enthusiasm. In contrast the lack of larger success stories is now a prominent consideration. It has been suggested that the field is characterised by a “plague of pilots” (Barlow, in Wyatt & Sullivan, 2005). Sociologically this is interesting, as it suggests the technology is resisted or integrated differently into social practice than what was initially anticipated in health politics, by the professional initiators and by technology developers. This was also the case for some of the particular technologies that I followed, and reflections on this issue became a central topic in the work here presented. My work is thus part of a general development within research on health ICT to look for alternative approaches to explain the diffusion and non-diffusion of technology. Whilst my work focuses on diffusion into patient settings, others have

approached diffusion into professional activity and health organisations (Berg, 2001; Dyb, 2011; Obstfelder, Engeseth, & Wynn, 2007; Tjora & Scambler, 2009).

The observations from the case project groups and the daily activities at the NST were available to me because I was an NST employee. These observational data have not been as systematically analysed and presented as the material from the interviews and the policy documents. Still, as previously mentioned, such observations were the first discoveries in the study, and had a central role in the development of research questions. In addition to my participant observations from the PatientLink and Web-based eczema counselling projects, I made further observations from participating in other daily activities, other projects, collaborations and individual assignments. In particular, my position as a research fellow in a larger European survey on health related Internet use deserves mentioning in a reflection on how my background from the NST has influenced on the study. The survey “E-health trends” was a 3-year research project funded by the European Commission, DG Sanco. Participation in an international project group including researcher teams from seven European countries opened a position from where I was able to observe differences and similarities in health ICT rhetoric across these groups. The observation of similarities was important for my interest in policy rhetoric’s and documents, and for the decision to study this topic on an international level. Further, the survey results in themselves formed an important part of the input for new research questions to pursue in my PhD project on patient-oriented ICT. In the surveys, I noted findings that could be interpreted as interesting contradictions from a sociological point of view; e.g the observation that more Europeans claimed they wanted the ability to communicate electronically with their doctors than the number who had actually tried, or even thought they would try such forms of communication in the future (Andreassen, et al., 2007).

The participation in the research and development community at the NST has also been important with regard to validation. The interdisciplinary research group at the NST includes researchers from several academic disciplines such as medicine, health sciences, psychology, sociology, political science, education science and informatics. Data extracts and preliminary analysis have been presented in numerous internal workshops, seminars and lectures during the PhD period. The project participants in the two cases PatientLink and Web based cczema counselling have been asked to comment on interview guides, findings and written texts on several occasions. Further, elements from the study have been presented to colleague social scientists outside the NST as well as to practitioners from the national and international health ICT sector in external seminars, workshops and conferences. Critical discussions and input from colleagues have contributed to strengthen the validity of the analyses.

My entry into the patients' spheres as a researcher associated with the University Hospital has of course influenced the interviews and the patients understanding of what I expected them to talk about, and how. Nevertheless, my affiliation with the NST and UNN was part of what made the entrance to these lay spheres possible. Without it, the access to lay users of health ICT would have been limited and scattered, as home based lay use of professionally initiated health ICT is still rather limited, in Norway as in the rest of the world.

Sampling

The overall research question on how patient-oriented ICT matters in performances of health and of the patient, is broad. The multi-faceted investigation has followed a theoretical and not a statistical logic. The aim has been to sample theoretically stimulating settings, not to generalise from representative samples. In practice this has meant that instead of interviewing as many patient users as possible, I also looked for aspects that the patients themselves could

not inform me about through direct conversation. Examples of such aspects are performances of the patient technology in health ICT project planning, in doctor interviews, and in policy and political rhetoric. This way of selecting cases and data can be labelled “theoretical sampling” (Mason, 1996; Silverman, 2000). The aim is to select groups and categories to study on the basis of their relevance to the research question; the researchers’ theoretical position; and the account that the researcher is developing (Mason, op.cit).

Stepwise research

The study has evolved through several stages of sampling, data production and analysis. The research started in observations from an empirical field and moved from data to concepts and theories. At the same time theoretical explanations and concepts were constantly checked towards the empirical material, and the theoretical accounts that developed during the analyses inspired new research questions that in turn guided the search for new data. The procedure can be described as “stepwise-deductive inductive method (SDI)” (A. Tjora, 2010, p. 155). In his outline of SDI Tjora describes the process of working from qualitative data and towards theory as induction whilst the simultaneous process of going back to the data to verify or check the theoretical accounts represent the deduction; the D in SDI. This method has guided the study. The stepwise process has led to six turns of data production (Participant observations in the Patientlink project, interviews with patients, interviews with doctors, new observations (from the Web based eczema counselling project), interviews with patients from this second project, and finally the document study). The method has thus resulted in what can be labelled several slices of data on one category (Glaser & Strauss, 1967), and allowed for a comparison of these. The overall category that all slices of data are used to highlight is health ICT – patient relations.

In some respects my research methodology share grounds with the tradition of grounded theory (Glaser & Strauss, 1967). This tradition is often associated with an inclination to go for qualitative data, theoretical sampling procedures and a stepwise research process constantly moving between analyses and data production (Dey, 2007). These are all aspects that characterise the presented study. Further, grounded theory place weight on the comparison of different slices of data, which has also been the analytical approach in this project. Grounded theory does however present a rather strict coding regime to be applied in the analyses of qualitative data that I have not related to, and place more importance on theory development than has been the case in my project.

The stages of the research project

Under this heading I will describe the different stages of the research process in more detail, as well as elaborate on how they relate to each other and to the overall research question on how patient-oriented ICT matters in performances of health and of patients.

The list of research questions have developed and the focus altered throughout the project. Each of the articles included can be read as a summary of one stage in the research process, where each stage involved an analysis that in turn formed the basis for new or refined research questions. These questions guided my search for new data.

The first data to be produced were the participant observations from the project group and the interviews of patients and doctors in the PatientLink project. A main finding from this analysis was that there were variations in the outcomes and implications of introducing electronic communication in different patient – doctor relationships. The relationships

between health ICT and the patients could not be summed up in a causal explanation model where health ICT led to certain social outcomes. Technology did not have a detectable singular effect on patient action, and neither could patients form technology as they wanted. This finding inspired a theoretical exploration of the technology – in – practice perspective to medical technology (Timmermanns & Berg, 2003).

Further, it became an important finding that the weight placed on the empowering potentials of patient-oriented ICT that were much advocated in the sector, and that formed an important part of the context for initiating the PatientLink project, was not reflected in the patients' version of how technology mattered to the doing of ICT and health. Hence, there was a divergence between the importance ascribed to technology as empowering in the health ICT research and development sector and the ignorance some patients showed to these aspects of technology. The theoretical interest was directed towards the science-technology studies (STS) tradition and the concepts "Affordances" (Hutchby, 2001) and "Scripts" (Achrich, 1992) turned out fertile tools in the analytical work. From medical sociology, the distinction between patient-centred and doctor-centred approaches to the medical encounter was an important analytical intake (May & Mead, 1999).

The findings indicated that the idea of an empowered patient could be interpreted as contested or ignored in some situations in everyday practice. This directed the project towards theoretical reflections on the concept of empowerment. These are summed up in paper 2 (Andreassen & Trondsen, 2010).

After having revisited and explored the concept of empowerment in-depth, it was time to include new slices of data. The findings indicating that the general expectations towards

patient empowerment in the sector could have been overestimated and that patients' use of the technology was more varied than expected was interpreted as new and interesting. As already mentioned, the amount of literature on health ICT that included patient informants was low at the time, and the call for more patient-focused research had been made explicit in sociology concerned with health ICT (Henwood, et al., 2003; Ziebland, et al., 2004). On this background the focus of the project was now directed away from the role of technology in the doctor – patient encounter and the curiosity centred on the relationship between patients and technology in patients' everyday life. A second NST project involving patient users of technology was selected: Web based eczema counselling. As described earlier, the methodological procedures were similar to those from the previous case, PatientLink. Contrary to the previous round however, and in accordance with the sub research question on patients relation to technology in everyday life, this interview study only included patient informants, or rather patient *families*. The health professional users were not interviewed.

Atopic eczema is mainly a children's disease, and it has been estimated that as many as 20 % of school children in western countries suffer from this condition (Williams, Robertson, & Stewart, 1999). For the majority, the problem is associated with childhood, and normally improves without treatment as the child grows older. Atopic eczema is a disease that patients and their caretakers have to deal with in everyday life. The condition requires patients' and their caregivers to deal with symptoms such as rashes, itches and sometimes infected sores. Eczema affects children's sleep and might be associated with tiredness, mood changes and psychosocial problems. As for the parents, the time to care for a child with atopic eczema has been estimated to range from 1.5 to 3 hours a day, and has been associated with reduced parental employment (Su, Kemp, Varigos, & Nolan, 1997). Atopic eczema is considered a chronic disease. For these patients, the sick-role might be permanent. In contrast, Parsons'

(1951) outline of the sick-role was one that assumed the patient to seek medical treatment in order to eliminate the illness (Frank, 1997). Rather than a disruption allowing for a return to the life one lived before illness, chronic conditions often end up altering everyday life on a more permanent basis. For the patients and their families, the symptoms of atopic eczema can thus be considered *everyday problems* rather than incidents of acute illness. At the same time, Internet and e-mail communication have become *everyday technologies* in Norway: 90 % of Norwegian households had Internet access in the latest national monitoring (Norwegian_statistics, 2010). Out of the households including children, the proportion who had Internet access was 99 %. Thus, “Web based eczema counselling” was a project introducing everyday technology to everyday problems, and this was the background for selecting this particular project for a study of the relation between patients and technology in everyday life. A primary finding in this second round of qualitative data production and analysis, was that the technology was rarely used but that the informants still were positive towards it and placed importance in it. This contradictory finding became an important analytical intake. A conclusion was that patients and family carers did not only relate to the technology as a tool for communicating with the doctor or as support in active treatment of their illness. It was equally integrated in other health-related practices in their everyday lives. This finding is the rationale behind looking for how technology is involved in performing *health* rather than limiting the study to how ICT – patient co-constructions perform in terms of the patient or a particular *illness*. In the everyday lives of the patient users, the relation to technology, their health practices and their illness practices were overlapping, interwoven and related. Restricting a study of health ICT to be about illness would thus imply research that restrained the explanations and descriptions in ways that did not resonate with the empirical material.

The analysis concluded that parents' relation to technology did not merely depend on the use of it in the intuitive sense of the concept. They related to it also when it was not used for doctor-communication. As in the study of patient users' relation to PatientLink, a main finding was variation and difference. Technology had multiple roles in the everyday lives of patients' families. These were not only due to differences between the patients and patient carers that caused them to use technology differently. The relationship between lay patient users and technology appeared as complex and multifaceted. Technological devices themselves, the everyday context and the patients' actions and interpretations were all important in a description of how the health ICT solution mattered. These findings were interpreted to confirm the relevance of a relational understanding of technology as a theoretical intake to answer how patient-oriented ICT matters. During the analytical work with these data, new literature from the STS tradition were explored and included. Of note, the discussions on how to relate to users of technology (as opposed to developers and implementers) were relevant (Oudshoorn & Pinch, 2003), and further the continuation of this focus in the discussion on how to include non-users (Wyatt, 2003).

The project now turned in two empirical directions simultaneously, looking for new slices of data that could supplement and possibly challenge the conclusions that had been reached. First, there was a need to go behind the researchers' observations from the NST projects, and aim for a look into "the hinterlands" of e-health technology development (Law, 2004). There is growth in the number of available patient-oriented ICT's. The repeated decisions to fund patient-oriented ICT projects can all be considered political statements; statements that draw on and contribute to a certain political context. Law claims that "A part of the hinterland of a statement is other related statements" (Law, 2004, p. 28). This project needed to look into whether there was empirical "evidence" to the claim that the patients' relations to technology

were more varied and locally situated than the dominant conceptual explanation models used by developers, politicians and policy makers took into account. Could my conclusion be challenged by going outside of the local and national contexts? To explore this, a document study was initiated. Empirically, the project was thus oriented towards language and rhetorical performance to look for more data that could challenge or confirm the conclusion that there existed a singular ideal for the health ICT - patient relationship, and that policy and professional voices perform a rational patient ready for more involvement and clinical responsibilities. To approach the documents, a methodology inspired by discourse analysis (Bacchi, 1999) proved fruitful. The document study concluded that the presentation of the patient and the patients' problems were indeed singular in the dominant explanation model in official e-health rhetoric.

At the same time that the document study was carried out, a collaboration project with a colleague sociologist working on professionals' relation to health ICT was initiated. Through a comparison of the data from patient settings with data from a professional setting, the generality of the conclusion on local differences in the co-construction of health and ICT in everyday life, as well as the potential for such an approach to generate new theoretical approaches to sociological studies of health ICT was explored. As for the production of empirical material for this last slice of data, the analysis rested on the comparison of two case studies. One of them was a family's illness story, including their relation to the technology, presented in one of the interviews from the eczema project described above. The other was a story of professional use of a telemedicine solution for communicating CTGs from a fieldwork carried out by a colleague sociologist at the NST. The cases were used to enter a discussion on ICT and social inequalities in health. The interest for structural inequality and

social distribution of health corresponds to a foundation within medical sociology, where this is a central issue.

The last step in the process was to summarise the findings and slices of data in this executive summary.

Main findings

The research questions and analyses address performances of health and of the patient on three levels: a level of micro practice, a conceptual level and a structural level. In this chapter, I will sum up the findings from each level.

Micro practice

On a level of micro practice, my studies have found multiplicity in patients and patients' families relations to health ICT (Andreassen, 2011; Andreassen & Trondsen, 2008). The technology was integrated into everyday health and illness practice even when it was not used as "prescribed" by the developers and the health professionals who recruited the patients. The intention in the two cases that were studied was that patients used health ICT for communication with their doctor on treatment and illness related issues. In this way technology was expected to facilitate the dissemination of information and knowledge to patients, and thus contribute to improved coping and patient involvement. When technology was introduced in the patients' homes however, it turned out that this was only one of several changes that the technology opened for. In some situations in some patient families the technology was used as expected, as riverbeds of information. Nevertheless, patients also

related to the health ICT tools as security lines, as shields to the medical gaze, as tokens of health competence and symbols of attention from the health care system.

Moreover, in the medical encounter, the reception of the health ICT was varied rather than homogenous (Andreassen & Trondsen, 2008). We found that patients not only used the health ICT to get more involved, but also to transfer responsibility back to the doctor. This illustrates how health ICT gets involved in patients and health professionals' practical negotiations with the ideal of patient involvement, and that the technology cannot be predicted to have patient involvement as an outcome. Patient involvement is a contemporary ideal for how to be a patient that patients and doctors relate to in their everyday practices. When they are introduced with health ICT, the technology is integrated in negotiations of this ideal, which means that technology might also be included in practices where this ideal is opposed or ignored.

The variation and multiplicity in patient – ICT relations illustrates the need for research on lay use of health ICT that moves beyond measurements of user-frequency and questions of how the technology will affect medical encounters. Patients live their lives and they perform health and patientness both in relations to health care institutions and elsewhere. When new patient – oriented technologies are presented, some patients will integrate them in their doing of health and illness, which takes place in local contexts. In our particular historical context expectations of patient involvement are important. On one hand, this gives patients opportunities for influencing the outcome from meetings with health professionals, but on the other hand, it also imposes large responsibilities on the individual patient. My findings indicate that this particular situation is part of what the patients use technology to handle. They collect information, and they make suggestions and participate in discussions relating to

their biomedical treatment in certain situations. In other situations, however, they rely on technology to establish shields and distance to biomedicine and health-political ideals of patient involvement. Further, they also use technology in other contexts than in the exact communication with health care professionals. When health ICT is used as a token of competence, a consequence is that the patient underline his or her understanding and acceptance of an extended patient role; a patient role that goes beyond hospital visits and doctor visits and also require an active relation to biomedicine and health knowledge in everyday life. My argument is that this deserves attention, as it means health ICT that reaches patients' homes not only matters in the performance of a traditional sick role that involves illness practice and interpretations of the disease. Rather, it actually contributes to performances that might challenge the definitions of what it means to be an involved patient, and what we understand by healthy living.

Conceptual level

On a conceptual level, I have found that the notion of “the empowered patient” is central in health ICT discourses. The notion of the empowered patient appear in policy documents as well as in research literature (Andreassen, submitted; Andreassen & Trondsen, 2010). It has opened for interesting sociological reflections on conceptualisations of the patient and of the patient – technology relationship. I have found that whilst the ideals of empowerment and patient involvement have many aspects and sometimes is struggled with on a level of micro-practice, this is not the case in official rhetoric. The dominant explanation model in European e-health policies presents a rather limited, singular understanding of patient involvement/ empowerment and of the patient and his/her problems. The policies perform a rational patient consumer whose challenge is to choose on a health (and technology) market (Andreassen, submitted).

Structural level

In the introduction I referred to the WHO definition of health: “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 1948, p.100). Not all individuals can achieve this. For many, even the goal of reaching a few moments of “complete physical, mental and social well-being” during an average mid-winter week might seem out of reach. In light of such reflections, a solution can be to relate to the WHO definition as an aspiration, and the road towards it as stepwise. For sociology, a next question would then be: Who will succeed in climbing such stairs? My analyses illuminate how health ICT might be integrated in everyday practices where more than illness is performed. Through its integration in everyday life health ICT might also become important to the performance of phenomena such as ethnicity, place, gender and labour market participation, which are some of the variables that are used to map the distribution of health and illness in population statistics (Andreassen & Dyb, 2010).

On a structural level, the expectations are of health ICT to disseminate information and access to expert medical advice to the population. Health ICT is hoped to contribute to equality in access to health care and to improve lay populations’ qualifications and thus encourage self-care. The aim is to diminish the pressure on health care services at the same time as fighting inequalities in health. I suggest we need an alternative approach to highlight the potential for change that health ICT might hold on a structural level. Health ICT is not only an opening for dissemination of standardised information and patient education in static definitions of what health and healthy living means. Through offering symbolic attention, security provision and shielding from pathologising practices, health ICT might also contribute to the opposite; flexibility in the everyday performance of health and of the patient. Thus, technology might open for local adaption and differences. Such an approach would oppose the dominant

rhetoric that stresses technology as a tool to eliminate individual and structural difference through standardized information regimes. It includes the technology as an actor in local performances of health and of the patient. Technology opens for local discussions and definitions of what is “healthy” use of health ICT, and what should count as appropriate patient practice.

Discussion: Expected changes and changed expectations

This study does not allow for exact predictions of how health ICT will affect future patient care. It does, however, indicate some issues and questions that should be reflected on when discussing how patient-oriented ICT might matter in the future.

Mol claims that technologies have an active role in the shaping of contemporary care in that “Technologies do more than is expected of them. What is more; they change expectations” (Mol, 2008, p. 49). I have described how health ICT opening for electronic doctor – patient communication is expected to have certain effects for patients, but that in practice they end up doing more than what is expected. The technologies I studied did not have one, but multiple roles in patients’ everyday lives. The multiple roles of technology illustrate how research on health ICT in patient care need not only attend to political goals and hence dedicate itself to measure and display how technology contribute to expected changes, like cost savings, increased levels of self-care and patient involvement. To understand how ICT is involved in the performance of health and of the patient in contemporary society we also need to start a discussion on how health ICT that reaches patients’ homes might change more than is expected of them, and also contribute to change expectations.

Both patients' expectations of public health care and society's expectations of patients are constantly negotiated. When new technologies are introduced they get involved in these negotiations. An important question is whether new health ICT will contribute to mould or to dissolve the patient ideals and health understandings that dominate contemporary health politics. My findings indicate both things might be happening at the same time. On a conceptual level policy documents perform a rational patient consumer, and their presentation of the patient's problem as lack of information ends up supporting the ideal of patient compliance (Andreassen, submitted). In micro practice however, health ICT open for a new flexibility in patients' relations to the health care sector that might have consequences for the performance of health and local difference (Andreassen, 2011, Andreassen & Dyb, 2010). This might in turn have consequences for the distribution of health on a structural level (Andreassen & Dyb, 2010).

Expectations of patients

In the introduction, I described how changes in health politics and health definitions throughout the post war period have laid the foundation for an era where patient involvement in health care is not only possible but required. Simultaneously, the increasing weight placed on health promotion as one of the important tasks for public health care has contributed to blurring the boundaries between two groups of citizens: the patients and the potential patients. People are expected to respond to and act in accordance with medical advice not only in order to be cured, but also to avoid illness and promote health in the first place. In this study, I have followed health ICT for patient follow ups from their conceptual shaping in political and policy rhetoric, through the process of design and development within the health care sector and to their final destination, the homes of lay patient users. The studies illuminate how the expectations for these technologies are in line with overall political developments within the

health care sector. In policy rhetoric, as well as in design and planning, significant efforts are set on describing the potential for new health ICT to increase patient involvement. This is mainly sought through designing and conceptualising technologies as riverbeds of information. However, technologies do more than is expected of them, which is how they might end up not only changing health care in ways that foster more patient involvement, but also to challenge contemporary expectations of what patient involvement is meant to be. Technology permits new everyday practices, new ways to deal with health and illness and new ways of being a patient. Examples include the way they act as security lines ensuring safe surroundings for doing health in everyday life, and as shields that allow patients to distance themselves and the ones they care for from the pathologising effects of biomedicine. The studies have illustrated that health ICT might cause conflict when they bring to the surface fundamental differences in the ways that some doctors and patients conceptualise patient involvement. They open for new interpretations of patient involvement when they enable patients to strengthen their tie to their health professionals, but at the same time to keep the professionals and their advice at a distance in everyday health and illness management.

Expectations of patients are not only formulated from health professionals. “The sick role” is negotiated in numerous relations. Expectations of what patients are to do are formulated by doctors, but also by patients themselves, by technologies, by families, friends and relatives, employers, and judicial constraints defining rights for sick leave and social welfare. In addition, when new health ICT – patient relationships are built, new expectations might become the outcome.

At the core of official policy rhetoric lies expectations of patient-oriented ICT to fuel patients’ engagement in self-care and contribute to patients becoming health experts. If technologies

can act as security lines, this might strengthen expectations of patients to involve in self-care; they do have the help at hand and should thus be able to manage without unnecessary doctor visits. However, other outcomes are also imaginable, and more questions could be asked. For instance: How will a new constantly available security line affect the patients' own and the family carers' expectations of the ill person to relate to alternative treatments? When you are safe and secure through constant access to medical expertise from your home, why not try absolutely all treatments that exist? On the other hand, it can be hypothesised that the provision of a security line to chronically ill patients might cause some to decline rather than embrace most treatment opportunities in order to spend less time on illness and self-care; the doctor is at hand in case of an emergency anyway.

A discourse related to performances of health and of the patient that I have not related to in the papers' analyses is one on nature and natural living. Typically, health and nature are entities that overlap; healthy is defined as natural and natural is defined as healthy. But sometimes they do not (Beck-Gernsheim, 2000). One outcome of health ICT that can be imagined based on the findings presented in this thesis is that the patients themselves and their environments place expectations on the patient to establish boundaries towards professional advice and aspire natural living in the meaning "non pathologised practice". Can this fuel a patient ideal where patients are expected to seek distance and not involvement in biomedical practices? And can such patient practices be read as health ICT contributing to limit the reach; the where and when, of the patient status? This interpretation would be in opposition to conclusions that ICT implementations are mainly increasing patients' responsibilities to act as the doctors' agents in the private sphere. However, an important discussion is if the distanced patient really is a conflicting ideal to the involved patient, or if these are overlapping. Is a reflected distanced patient not, in fact, an involved patient who has truly been empowered and

used his or her power to define where and when to involve professional medical care? Is this the way that ICT is empowering the patient?

Expectations of health care

Expectations of patients are related to expectations of health care. In the introduction, I described how the mandate of public health care has changed from merely treating ill patients to also preventing illness and promoting health among citizens who are not yet ill. In health politics and policy, illness treatment and health promotion are two rather different tasks that require different kinds of effort and resources. The distinction between illness treatment and health promotion highlights differences in political and professional prioritising and practice, and is helpful when discussing resource allocations in the health care sector. In the everyday life of patients however, the distinction between illness treatment and health promotion is often fluid. This can explain some of the differences between expected changes and actual change that appeared in my material. Hospitals are highly specialised institutions dedicated to illness treatment. When a hospital offers a new service to its patients the expectations are formulated in relation to the hospital's agenda, which is to cure ill patients. Once a technological device introduced by the hospital reaches the patients' home, however, the technology is integrated in multiple health-related practices. The technology not only matters to the patients' actual day to day illness treatment, but also in everyday practices that could be labelled illness prevention or health promotion. Examples are patients' use of the technology as a security line in cases of emergency, and as a shield to what they label "pathologising" practice.

An important question for the organisation of future health care is whether the distinction between illness treatment and health promotion will be further blurred, and if this will affect

patients expectations to their health providers. Might illness treatment, the design of treatment plans and the prescription of drugs be reduced to less prominent tasks for doctors as patients grow in number and are increasingly focused on feelings of security and (technological) access to (everyday) health advice? And if so, how does the health care system handle such expectations? Is the solution to ignore them and keep on organising health care as before, to follow up on them, or to actively challenge them?

Concluding remarks

My empirical studies have shown that the outcomes of new technologies cannot be predicted or governed in advance. This is similar to previous research on human – technology relations (Akrich, 1992; Bijker, 1995; May, Finch, Mair, & Mort, 2005; Mol, 2002). To understand how patient-oriented health ICT matters to contemporary performances of health and of the patient, we need both to look into how this technology is “prescribed” to be used, and how this “prescription” is received in patient settings. Policy plans and professional rhetoric perform their version(s) of health and patientness. In everyday practice patients and technologies perform versions that might be similar or different.

Health ICT matters to patients through its integration in the performance of these very entities: health and patients. Like many other technologies that are present in our homes, such as TV’s or mobile phones, health ICT invites moral reflections about their use (Sørensen, 2006). How often are they turned on? Is it wrong to use them too often? Or never to use them once you have them? When it comes to the particular technologies that I have studied on health ICT directed towards patient users and that can be used to communicate with health professionals, these moral discussions on use are linked to the understandings of what health and patientness is supposed to be. The findings in this study illuminate that the importance of

patient oriented ICT in the moral and social performance of health and of the patient also go beyond such discussions on use. Patients relate to ICT in a number of situations. Some of these relations remain invisible in user statistics, e.g when patients rely on ICT as a security line this need not involve hands on use. Non-use and alternative uses deserve equal attention in discussions on how health ICT matters to performance of health and of the patient in contemporary society.

With regard to theory, I have argued that the diffusion of health ICT into lay patient spheres is best studied through a combination of perspectives. A question raised in this thesis is if there are possibilities for establishing a social science position from where we can discuss health and technology as flexible micro practices and at the same time address historically situated structures (Andreassen & Dyb, 2010). The analyses presented suggest the answer might exist in combining the STS relational approach to technology with traditional medical sociology approaches to study the structural aspects of health and medicine. STS illuminates how technology matters, not only as a passive tool, but through engaging in micro level relations with other actors such as patients, doctors and local contexts. Through concepts such as medicalisation (Conrad & Schneider, 1980; Illich, 1976) and an interest for social inequalities in health (Scambler, 2002), medical sociologists have identified differences in patient and health professional power and approaches to everyday health and illness management. These perspectives have enabled sociology to search for and bring to the forefront both patient and professional perspectives, and not presume them to be overlapping. This is how these insights should inform studies of patient-oriented health ICT.

The thesis presents the outcome of applied social science research in the health care sector, which requires some conclusions on *how* it can be applied. For the policy field, a main

message is that the singular explanation model where a rational patient consumer uses passive ICT to download and send off information can be adjusted. This currently dominant model for describing the patient – ICT relationship has limited explanatory value in practice. If patient empowerment means patient consumerism and creating rational patients making informed choices on as many details as possible, then the concept is not applicable to describe the complexity in how health ICT matters for patients. My findings indicate that these expected changes do not always go as planned, and are not the only outcomes of introducing health ICT in patient homes. However, if we interpret patient empowerment to mean health care sector flexibility and openness for the patient to perform situated versions of health and of the patient in their local context, then it might be a suited concept to describe some of the changes that patient-oriented ICT permit. For health professional practice, it should be an interesting finding that the ICT's I have studied (electronic addresses to health providers) in some situations seems to matter more for patients' feelings of everyday security and for their ability to distance themselves from their illness in everyday life, than for their involvement in medical decisions and treatment programs. Health ICT that has been implemented in patients' homes matters in more situations than the actual treatment practices and doctor – patient communications.

When health ICT and patients meet in everyday health and illness practice they do health management. Not only do they manage professional prescriptions, treatment procedures and healthy diets and exercise. They also manage doctor – patient relationships, social expectations of patient involvement, patient responsibilities and structural powers. Haraway (2008, p. 15) suggests that through meetings between nature, culture, science and technologies, “the great divides ...flatten into mundane differences – the kinds that have consequences and demand respect and response – rather than rising to sublime and final

ends.” In the case of health ICT meeting human doctors and patients and their illnesses, there are two main divides that are potentially minimised: the involved/ the uninvolved patient and healthy / unhealthy living.

Summary of the papers

From different angles, all 5 papers included in this thesis shed light on how patient-oriented ICT matters to performances of health and of the patient.

1. Andreassen & Trondsen (2008). Pasient på e-post (“patient on e-mail”). In Tjora (edt.) *Moderne pasienter* (“modern patients”). Oslo: Gyldendal.

Based on an interview study among patients and their general practitioners, this paper illuminates how new technology matters in patient-doctor interactions. The paper set out to discuss the research question; “Will the ‘effect’ of introducing ICT solutions be patient involvement? And will this ensure the patient a stronger position (empowerment) in relation to her/his doctor?” The patients and doctors included in the study had participated in the piloting of an electronic communication tool, PatientLink, for one year. Differences in use and experiences were identified and discussed. The variation was interpreted to relate to the patients’ and the doctors’ “affordances” (Hutchby, 2001), to the tension between a patient – and a doctor-centred model for the clinical encounter and to the technology itself and the “scripting” of it (Achrich, 1992). The analysis revealed a need to go deeper into the topic of ICT and patient empowerment and involvement.

2. Andreassen, H. & Trondsen, M. (2010). The empowered patient and the sociologist. *Social Theory and Health*, 8(3), 280-287.

The second paper included is a discussion paper. In this paper, the general use of the empowerment concept in health and studies thereof is pursued. The paper seeks to answer how the concept of empowerment is related to the opposing traditions of realism and constructivism in social theory. The paper explores use as well as critique of the idea of patient empowerment in medical sociology and related literature. Conflicting approaches related to basic differences between realist and constructivist methodologies are identified. The paper argues there is a need to discuss the relevance of focusing on patient empowerment in health care. At the same time, it is underlined that sociology needs to take seriously the micro level changes associated with the empowerment paradigm in health promotion. Thus, this paper guided the empirical look towards patients' actions in micro level settings.

3. Andreassen, H. (2011). What does an e-mail address add? Doing health and technology at home. *Social Science and Medicine*, 72(4), 521-528.

Paper number three reports from 12 in-depth interviews with parents of children diagnosed with atopic eczema, who were offered the possibility to communicate electronically with their children's hospital specialist. The project was called "Web based eczema counselling". The research question for the paper reads: "How are e-health technologies integrated in patients' everyday performance of health and illness?". Contrary to the first study, this one excluded the doctors, and directed its full attention towards the patient users and their own descriptions of how they related to the health ICT tool in their homes and everyday lives. As an analytical approach, the electronic *address* was identified as the technology to be investigated, instead of the actual messages sent or the software used. This allowed for a broader range of experiences and everyday situations to be included in the analysis. The presence of the address might matter to the patients (or as in this case, the parents of patients), also in all of those moments when it is not used. This analytical move revealed frequency of use as an insufficient

indicator of technology-importance and a restraining starting point for research on patients' relations to health ICT. A patient perspective on health ICT needs to include everyday practices that go beyond the moments of treatment and professional contact. Technological tools have multiple roles in private settings and a micro level everyday focus is necessary when trying to understand health technologies and health and illness in the making.

4. Andreassen, H. (submitted). E-health is the solution; what is the problem? *Health Policy*: submitted.

The fourth paper is a document study and a discourse analysis. It illuminates how e-health is conceptualised in political and policy rhetoric in the European Union (EU). In this paper, official e-health documents from the EU are subject to a conceptual analysis, tracing the dominant explanation model on patients and ICT. In line with Law's (2009) analysis of how the Eurobarometer survey limits our vision and our conceptualisations of the European consumer, the analysis aim to highlight how these documents contribute to one particular version of the patient ICT user being performed and enacted, whilst other versions that exist and are possible are elbowed out. The research question read; "what's the patient's problem presented to be in European e-health policies?" The analysis reveals how two discourses overlap in e-health rhetoric; a discourse on 'patient involvement' / 'patient empowerment' is woven into one on (patient- and health) consumerism. This is the background for the e-health paradox; a rhetoric explicitly leaning on a discourse of patient involvement and empowerment, that in practice ends up strengthening an ideal from an opposing discourse on patient compliance. The paper show how the patient- ICT relationship is conceptualised as a relationship between a passive technology and an active rational consumer human. The limitations, practical consequences and possible alternatives to such an approach are discussed.

5. Andreassen, H. & Dyb, K. (2010). Differences and inequalities in health – empirical reflections on telemedicine and politics. *Information, Communication and Society*, 13(7), 957-975.

The fifth and last paper included in this work presents two empirical cases: one from the patient interview study reported in paper number 3, and one from an observation and interview fieldwork among health professionals. Through the empirical examples, the discussion on differences in use outlined in papers 1 and 3 is followed up on and related to a major discussion within medical sociology: the one on social inequalities in health. In line with Haraways (2004) reflections on the need for technology in practice studies to deal with asymmetry as a historical structural problem the paper aims to answer the question: “How might an analysis of the performance and co-construction of IT and health in local settings reveal alternative ways of understanding relations between new IT and social inequality in health?” In line with the analyses in papers 1 and 3, the empirical material illustrates how ICT can be a resource for patients and health professionals in ways that go beyond the explicit political and professional expectations. It argues an approach to the relationship between patients and ICT that departs from the fundamental question on how ICT matters for everyday health performance might provide us with new tools to explore social inequalities in health, and that contrary to the dominant discourses within policy and political debates (as outlined in paper 4), these might foster a new understanding of how ICT matters to social inequalities in health.

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Articles 1-5



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