**KTH Computer Science
and Communication**

To Share or Not to Share?

Expectations of and Experiences with eHealth Services
that Allow Users Access to their Health Information

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Abstract

This thesis investigates expectations of and experiences with eHealth services that allow users access to their health information. Although eHealth services are endorsed by many politicians and patients, they are met with strong resistance by health care professionals. Lacking this support hinders the uptake of the full potential of the service, especially with relation to patient participation and empowerment.

This research investigates the frames of reference that are constructed by stakeholders in relation to eHealth services, such as direct-to-consumer genetic testing and electronic health records. The results are based on empirical data gathered during an experiment with media informatics students in Germany, and from interviews with physicians in Uppsala, Sweden.

The eHealth services in question were framed by the participants of the conducted studies as potentially harmful for its users. The negative expectations were based mainly on a generalized view of patients as not sufficiently knowledgable and hence unable to understand the health information provided by the service. The participants in the reported studies (physicians and students in their role as designers) felt a responsibility to prevent any potential harm for the users of the eHealth service. Due to the framing based on assumed negative consequences for a supposedly vulnerable user group, the participants preferred to advocate against access rather than for patient empowerment and participation. Accessing health information was associated as holding little value for the users.

This research enhances the understanding of the elements underlying this skepticism and concern. It shows that a specific view of patients and/or prospective users of an eHealth system can result in incongruent technological frames and value attribution. In line with participatory and value-sensitive design approaches as well as the aim to increase technology acceptance, patients and health care professionals should not only be included in the design process but also engage in joint activities in order to enable reframing.

Sammanfattning

Avhandlingen undersöker förväntningar på och erfarenheter av e-hälsotjänster som ger användare tillgång till sin egen hälsoinformation. Även om e-hälsotjänster har fått stöd av många politiker och patienter har de mötts av starkt motstånd från sjukvårdspersonal. Utan deras stöd blir det svårt att realisera tjänstens fulla potential, särskilt när det gäller patientens delaktighet och egenmakt.

Forskningen undersöker de referensramar som konstrueras av intressenter för att förstå e-hälsotjänster, till exempel genetisk testning direkt till konsument och elektroniska patientjournaler. Resultaten baseras dels på empiriska data som samlats in i ett experiment med studenter i Tyskland, dels på intervjuer med läkare i Uppsala.

De undersökta e-hälsotjänsterna upplevdes (were framed) av studiernas deltagare som potentiellt skadliga för användarna. De negativa förväntningarna baserades huvudsakligen på en allmän syn på patienter som inte tillräckligt kunniga och därmed oförmögna att förstå tjänstens hälsoinformation. Deltagarna i de rapporterade studierna (läkare och studenter i rollen som formgivare) kände ansvar för att förhindra eventuella skador för e-hälsotjänstens användare. Beroende på de förväntat negativa följderna för de förmodat utsatta patientgrupperna föredrog undersökningens deltagare att ta ställning emot patienternas åtkomst snarare än att ta ställning för deras deltagande och ökade egenmakt. Att ha tillgång till hälsoinformation bedömdes vara av lågt värde för användarna.

Forskningen ökar förståelsen av de element som ligger till grund för deltagarnas upplevda skepsis och oro. Den visar att en specifik bild av patienter och/eller framtida användare av ett e-hälsosystemet kan leda till inkongruenta tekniska referensramar och värdebedömningar. I linje med inriktningarna deltagande design och värdebaserade design samt målet att öka teknisk acceptans, bör patienter och hälso- och sjukvårdspersonal inte bara ingå i designprocessen, utan också delta i gemensamma aktiviteter för att möjliggöra omtolkningar av sina tekniska referensramar.

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Acronyms

QS Quantified Self. 2

SUSTAINS Support USers To Access INformation and Services. 19

TF Technological Frames. 12, 13

Preface

This thesis investigates aspects of Human-Computer Interaction (HCI) in health-care, especially with regard to eHealth services. Both domains, HCI and healthcare, are also part of my background. After leaving high school I was trained as a medical assistant at a General Practitioner. After three years of training, I worked for another five years in my profession at a Urologist. It was not before 2005 that I started my studies in Media Informatics at TH Köln University of Applied Sciences, in which HCI is an integral component of the curriculum.

In the course of my PhD research I started to collaborate with other researchers who are part of the research project *Deployment of Online Medical Records and E-Health Services (DOME)* and became a project member myself. DOME is a collaborative consortium between different universities (University of Lund, University of Skövde, Uppsala University, Örebro University, and KTH Royal Institute of Technology Stockholm) and is funded by VINNOVA, the Swedish Governmental Agency for Innovation Systems. The project's purpose is to *"build knowledge about the implementation and the use of eHealth services"*, especially electronic health records (DOME 2015). The data analyzed in Paper II and III was gathered in advance in the DOME project prior to my participation.

The title *"To Share or Not to Share?"* is a modification of the phrase *"To be, or not to be…"* in Shakespeare's play *Hamlet*. The aim here is to elucidate the indecisiveness when it comes to sharing health information with patients and consumers. While for example many patients and patient advocates deem access to the health records as important, health care professionals are deeply worried what this would do to their patients.

List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

Paper I	**Using Online Reviews as Narratives to Evoke Designer's Empathy**
Authors	Christiane Grünloh, Åke Walldius, Gerhard Hartmann, Jan Gulliksen
Publication	Proceedings of 15th IFIP TC.13 International Conference on Human-Computer Interaction - INTERACT 2015, Bamberg, Germany. September, 14-18, 2015.
Short Summary	This conference paper describes a quasi-experiment in which we examined whether narratives in form of online reviews are able to evoke designer's empathy when developing an online platform for a direct-to-consumer genetic testing service. The results suggest that narratives can help designers to engage with and take the perspective of the prospective user, who is then represented in more detail. We conclude that lacking narratives from real people leaves the designers to their own imagination, which can lead to the use of rather abstract stereotypes that do not enable an understanding of the user, but affect the subsequent design decisions.
My Contribution	I am the main author of this paper. The study was elaborated and designed by all authors. I was responsible for preparing and conducting the experiment, the data collection, analysis of the collected data, writing of the paper, and presenting it at the INTERACT 2015 conference. Feedback has been given by the co-authors.

Paper II	**Worlds Apart - Doctors' Technological Frames and Online Medical Records**
Authors	Åsa Cajander, Christiane Grünloh, Hanife Rexhepi
Publication	Adjunct Proceedings of 15th IFIP TC.13 International Conference on Human-Computer Interaction - INTERACT 2015, Bamberg, Germany. September, 14-18, 2015. Workshop on Interactivity in Healthcare Systems.
Short Summary	This workshop paper describes the analysis of interviews with two oncologists in relation to online medical records. The main focus in the analysis was to understand the expectations and assumptions towards patients accessing their medical records online, in particular with relation to Patient Empowerment. We conclude that medical doctors have different assumptions and perspectives, that affect their use of technology.
My Contribution	I am an important contributor to this workshop paper. The interviews have been conducted previously by other researchers in the DOME project. All three authors of this paper contributed equally in the analysis of the data and had a joint responsibility for writing the workshop paper.

Paper III	**"The Record is our Work Tool!" - Physicians' Framing of a Patient Portal in Sweden**
Authors	Christiane Grünloh, Åsa Cajander, Gunilla Myreteg
Publication	Journal of Medical Internet Research (forthcoming). doi:10.2196/jmir.5705

Short Summary This journal paper presents the results of a qualitative study where interviews with twelve physicians from different specialties (Oncology, Orthopedics, Emergency Medicine, Internal Medicine) are analyzed and discussed based on the theory of Technological Frames. We conclude that transferring paper-based processes into digital processes has consequences for the work environment, e.g. change of work practices. The physicians mainly expressed concerns, which based to some extent on a generalized view of patients.

My Contribution I am the main author of this paper. The interviews used for this journal paper have been conducted previously by others researchers in the DOME project. Analysis and coding was mainly done by the first and second author, while all authors contributed in discussions and in writing of the paper.

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Contents

Chapter 1

Introduction

Several industries have faced dramatic changes due to the introduction of Information and Communication Technology (ICT) in their respective sector (cf. Topol 2015, p. 5), e.g. online banking in finance; eBooks, music streaming, and video-on-demand services in entertainment; web 2.0 technologies in journalism. Technological developments revealed tremendous opportunities, but were also accompanied by concerns and challenged traditional business models to some extent. The aforementioned technologies for example provide customers 24/7 access to content via the Internet - on demand services, regardless of opening hours - and also empower them to take action themselves (e.g. produce and publish content). At the same time the concerns were manifold, e.g. regarding data security (online banking), threat to revenue (media industry), or even threatening the right to exist (publisher), while also on the company side opportunities like cost reduction (e.g. lower production and distribution costs) and new business models emerged (e.g. video on demand; music streaming).

The use of the Internet has increased profoundly. According to the World Development Report, the number of internet users has more than tripled in the last decade from 1 billion to an estimated 3.2 billion (World Bank 2016). Most of people's everyday life is influenced, organized, or supported by information or services online - often immediately on demand. It is not surprising then, that this kind of technological support and on demand services are emerging also in healthcare. Some are predicting that this will radically change the way healthcare is provided and received (e.g. Topol 2015). Powerful technologies that are increasingly available and affordable have already enhanced the opportunities for people to not only gather data themselves, but also acquire information, exchange with others, and educate themselves. What may have started in the consumer market in terms of self-tracking apps or wellness gadgets is more and more also entering the healthcare domain. People are becoming more aware and more active regarding their lifestyle and behavior and it seems to be a natural consequence that they also want to have access to their health information, e.g. to complete and combine their own records

with those generated and stored by others. National and international strategies consider the development of eHealth services as a way to increase patient participation and patient empowerment and by this to improve also the quality of care in general (e.g. European Commission 2010). However, due to the sensitivity of health information and the role clinical documentation plays in healthcare, people considered as 'laypeople' accessing this kind of information independently raises considerable concerns and resistance, e.g. among health care professionals. This thesis focuses on users' access to their health information via online services like Direct-to-Consumer (DTC) genetic testing services and Electronic Health Record (EHR) and the conflicts that arise between the involved actors.

1.1   Problem Description

Technological innovations, e.g. in-built sensors in smartphones enabled the development of self-tracking apps and even the rise of a movement: the Quantified Self (QS). QS is a community, where *"both health enthusiasts and diagnosed patients meet in an environment of trust to share the quantified self-tracking projects they have been doing in the format of monthly show-and-tell groups"* (Swan 2012, p. 108). Devices, services, and apps can be sold directly to consumers, who are then able to take on more responsibility and to engage in their own healthcare. Self-management is however not a new phenomenon. Diabetes patients for example are already responsible for 98 % of their own care (Anderson & Funnell 2010, p. 4). The possibility to track health related data e.g. with a smartphone and aggregate those to useful information through apps, makes it more convenient and comfortable to track even more data than one may initially have thought about (e.g. tracking sleep cycles). Taking together all this data from an unthinkable number of users opens up research opportunities, which has been seized by Apple recently. The company developed a framework named *ResearchKit* in order to connect medical researchers with people affected by the specific disease they want to investigate, e.g. Autism, Epilepsy, Melanoma, Asthma (Apple Inc. 2015). By use of the *ResearchKit* researchers can develop specific apps for study purposes, which simplifies the recruiting and data gathering process in that potential participants simply download the app in order to take part in the study.

While providers of medical products have to apply for approval by regulatory authorities (e.g. Medical Products Agency (MPA) in Sweden), services that are not clearly identifiable as medical-related might be able to evade these processes. Although for example the Apple Watch is capable to track several health related data, the CEO Tim Cook recently stated, that they *"don't want to put the watch through the Food and Drug Administration (FDA) process. I wouldn't mind putting something adjacent to the watch through it, but not the watch, because it would hold us back from innovating too much, the cycles are too long"* (Heath 2015). Those devices adjacent to a smartphone enable also non-professionals to perform medical tests autonomously without having to consult a physician (e.g blood pressure

(Withings 2015), blood glucose (iBGStar 2015)). Even urine tests can be performed by help of the smartphone, e.g. Scanadu (2015) which is seeking FDA clearance for their urine test kit. While patients living with chronic diseases used medical devices before, the combination with a smartphone or tablet offers more opportunities, e.g. in terms of visualization, automatic long-term documentation, and the combination of different data sources.

Another service has gained much attention: Direct-to-Consumer genetic testing services, which offer testing kits for genetic analysis directly to the consumer, i.e. without necessitating contact to a health care professional. That there is a growing demand for DTC genetic testing services can be seen in that the Global Testing Market accounted for $ 3.2 billion in 2014 with expected growth in the years to come (PR Newswire 2015). As Caulfield & McGuire (2012) concluded in their comprehensive view on DTC genetic testing, the field has tremendous potential, but also rises social, ethical, and regulatory concerns. The emotional consequences of negative results is one of those concerns, e.g. that learning about having a predisposition to a serious disease might lead to undue anxiety and distress. However, research indicates that this concern might be unsubstantiated, in that the provision of genetic risk information has little influence on neither the psychological state nor the subsequent behavior (Caulfield 2011, p. 24).

Similar concerns about causing anxiety have been expressed when it comes to giving patients access to their Electronic Health Record. What might be seen as repurposing the professionals' work tool for clinical documentation, can also be interpreted as a continuation of the digitalization of previously paper-based processes. In many countries citizens have the right by law to inspect or request a copy of their health records in writing or in electronic format, except for cases in which a therapeutic reason militate against inspection (cf. § 630g German Civil Code *Inspection of the medical records*; Swedish Patient Data Act 2008:355). There are many potential benefits for patients accessing their health records, e.g. memory aid, appointment preparation, increasing the understanding of their medical issues, improving the communication and interaction with the physician (Fisher et al. 2009; Rexhepi et al. 2015). However, health care professionals are concerned for example that a) by sharing their notes, patients might get worried, b) that patients do not understand the medical language in the records and thus ask numerous questions, and c) that changing the way of writing would decrease the efficiency of the communication between the doctors (Walker et al. 2015, p. 3). While further research is still needed, research in the U.S. showed minimal effect on doctors who shared the records (Walker et al. 2015, p. 3). In Uppsala County the deployment of an eHealth service that gives patients access to their EHR was met with considerable resistance. The doctors viewed the EHR as their working tool and contested patients' access altogether (Erlingsdottir & Lindholm 2014, p. 22).

Different views on risks and benefits of patients' access to EHR influences the deployment and adoption of these kinds of eHealth services. Active resistance or inertia instead of endorsement by health care professionals might even lead to a low adoption of eHealth services by patients. Within patient-centered care the active

engagement of patients and the respect of individual patient preferences, needs, and values is paramount, which *"highlights the importance of clinicians and patients working together to produce the best outcomes possible"* (Barry & Edgman-Levitan 2012, p. 780). This highlights that healthcare is a collaborative endeavor. *"If we build it, they will come"* is not going to happen, if *"the desired improvement conflicts with what people are motivated to do"* (Markus & Keil 1994, p. 24). The aim of an eHealth service to increase patient participation might not be achievable, if health care professionals have fundamentally negative attitudes towards the system.

The deployment of eHealth services is also dependent on the local regulations, national laws, and structures in health care, which differ between the countries to some extent. Comparing the U.S. with other countries of the Organization for Economic Co-operation and Development (OECD) for example, differences are related to the amount of expenses, the share of health expenditures funded by government, and the mix of services that are provided (technology intense versus more basic care) (Fuchs 2013). The systems and laws in the different countries are of course also subject to change, as seen in e.g. the introduction of the Affordable Care Act in the U.S. (Kocher et al. 2010), or law changes to respond to technological developments such as the Patient Data Act in Sweden (Erlingsdottir & Lindholm 2014, p. 16). The particular legal and structural situation with relation to health care have to be taken into account when developing an eHealth in this particular country. In the same way, the applicability of this thesis' results have to be evaluated in terms of possible regional differences that may interfere. For example, telemedicine and eHealth services may be rather welcomed in regions where hospitals and medical practices are scarce and waiting times for a personal encounter are lengthy. Another example refers to concerns related to work processes, which might be not transferable to other work places that have different structures and work flows.

However, in order to get people on board who are reluctant or openly negative towards a system, it is important to understand their expectations and interpretations of the system and its purpose. In particular regarding health care professionals, it is important to understand also how they experience and assess the effect of the system on their work environment and on the relationship with their patients. This investigation might uncover misunderstandings, misinterpretations, or design implications that should be addressed in the development and deployment process.

1.2   Stakeholders

A *Stakeholder* has been defined as an *"individual or organization having a right, share, claim or interest in a system or in its possession of characteristics that meet their needs and expectations"* (ISO 9241-210 2010, p. 3). The stakeholders of eHealth services that allow users access to their health information are manifold, e.g. health care professionals (HCPs) (e.g. physicians, nurses, doctor's assistants, etc.), patients and their relatives, governmental organizations like the ministry of

health and regulatory authorities[1], system developers, and vendors. This list is not exhaustive. Depending on the focus of research there may be other stakeholders to be involved as well (e.g. advertising industry, who might be interested in the data). Friedman et al. (2002, p. 3) emphasize the importance to consider not only the direct but also the *indirect* stakeholders, who too often have been ignored in systems development. While direct stakeholders interact directly with the system or its output, indirect stakeholders are all other parties who are affected by the system. Interestingly, Friedman et al. (2002, p. 3) exemplify this with the development of Electronic Medical Record (EMR) systems, where too often the patient has not been considered in the design process.

In the system engineering process used for the eHealth service development in Uppsala, patients were identified as the end-user and represented in terms of three personas (an old demented woman and her relatives, a disabled child and his parents, and a woman with multiple diagnoses) (Scandurra et al. 2013, p. 376). The medical profession as such, however, *"was not really perceived as a legitimate actor in the development process"* (Erlingsdottir & Lindholm 2014, 20), despite raised concerns that enabling access to EHR could potentially harm patients. Although health care staff are not the primary users of the eHealth service, they are nevertheless providing the content of the EHR and therefore could affect the service as such in a negative way (e.g. by changing the way of documenting their work) (Lind 2014, p. 31). Additionally, the doctors consider themselves to be "affected" by the service in terms of increased workload.

The main focus within this thesis is on the stakeholders who are directly involved in the design, provision, and utilization of an eHealth service (Paper I) and in generating and accessing the Electronic Health Record (Paper II, III). The stakeholders are categorized as follows:

Designers are all people involved in the design and provision of eHealth services, that enable its users accessing their health information (e.g. results of genetic testing services, EHR). These are especially addressed in Paper I, because their views and attitudes influence the design of the end-product.

Accessors comprise all people who access health information of themselves (i.e. consumers, patients, citizens) or next of kin (e.g. records of their children, care recipients, relatives, spouse, etc.). It should be noted, that for the scope of this thesis, these stakeholders were not directly involved in the studies described in the papers, but were considered implicitly.

Health care professionals (HCP) entail all medical staff who are generating and accessing health records for professional purposes (e.g. physicians, medical assistants, nurses, etc.).

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[1] e.g. FDA in the U.S., Medicines and Healthcare Products Regulatory Agency (MHRA) in the UK, MPA (Läkemedelsverket) in Sweden, Bundesinstitut für Arzneimittel und Medizinprodukte (BfArM) in Germany.

1.3   Research Question

This thesis focuses on eHealth services that enable its users to access their health information, which is seen as having the potential to contribute to patient empowerment. However, the development is accompanied by concerns and resistance. In order to better understand this situation, the research question is formulated as:

>   *What are the frames of reference of different stakeholders regarding*
>   *eHealth services that allow users access to their health information?*

In this thesis, the concept of *frames* comprises the assumptions, expectations, knowledge, and experiences that are applied by the individual to understand the technology, i.e. the eHealth service in question. The concept is described in more detail in section 2.2. *Health information* refers to the aggregation of data related to a person's health, e.g. test results or clinical notes stored in an EHR. Data can be considered as pieces or bits of information (e.g. a single blood test result), that is then processed and structured. This understanding of data and information is based on the definition by Davis & Olson (1985) as cited in Liu et al. (2012, p. 13):

>   "Information is data that has been processed into a form that is
>   meaningful to the recipient and is of real or perceived value in current
>   or prospective action."

Attempts to label the target audience for eHealth services for accessing health information turns out to be a predicament. For the aforementioned genetic testing services, the acronym DTC for *direct to consumer* has already been established, hence one might be tempted to label the target audience 'consumers'. However, this would be a bad fit to the target group for EHR. As Deber et al. (2005, p. 346f) pointed out, this label carries also connotations and implications: "Implicit in consumerism is that the consumer is the sole arbiter of his or her needs, and that the role of the tradesman is to satisfy them." In relation to a the EHR the label 'patient' is mainly used, which carries connotations of passivity and deference to physicians due to the origin of the word (having/showing patience, suffering) (Deber et al. 2005, p. 346). In a study investigating preferred labels for people receiving health care, Deber et al. (2005) found that the respondents tended to reject most of the alternatives to replace 'patient' (such as consumer, client, partner, survivor, or customer). However, 'patient' was not strong supported but rather moderately preferred, while it remains unclear whether healthy individuals would endorse such a label (Deber et al. 2005, p. 350). A similar discussion takes place in HCI around the term 'user'. According to Norman (2006), labels like 'user', 'customer', and 'consumer' are degrading and thus one should talk about 'people', 'person', or 'humans'. However, in this research, 'people' or 'person' would be ambiguous for example in relation to medical staff, who also access the EHR.

Lacking an all-encompassing label, this thesis talks about 'users' to refer to people who use an eHealth service to access health information of themselves or

next of kin. Hence, this includes both the DTC genetic testing and the EHR. When discussing a particular eHealth service, and when describing how participants referred to the person in question, the corresponding label 'customer' or 'patient' will be used.

1.4 Delimitations

This thesis focuses on users' access to their health information in general and on users' access to the their EHR in particular. Services aiming to connect patients supporting each other (e.g. patient networks and platforms like `healthtalk.org`, or `patientslikeme.com`, or doctor review websites like `healthgrades.com`) are outside the scope of this thesis. Furthermore, systems used in health care by HCP only are also not considered.

The experiment in Paper I has limitations in that it entailed a limited number of participants, which were students in Media Informatics. The results might therefore not be directly applicable to professional designers with several years of experience.

In the interview study described in Paper II and III only physicians have been interviewed, hence other relevant stakeholders were not included in this particular study (e.g. patients, their relatives, and HCP apart from physicians). Additionally, the investigated experiences with the deployed eHealth services are related to the time after launch until the interviews took place (i.e. about 6 months). These issues will be addressed in future research, where follow-up studies are supposed to include the aforementioned stakeholders and address long-term experiences with the system (see chapter 6 Conclusions and Future Research).

Regarding access to EHR via the Internet, this thesis focuses on the deployment of eHealth services in Sweden, particularly in Uppsala County. According to the *EU eHealth Action Plan 2012-2020* and the *Digital Agenda for Europe*, other European countries can be expected to implement similar services in the future (European Commission 2012b). The results and conclusions presented in this thesis may not or only partly be applicable to other countries, e.g. due to varying national legislations (e.g. a new eHealth Act is currently being drafted in Germany (BMG 2015)). Furthermore, the process of development and implementation was unique in Uppsala (cf. Erlingsdottir & Lindholm 2014). However, although not all results may be applicable to other counties and countries, still much can be learned from this real life project in Uppsala, e.g. understanding of technological frames in relation to technology acceptance.

Finally, eHealth services that aim to enable patients to access their EHR require the availability of the technology and often also Internet access. However, according to the recent World Development Report, the digital divide still persists in that "nearly 60 percent of the world's people are still offline and can't participate in the digital economy in any meaningful way" (World Bank 2016, p. 2f). Thus, aiming for an increased patient participation through ICT excludes inevitably parts of the population, which is however also outside of the scope of this thesis.

Chapter 2

Theoretical Background

This chapter is dedicated to the theoretical background of this thesis. In the first section a brief overview of Human-Computer Interaction HCI and its development over time is given. Afterwards two important concepts underlying this research are introduced and discussed: Technological Frames and Patient Empowerment. The closing section deals with eHealth services that provide access to health information, in particular direct-to-consumer genetic testing and online accessible Electronic Health Record.

2.1 Human-Computer Interaction

In 1992 Human-Computer Interaction has been defined as "a discipline concerned with the design, evaluation and implementation of interactive computing systems for human use and with the study of major phenomena surrounding them" (Hewett et al. 1992). HCI is an interdisciplinary research field, which developed as sub-disciplines in the three fields human factors, management information systems, and computer science (Grudin 2011, p. 369). The tremendous technological progress in the last five decades also affected the HCI field, especially regarding research focuses, which is discussed in the following.

Several authors have identified and discussed three stages of development or research threads in HCI, albeit under different terms[1] like *faces* (Grudin 2005), *waves* (Bødker 2006, 2015), or *paradigms* (Harrison et al. 2007, 2011). This way of analysis, i.e. an evolvement of HCI through stages, was recently challenged in that it would be a mistake to suggest that the old problems have completely lost their significance (Oulasvirta & Hornbæk 2016). However, as Harrison et al. (2007) emphasize, evolving or new paradigms do not disprove or dismiss existing ones, but rather co-exist and provide alternative ways of thinking. Therefore the stages will be summarized briefly in order to enable a framing or positioning of this thesis.

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[1] In the following, the term 'stages' will be used as an umbrella term.

Grudin (2005) discussed three "faces" of HCI, which evolved from Human Factors and Ergonomics (HF&E) research for computer operation to Information Systems (IS) management in business computing. The focus of HF&E and IS on improving efficiency shifted after computer use by choice became more popular, which resulted in HCI focusing on individual and discretionary use. People also learned that software is flexible, which increased the expectations that had to be addressed by competing vendors in terms of usability and ease of use (Grudin 2005, p. 48).

Bødker (2006) identified three "waves" of HCI, which reflects the moving character of the field. She builds on the transition from *human factors to human actors* identified by Bannon (1991), which constitutes the shift from first to second wave HCI. The *first wave* was highly influenced by human factors and cognitive science and focused on human beings as study subjects (Bødker 2015), like the first face described previously. Grudin's *second face* and Bødker's *second wave* are also quite similar in that both describe a step from the individual towards group work and work processes. The *third wave* however is not solely about discretionary use as described by Grudin, but is characterized by broadened and intermixed use context and application types, which now also include culture, emotion, and experience (Bødker 2006, p. 1f).

According to Harrison et al. (2007, 2011) each "paradigm" in HCI implicates a particular metaphor of interaction, which brings certain phenomena into the center of investigation, while consequently marginalizing others. At the same time, an underlying metaphor also suggests questions that are interesting to ask and methods for arriving to answers (Harrison et al. 2007, p. 4). A paradigm shift then occurs, when problems that used to be marginalized are brought to the center. Similar to Grudin and Bødker, the *first paradigm* is related to engineering and human factors. The underlying metaphor for interaction is "man-machine coupling", where meaning and meaning construction is mostly ignored (Harrison et al. 2007, p. 7,10). The metaphor of the *second paradigm* regards interaction as information communication and consequently understands meaning in terms of information flow (Harrison et al. 2007, p. 7,10). According to Harrison et al. (2007, p. 7) research in both paradigms tended to focus on aspects of activities that are easily automated. The shift towards a new, *third paradigm* is characterized by the metaphor of interaction as phenomenologically situated and a central focus on meaning and meaning construction. Although meaning derives from information, it cannot be summarized in terms of an information flow; instead it is connected to "viewpoints, interactions, histories, and local resources available to those making sense of the interface and therefore to some extent beyond the reach of formalization" (Harrison et al. 2007, 7). According to the authors, third paradigm research acknowledges among others

- that meaning is constructed on the fly and often collaboratively

- that the specifics of particular contexts define the meaning and nature of an interaction

- that researchers' knowledge is also situated (i.e. multiple interpretations which give a rich sense of the site are preferred)

- the importance of context-dependent success criteria (e.g. value-based approaches)

This thesis takes on various of the aforementioned aspects of HCI. Grudin (2005) discussed **nondiscretionary and discretionary use**, i.e. "Sometimes we have a choice, other times we don't." In Grudin (2005) this is related to the individual person, whereas in the case of the Electronic Health Record (EHR) in Uppsala, this is a combination of both types of usage between different individuals. While physicians have to use the EHR system, patients and relatives do have a choice, since they do not necessarily have to use the patient portal.

With relation to the third wave, Bødker discusses **mediators that cross between work and human life**, e.g. the use of a personal e-mail account for work purposes. She elaborates that "we face a blurring of the boundaries between work and other parts of life"(Bødker 2006, p. 4). This is also related to the individual, in that she calls for open technological designs and to embrace "people's whole lives and transcend the dichotomies between work, rationality, etc. [leisure, arts, and home] and their negotiation" (Bødker 2015, p. 27). This thesis contributes to and extends this, by investigating technologies that not only transcend the dichotomies between work and life in the individual, but between different people. eHealth services like the EHR can be considered as a mediator, that crosses the boundaries from work activities of some (i.e. doctors and other health professionals) to non-work activities of others (i.e. patients and relatives).

Related to the third paradigm, this thesis also focuses on **situated knowledge and meaning making**, that is "entailed by the analytic frame employed by the designers and analysts, and also by the users and other stakeholders in the situation of use" (Harrison et al. 2007, p. 2). This is addressed twofold: that the stance taken by designers shapes the products of design (Harrison et al. 2011, p. 390) is addressed in Paper I, whereas framing of physicians as stakeholders is the focus in Paper II and III.

2.2 Framing and Technological Frames

The concept of cognitive frames has been used to explain how people interpret and make sense of everyday situations. In the data-frame theory of sensemaking by Klein et al. (2007, p. 118) a frame is an explanatory structure for accounting for the data, guiding the search for more data, and can take the form of a story, a map, a script, or a plan. While there are many other concepts like schema and scripts, Klein et al. (2007, p. 119) use "frames" as a synthesis of these concepts.

According to Klein et al. (2007, p. 118f), a frame reflects a person's compiled experiences and its purpose is to

- define the elements of the situation,

- describe the significance of these elements,

- describe their relationship to each other,

- filter out irrelevant messages, and

- highlight relevant messages

Furthermore, the authors describe an interdependency in that the data identify the relevant frame, and the frame determines which data are noticed, but neither comes first (Klein et al. 2007, p. 118). Which data elements are perceived and recalled by individuals depends also on their goals and experiences, and the data elements are rather constructions and abstractions from the environment than a perfect representation of the world (Klein et al. 2007, p. 121). Abstractions allow us to "function in an infinitely complex environment", however the process can result in distortions of sensemaking, e.g. if the abstracts are oversimplifications, so are the explanations (Klein et al. 2007, p. 122).

A connection can be drawn to the well known concept in HCI, *mental models*, which are "conceptual models in people's minds that represent their understanding of how things work" (Norman 2013, p. 26). Multiple models of the same item may not only exist between different people (e.g. the user's might differ from the designer's mental model), but also in a single person and they also can be in conflict (Norman 2013, p. 26). As Norman elaborates further, these models are often erroneous and thus lead to difficulties in using the device in question.

In this sense, mental models and frames can be seen as tools, used to support the sensemaking process. They can be facilitating, especially in ambiguous and complex situations, by reducing some of the uncertainties and thus providing a basis for taking action (Orlikowski & Gash 1994, p. 176). As part of the sensemaking process, frames can be elaborated by adding details, but also by questioning the frame or by putting the provided explanations in doubt (Klein et al. 2006, p. 88). However, frames are potentially inaccurate and can be constraining when they "reinforce unreflective reliance on established assumptions and knowledge, distort information to make it fit existing cognitive structures, and inhibit creative problem solving" (Orlikowski & Gash 1994, p. 177). One strategy to deal with inconsistencies in the data at hand is *reframing*. This is described as another sensemaking cycle which leads to the reconsideration or rejection of the initial frame in order to replace it with a more accurate one (Klein et al. 2006, p. 88). Reframing is also used in design as "a method of shifting semantic perspective in order to see things in a new way" (Kolko 2010, p. 23).

The concept of Technological Frames (TF) was developed by Orlikowski & Gash (1994) in order to focus particularly on the subset of organizational frames that concern the "assumptions, expectations, and knowledge" people use to understand the technology in their organization (Orlikowski & Gash 1994, p. 178). Furthermore, these frames do not only concern the role and nature of the technology, but also its conditions, consequences, and applications. Although TF are individually held and

thus reflect individual variations, they can also be shared in that the TF of individuals may have some cognitive elements in common (e.g. through socialization, interaction, or negotiation) (Orlikowski & Gash 1994, p. 177).

In order to characterize participants' interpretations about the technology, Orlikowski & Gash (1994, p. 183) identified the following three domains:

Nature of Technology People's view of the technology and their understanding regarding its capabilities and functionality

Technology Strategy People's understanding regarding their organization's motivation / vision for the implementation of the technology and the adoption decision, as well as the likely value to the organization

Technology in Use People's understanding how the technology will be used and the conditions and consequences of its use

These domains can be interpreted as the frame *structure*, while the frame *content* is seen as the specific knowledge within a domain (Davidson 2006, p. 25). According to Orlikowski & Gash (1994, p. 200f) these domains of technological frames can be used as guidelines to examine and articulate people's interpretive relations with technology.

The alignment of frames on key elements or categories is described by Orlikowski & Gash as *congruence* in technological frames. *Congruent frames* are not necessarily identical, but related in structure and content, which implies e.g. similar expectations regarding the technology or the nature of its use (Orlikowski & Gash 1994, p. 180). *Incongruent frames* "imply different ways of knowing and making sense of technology" (Orlikowski & Gash 1994, p. 203), which may lead to difficulties when it comes to the adoption and acceptance of technology. The development of interventions to reach frame alignment could be seen as a way to overcome those difficulties, however, these have to be considered carefully. The alignment of frames as such might be seen as a political approach, in that it imposes a dominant frame, while at the same time frame incongruence is not always problematic (Davidson 2006, p. 36). However, the identification of incongruent frames can be seen as a first step to understand the differences, in order to initiate the construction of a *shared understanding* (Gulliksen & Lantz 2003, p. 13f).

In this thesis, the concept of *frames* comprises of the assumptions, expectations, knowledge, and experiences that are used by the individual to make sense of the technology in question, i.e. the eHealth service. Orlikowski & Gash do not define how assumptions and expectations differ in their concept of technological frames. However, in this thesis and in relation to technological frames *assumptions* relate to things that are accepted to be true without question or proof (in the present), while *expectations* relate to beliefs that something will happen or will be the case (in the future) (cf. Cambridge Dictionary 2016a, b). Hence, in this thesis the concepts are discerned in relation to a time aspect.

2.3   Patient Empowerment

Already in 1969, Balint called for a shift from illness-centered to a patient-centered medicine, which not only aims at finding, diagnosing, and treating a "localizable fault", but instead examine the whole person and understanding the patient as a unique human body. The patient-centered approach has been developed further, and also the doctor-patient relationship has changed towards an active patient participation or even shared decision making (Deber 1994; Deber et al. 2007). While previously the subjectivity and personality of a doctor was regarded as not impacting the diagnosis and treatment, patient-centeredness is seen as a 'two-person medicine', where doctor and patient cannot be considered separately (Mead & Bower 2000, p. 1090f).

Sharing of power and responsibility has been identified as one of the key dimensions of patient-centeredness (Mead & Bower 2000), which might be reflected in attempts to increase patient participation, patient engagement, and patient empowerment (which are often used interchangeably). According to Holmström & Röing (2009), the concepts patient-centeredness and patient empowerment do not oppose one another, but are complementary. Both concepts include a shared responsibility, and a partnership between health care professional (HCP) and patient that is based on mutual trust and respect (Holmström & Röing 2009, p. 169). The authors conclude that the concept of patient empowerment appears to be broader than patient-centeredness. While the latter can be of great value in the process of patient empowerment, including identifying those who prefer a passive role, patients can also empower themselves (Holmström & Röing 2009, p. 171). Patient-centeredness can be seen as a goal of an encounter in itself between patient and HCP, as well as an approach that plays an important role in the *process* of patient empowerment, resulting in an empowered patient (i.e. the *state* of being empowered) (Holmström & Röing 2009, p. 171).

In an attempt to clarify the concept of empowerment and correct common misconceptions, adopting from Paulo Freire's work on empowerment, Anderson & Funnell (2010) also distinguish between empowerment as a process and empowerment as an outcome:

> "Freire viewed empowerment as both a process and an outcome. Empowerment is a process when the purpose of an educational intervention is to increase one's ability to think critically and act autonomously. Empowerment is an outcome when an enhanced sense of self-efficacy occurs as a result of the process. However, while empowerment is an outcome, it is not a dichotomous variable, in that one is or is not empowered. Instead, empowerment is a continuous variable, more similar to a direction than a location." (Anderson & Funnell 2010, p. 2)

Anderson & Funnell (2010, p. 3) identified several misunderstandings about patient empowerment, which may be based on the HCPs' socialization to a set of

responsibilities and expectations, that defines their personal identity. This social-
ization to take the responsibility for patients, can conflict with patients that already
engage in self-management, e.g. controlling a chronic disease like diabetes. Based
on their research on diabetes care, Anderson & Funnell advocate a collaborative
partnership, that acknowledges the equivalent importance of patients' expertise and
HCPs' expertise. While HCPs may know, what is best for a patient from a medical
perspective, that does not mean they also know what is best for that patient's life.
In relation to this, Anderson & Funnell (2010, p. 5) stress that empowerment is
the "antithesis of compliance", since the purpose of interventions is to help patients
think critically and make informed decisions. The philosophy underlying empow-
erment views human beings as having the right and ability to chose by and for
themselves (Aujoulat et al. 2007, p. 15).

Being empowered is not an absolute 'state'. Some patients ask the HCP for
recommendation at certain times (especially in early phases of their illness), they
may vary the extent of responsibility they take on for different aspects of their
treatment, or they do not want to be empowered at all (Anderson & Funnell 2010,
p. 5). However, as the authors point out, it is the patient who is in charge of
determining the decisions they want to make themselves, and those that should be
made by the HCP.

The varying preferences for participation in decision making have also been
discussed by others (e.g. Levinson et al. 2005; Deber et al. 2007). According to a
study by Deber et al. (2007), the passive role was more likely be preferred by older
and less educated individuals. However, the results suggest that "the preferred
relationship recognizes patient autonomy, not as control, but as an active role in
treatment decision-making within in [sic] the context of a shared relationship with
a trusted provider" (Deber et al. 2007, p. 256).

Consequences of the shared relationship, connected to the aforementioned so-
cialization of HCPs' responsibility, have been discussed by Aujoulat et al. (2007,
p. 16), in that as a result of the empowerment process not only the patient may
have changed, but also the professionals, who "have to unlearn being in control".
As Anderson & Funnell point out:

> "The empowerment approach does NOT involve convincing, per-
> suading, "empowering," or changing patients (or getting them to change).
> Empowerment does not involve doing something to patients." (Ander-
> son & Funnell 2010, p. 8)

Instead, in relation to their research in diabetes management, Anderson & Fun-
nell (2010, p. 8) conclude that the empowerment approach involves facilitation
and supporting patients to reflect on their experience of living with diabetes. This
can be related to Holmström & Röing (2009, p. 170f), who stress that patient
empowerment may place greater demands on HCPs in that they have to develop
educational skills necessary to empower people making informed choices and teach-
ing them problem solving and self-management skills. In addition, some HCPs

might need to be taught how to enact empowering practices and behaviors in order to avoid positioning as the expert or sole authority (Paterson 2001, p. 579). Furthermore, the success of both, patient-centeredness and patient empowerment, depends on a) motivation of patients wanting to be involved in decision-making or being empowered and b) how well patients and HCPs can communicate with each other (Holmström & Röing 2009, p. 170)

The focus of this thesis lies on ICT that is supposed to contribute to patient-centeredness and patient empowerment by allowing users to access their health information. It has been discussed that ICT aiming to give patients access to their own health information have significant potential for patient empowerment (Baudendistel et al. 2015). The particular services related to this thesis are further discussed in the next section.

2.4   eHealth services

eHealth as a term and concept has been defined as

> "e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology." (Eysenbach 2001)

The "e" preceding the word "health" does not only stand for "electronic" to indicate the way the service is delivered, but encompasses essential aspects such as: efficiency, enhancing quality of care, evidence based, empowerment, encouragement, education, enabling, extending, ethics, and equity (Eysenbach 2001). This is similar to the related concept of e-patients, which describes individuals who are equipped, enabled, empowered, and engaged in their health and health care decisions (Ferguson 2007).

A systematic review of published eHealth definitions found that eHealth is mostly viewed both as a tool that enables a process/function/service and as the embodiment of eHealth itself, e.g. in the form of a website (Oh et al. 2005). In addition, the technology serves rather as means to expand, assist, and enhance human activities, rather that to substitute them (Oh et al. 2005).

Due to the market potential and expected benefits, widespread adoption of eHealth is also on the political agenda, which is reflected in the *eHealth Action Plan 2012-2020* of the European Commission (European Commission 2012a). Part of the action plan is to address the barriers that continue to exist, e.g. lack of awareness of and confidence in eHealth solutions among patients, citizens, and HCP (European Commission 2012a).

Although it was stated in section 1.4 (Delimitations) that aspects concerning the digital divide is outside the scope of this thesis, it is worth mentioning here that an attempt to foster patient empowerment by giving access through ICT automatically excludes people, who e.g. do not have the equipment, internet access, or skill to use the services. This concern is in line with the definition of eHealth by Eysenbach (2001), which includes *equity* and the possible threat that eHealth may deepen the digital divide. Thus, a comprehensive patient empowerment approach through ICT should also consider alternative ways to meet the information need by patients, who are unable to use the eHealth services.

The types of eHealth services are manifold, e.g. electronic health record, telemonitoring, telemedicine, ePrescribing (BEUC 2011), to name only a few. In the following, two types of eHealth services will be discussed that are relevant for this thesis and which are part of the studies described in the included papers: Direct-to-Consumer Genetic Testing (Paper I) and Electronic Health Record (Paper II, III).

Direct-to-Consumer Genetic Testing

The technical advancements in genetic testing has lead to a tremendous decrease in testing costs, which made it possible to offer these tests directly to the consumer (DTC) (Caulfield & McGuire 2012). These DTC genetic tests raise multiple concerns, e.g. causing confusion, increasing anxiety, exaggerating the tests' benefits, resulting in an inappropriate increase in demand for testing services, and bypassing recommended pre- and post-test counseling (Wade & Wilfond 2006, p. 285). The United States Government Accountability Office (GAO) investigated companies selling DTC genetic tests and found that the results were misleading and of little or no practical use (Kutz 2010). The lack of assurance regarding an analytical or clinical validation for the test lead the FDA to take action against the genomics company 23andMe. After a warning letter by the FDA (Public Health Service Food and Drug Administration 2013) and a pending authorization, the company was forced to stop providing health information to new customers in the U.S. for almost two years, whereas in the UK the service was approved by MHRA (Gibbs 2014). However, in October 2015 the company announced in a press release that it will launch a new Personal Genome Service, for which it had then received authorization by the FDA (23andMe 2015a).

However, while this regulation was welcomed by some, others criticized it as a threat to the personal autonomy of consumers (Vayena 2015). According to Su (2013, p. 361), the most often used argument for marketing genetic testing to consumers is indeed empowerment, which is also highly emphasized as a benefit and a good motivation for testing (Covolo et al. 2015). In line with the definition of empowerment in section 2.3, i.e. to increase one's ability to think critically and act autonomously, it has been argued that knowledge about an increased risk may allow individuals to modify their behavior (Howard & Borry 2008, p. 318).

DTC genetic testing has stimulated an intense debate, due to the inherent ethical, legal, and social issues involved (Caulfield & McGuire 2012). The conflict arises due to concerns about unnecessary anxiety creation and a call for more regulatory control, while these concerns might not be substantiated (Caulfield 2011). The study described in Paper I used DTC genetic testing especially because it provides a multitude of information related to health, wellness, or medicine. Additionally, it includes the conflict how to balance between customers' demands and the need to protect them from harm.

Electronic Health Record (EHR)

The European Commission published a *Digital Agenda* that includes actions to foster the deployment of eHealth technologies, which can "improve the quality of care, reduce medical costs and foster independent living, including in remote places" (European Commission 2010, p. 29). Furthermore, the agenda stresses that it is essential, that these technologies "incorporate the right of individuals to have their personal data safely stored within a healthcare system accessible online" (European Commission 2010, p. 29). To achieve this, the commission specified in *Key Action 13* to undertake pilot actions to equip Europeans with secure online access to their medical health data by 2015.

Technologies for storing and accessing health information are known by different names, e.g. Electronic Health Record (EHR), Electronic Medical Record (EMR), Electronic Patient Record (EPR), or Personal Health Record (PHR), and can also imply different aspects. Häyrinen et al. (2008) conducted a systematic review, in which they found a wide range of definitions and types of EHR, e.g. records that focus generally on medical care (EMR); contains clinical information from a particular hospital (EPR); or which are controlled by the patient and contain also information entered by the patient (PHR).

The International Organization for Standardization (ISO) defines EHR for integrated care as follows:

> "repository of information regarding the health status of a subject of care, in computer processable form, stored and transmitted securely and accessible by multiple authorized users, having a standardized or commonly agreed logical information model that is independent of EHR systems and whose primary purpose is the support of continuing, efficient and quality integrated health care" and "contains information which is retrospective, concurrent and prospective." (ISO/TR 20514 2005)

It is pointed out, that this is considered to be the primary definition, although there may be current variants of the EHR, that do not comply with this. This is why the ISO also includes the basic generic form: "repository of information regarding the health status of a subject of care, in computer processable form" (ISO/TR 20514 2005). However, this thesis relates to the primary definition and focuses in

particular on the aspect that the record is accessible by multiple authorized users. The term *patient portal* will be used in this thesis to refer to the *portal* that enables to access to the different services, e.g. booking appointments, tracking referrals, examining the EHR.

As stated above, the uptake of EHR is supported on the political level for some years. The eHealth Stakeholder Group of the European Consumer Organisation (BEUC) published a report on the national views and experiences of its members regarding EHR, which shows the differences at the national level (BEUC 2013). For example, while in Estonia physicians and patients have equal viewing access, there is no possibility for German patients to track their records (BEUC 2013).

This thesis focuses on the developments in relation to EHR in Sweden. According to the action plan of the Swedish Centre for eHealth (CeHis; *Center för eHälsa i samverkan*), all residents are supposed to be able to access their health records throughout health and social care through a patient portal (b 2012, p. 12).

The development of the patient portal *Mina Vårdkontakter* (My Healthcare Contacts) in Uppsala, including the EHR named *Journalen* took place between 1997 and 2012 (Erlingsdottir & Lindholm 2014). The system was launched as part of the EU project *Support USers To Access INformation and Services (SUSTAINS)*, carried out by a consortium of nine countries, and was committed to the implementation of the aforementioned *Key Action 13* of the Digital Agenda for Europe (SUSTAINS 2016). The project aims to contribute to three major issues in healthcare: empowerment of patients, quality of care, and efficiency and economy. However, the launch that took place in 2012 was accompanied by a strong reaction of the HCP (Erlingsdottir & Lindholm 2014). Concerns raised by the HCP were connected to patient security and that patients might not understand the content of the EHR. In addition, the doctors union demanded a respite of 14 days before any information was shown, whereas the patient union was determined that this is something for the patient to decide (Lyttkens 2015, p. 11). A public debate in the media accompanied the project, as well as a law suit and a change of a law, that made patient's digital access to their health record legal (Erlingsdottir & Lindholm 2014, p. 15f). However, the EHR continues to be a debated topic in the Swedish media until today.

The resistance towards EHR by medical professionals is not a phenomenon that is limited to Sweden. The concerns expressed by the doctors union are reflected also in the literature, e.g. impact on workload, risk to privacy, increase of worries (e.g. de Lusignan et al. 2013; Ross et al. 2005). However, research suggests several benefits for patients, e.g. the improvement of shared management, quality of care, and the ability to make decision about their health (Fisher et al. 2009).

According to Fisher (2015), the main hurdles are cultural and professional and although the adoption of EHR might never be risk-free, the benefits substantially outweigh the risks. This is also reflected in the research on the U.S. OpenNotes initiative, which provided almost 5 million patients online access to their records by the end of 2014 (Walker et al. 2015). However, the resistance or hesitation by the medical profession might inhibit the adoption of EHR, since their endorsement

and engagement is considered as an important factor (Wald 2010; Nazi 2013). This
thesis contributes to the understanding of underlying factors that impede HCP and
other stakeholders to see potentials for benefit.

Chapter 3

Research Approach & Methods

As stated in section 2.1, the underlying metaphor in each paradigm in HCI suggests both questions that are interesting to ask and also methods for arriving to answers (Harrison et al. 2007). Shifting the research focus in HCI implied also an adaption or development of research methods (Lazar et al. 2010, p. 3).

This research focuses on studying the expectations and experiences of people, i.e. the social world, for which positivist approaches are less suited (Oates 2005, p. 288). The philosophical paradigm that guides this research is *interpretive*, which assumes that "knowledge of reality is gained only through social constructions such as language, consciousness, shared meanings, documents, tools, and other artifacts" (Klein & Myers 1999, p. 69). The acknowledgement of the researcher's role is also reflected in the changing convention of using the third person in written research reports. The use of first person active to indicate the active involvement of the researcher is becoming more acceptable, (e.g. "We designed the experiment..." instead of "An experiment was designed...") (Oates 2005, p. 312).

In the following, the methods used for data collection and analysis are briefly introduced: experiment, interview, and thematic analysis. The more detailed descriptions of the applied methods can be found in the corresponding method section of Paper I-III. This chapter closes with a brief description of reflective research, which corresponds to the role of the researcher and his or her own subjectivity that is emphasized in interpretive research (e.g. Walsham 1995, p. 77f; Klein & Myers 1999, p. 74f; Oates 2005, p. 292f).

3.1   Experiment

The study described in Paper I included an experiment, which might be seen as inconsistent with the interpretive approach in that experiments are based on the positivist paradigm. And indeed, we discussed an independent variable, which according to Klein & Myers (1999, p. 69) is not part of interpretive research.

However, the data gathered comprised of video recordings of the group discussions, which were then analyzed using *thematic analysis* (see section 3.3).

We designed the experiment as a *quasi-experiment*, which is characterized by the involvement of multiple groups or measures, where the participants are not randomly assigned to different conditions (Lazar et al. 2010, p. 42). Usually the quasi-experiments are used "to concentrate on observing events in real-life settings, where there is a 'naturally occurring' experiment" (Oates 2005, p. 134). Hence, in a quasi-experiment the experimental treatment is usually not controlled by the researcher (Punch 2013, p. 213). We adapted this in that a) the experiment took place in a laboratory setting, b) we controlled the exposure to an independent variable (i.e. the material the groups where provided with), and c) we controlled the confounding factor by matching the group members. Thus, the variant in Paper I lies in between a true experiment and a quasi-experiment.

The material the experimental group was provided with consisted of five short texts extracted from real customer reviews relating to the DTC genetic test provider 23andMe. As described in the method section of Paper I, both positive and negative reviews were include, which also gave hints regarding the customer's motivation to buy the test (e.g. knowledge of a certain disease in the family; being adopted etc.). Two of the five reviews are provided here as an example, where the first review was positive and the second quite negative about the service provided.

> **Shirley wrote**: *Some things I've learned since I tested, of course, but most everything I wrote is spot on several years later. For instance I'm pretty darn sure now that my father is my real father, and anyone who knows me could've told me that but hell I wanted to know. I found out that I'm related to my son-in-law, quite Appalachian, there. I'm not Jewish I'm 99 % northern European with 2% American Indian. On my father's side, my two brothers tested, and they are 99% European, 1% African. Our family shows high to average amounts of Neanderthal genes. Now tell me would you ever get that kind of information in a doctor's office? Early on the test didn't say specifically that we had Neanderthal genes. It showed up in other DNA programs that enthusiasts had built to study their genomes. I was hesitant to add that we might have Neanderthal genes at the time. Later [this service] added graphics to show everyone who tested how much or how little Neanderthal genes they had inherited. It was great fun! Good news for Alzheimer's genes, low risk. I show an intolerance to wheat. That was the biggest find for me. I'd toyed with starting and stopping eating wheat products, even though wheat will send my brother to the emergency room, I still doubted that I had a problem because the symptoms were so hard to pin down. Stopped the bread, the wheat, and I am so happy to say I feel not just better for it, but wow! I've bought some Glutenease now, and take it when I eat a verboten pizza or roll, but I can say that knowing that I'm prone to Crohns Disease changed my life.*

> **Shelby wrote**: *My ancestry results were vague and totally missed the mark. My health report was amusing to say the least. Apparently I have curly red hair and I'm likely to have either brown or green eyes. Well, I have straight jet black hair and my eyes are as dark, too. For my husband's it claims he doesn't have the bald gene —- tell that to his bald spot. It claims I can eat dairy. Nope. Never could. The list goes on and on. It's a waste of money [...] All of the supporters of [this service] blindly accept their results, but most are not able to read raw data and decipher what is what. I cannot express my disappointment more, really. If only I could give this product a zero rating for a big fat fail.*

Although we had initial expectations about how the participants in the study might act, we were open to alternative outcomes and explanations, which is in line with the third paradigm of HCI and its "preference for multiple interpretations that give a rich sense of the site of interaction" (Harrison et al. 2007, p. 8). This corresponds also to the interpretive approach, in which it is desirable "to preserve a considerable degree of openness to the field data, and a willingness to modify initial assumptions and theories" (Walsham 1995, p. 76).

3.2 Interview

Interviews are used in HCI in order to "help build an understanding of the needs, practices, concerns, preferences, and attitudes of the people who might interact with a current or future computer system" (Lazar et al. 2010, p. 180). The objective of the interviews conducted in Paper II and III was to build an understanding of the views and expectations of physicians from different medical specialties in relation to the deployed eHealth services. Interviews in combination with content analysis are regarded as a viable method for investigating technological frames (Orlikowski & Gash 1994, p. 202).

I was not involved in the development of the interview template, since the interviews had been conducted before I joined the project. The interviews were semi-structured, which allows for exploring topics further, e.g. when comments of interviewees lead to questions the researcher might not have thought of in advance (Lazar et al. 2010, p. 189f). The research team had an ambitious plan regarding the recruitment of suitable participants, however finding physicians willing to participate turned out to be very difficult. The interviews were conducted in Swedish, which necessitated a translation to English for me being able to engage in the analysis. This was done by the Swedish co-authors involved in the project, which resulted in their familiarization with the data on a deep level. Lacking the sufficient skill in the Swedish language myself, reliance on this translation was necessary, while I nevertheless made use of both the Swedish and the English transcripts. Although it is preferable to speak the local language, not being able to is no impediment for conducting interpretive research (Walsham 2006, p. 323f). It is important however

to be aware that certain aspects in the language may be missed or misinterpreted, which makes it even more important to analyze and discuss the material together with researchers who speak the local language.

3.3   Thematic Analysis

Qualitative data is often analyzed in terms of abstracting from the data, which the researcher regards as important to the research topic (Oates 2005, p. 267). This abstraction is done by categorization or *coding*, i.e. organizing the data into meaningful groups. The categories can derive from theory from literature (deductive approach) or can be observed in the data (inductive approach) (Oates 2005, p. 269). The Grounded Theory approach, as initially proposed by Glaser & Strauss (1967), is an inductive approach in which concepts and theory are supposed to 'truly emerge' from the data; without any preconceived theoretical ideas (Lazar et al. 2010, p. 284). However, according to Alvesson & Sköldberg (2009, p. 58), contemporary scientific theory by and large agrees that all facts are 'theory-laden'. The authors add that "we always insert a whole set of cognitive and theoretical frames of reference into our perception of reality" (Alvesson & Sköldberg 2009, p. 58). Miles & Huberman (1994, p. 56f) also emphasize that data collection is a *selective* process and that the "challenge is to be explicitly mindful of the purpose of your study and of the conceptual lenses you are training on it - while allowing yourself to be open to and reeducated by things you didn't know about or expect to find."

Grounded Theory has been developed further, but Glaser & Strauss disagreed on how it should be done and in particular, whether the theory could be formalized into guidelines and procedures (Lazar et al. 2010, p. 284). Glaser criticized the over-emphasis of rules in the research process, instead of the "free emergence of theory from data" (Alvesson & Sköldberg 2009, p. 74). A similar critique regarding a set of principles in relation to interpretive research was also mentioned by Klein & Myers (1999, p. 68) in that some regard a set of principles as "violating the emergent nature of interpretive research". However, Klein & Myers argue that there are nevertheless standards by which interpretive research can be judged, even if a pre-determined set of criteria cannot be applied in a mechanistic way.

This relates to Braun & Clarke (2006, p. 98), who point out that it is important to discuss how to do the analysis in order to make the method accessible instead of mysterious and elitist. The authors also discuss the *active* role of the researcher, which is often poorly reflected in the description of the analysis when a passive account of themes 'emerging' or being 'discovered' is given (Braun & Clarke 2006, p 80). Similar to Oates (2005, p. 274), Braun & Clarke (2006, p. 81) criticize, that although Grounded Theory seems to be used quite a lot, many researchers do not fully subscribe to the theoretical commitment implied, and instead conduct a thematic analysis. Since the method is widely used without an agreement how to do it, Braun & Clarke provide a description and a 6-phase guide to performing

thematic analysis, including quality criteria. The analysis in paper I and III followed these guidelines.

3.4 Reflective Research

As mentioned in the introduction of this chapter, interpretive research emphasizes the role of the researcher as being not neutral. Thus researchers must acknowledge their influence on the research and on those they are studying, i.e. they must be reflexive or self-reflective (Oates 2005, p. 292f). According to Oates, both terms are used, while Alvesson & Sköldberg (2009, p. 8) explicitly distinguished between reflective and reflexive, "viewing reflexive as a particular, specified version of reflective research, involving reflection on several levels or directed at several themes".

The acknowledgment that people construct their social reality should also include the researcher; especially within the qualitative interpretative area (Alvesson & Sköldberg 2009, p. 269). This relates to thematic analysis, which emphasizes the *active* role of the researcher in identifying patterns and themes, selecting, and reporting which are of interest (Braun & Clarke 2006, p 80). Social construction therefore is not solely reserved for the object of study (e.g. the physicians in paper II and III), but should also include the researcher. Alvesson & Sköldberg define reflection as follows:

> "Reflection means thinking about the conditions for what one is doing, investigating the way in which the theoretical, cultural and political context of individual and intellectual involvement affects interaction with whatever is being researched, often in ways that are difficult to become conscious of." (Alvesson & Sköldberg 2009, p. 269).

Reflection is not only important when it comes to the data analysis, but also for example during data gathering. As Klein & Myers (1999, p. 74) state: "the 'data' are not just sitting there waiting to be gathered, like rocks on the seashore. Rather, interpretivism suggests that the facts are produced as part and parcel of the social interaction of the researchers with the participants." Although I did not conduct the interviews used in paper II and III myself and therefore did not directly interact with the participants, reflection is nevertheless important, since "the researcher's preconceptions about the participants still affect the construction, documentation, and organization of the material" (Klein & Myers 1999, p. 74)

The relevance of the researcher's biography has been discussed in relation to ethnographers and anthropologists, who have been concerned "how their biographies intersect with their interpretation of field experiences" (Finlay 2002, p. 210). In my research this was especially relevant due to my professional experience in the health care domain (i.e. on the health care *providing* side), which can influence how I interpret and analyze empirical material. However, this is not necessarily a

disadvantage, since it can facilitate to empathize with the health care professionals and relating to their way of sensemaking.

Reflecting on one's experiences and personal meanings can lead to insights which then "form the basis of a more generalized understanding and interpretations" (Finlay 2002, p. 214). In my research this was done by writing notes throughout the process and engaging in discussions with others. The act of writing supported me in clarifying my ideas, while the re-reading of previous notes revealed, how my early assumptions and viewpoints changed in the course of my research. In addition to that, the feedback given by supervisors, reviewers, and discussants (e.g. during PhD conferences and doctoral consortium) helped me to clarify my thoughts and sharpen my arguments. Even though I might have disagreed with some points, expressing this in writing helped me to reflect in-depth on the different viewpoints and potential misunderstandings.

Chapter 4

Results

The results are presented in relation to the research question the thesis aims to answer:

> *What are the frames of reference of different stakeholders regarding*
> *eHealth services that allow users access to their health information?*

The results from Paper I contribute to the question with relation to frames of designers, whereas the results from Paper II and III contribute to the question by relating to physician's frames. In addition, there are other results of the studies that are only described in the results section of the respective paper.

4.1   Designer's Perspective

The initial motivation to use DTC testing service as the proxy for eHealth services in the experiment was related to the provision of a combination of both trivial and potentially life-changing tests. We expected that evoking or elevating empathy would increase the awareness of the experimental group about possible negative outcomes (i.e. how customers would feel when receiving serious test results through an online service) and thus that the participants would be more careful when designing the online platform compared to the control group.

Surprisingly, the results showed rather the contrary. Both groups shared several concerns with regard to the testing service, e.g. the possibility to reveal serious test results online, whether laypeople could understand the technical terms, and unauthorized data access by others. However, in combination with a rather stereotypical view on the prospective users who have to be protected (even from him- or herself), the design decisions of the control group differed noticeably from the experimental group. They discussed mainly extreme examples and possible consequences, e.g. hypochondriac or suicidal persons and their possible reactions. In the end, the control group went so far that they a) wanted to deny users access to serious results

altogether, and b) consequently jeopardized the whole business model of the service (i.e. direct-to-consumer).

The experimental group that was exposed to narratives of real users reacted differently. By reading and also using the narratives during their discussions, they frequently came back to the point that the customer made a deliberate choice by ordering the test; he or she "wants to know". In contrast to the rather abstract representation of the users in the control group, the experimental group described them in much more detail, including their background, interests, motivation, and needs. In the end, the experimental group decided to enable users access to serious tests results and tried at the same time to counteract possible negative consequences. Thus the experimental group respected customer's autonomy. Empathy might have been enhanced by the narratives, but not in terms of being more risk aware, but in relation to the underlying motivations for ordering the test. The narratives provided to the experimental group may have helped them to overcome possible preconceptions and to take a more nuanced view.

As stated before in section 2.1, the importance of *situated knowledge* and *meaning making* does not only apply to users, but also to the stance taken by designers, which shapes the products of design. The results of the quasi-experiment described in Paper I showed the extent of this. Moreover, the differences between the two groups illustrated how the design decisions were highly influenced by the way the participants viewed the prospective users. The groups often discussed the users as 'patients', probably due to the health-related tests. Hence, their view of the users might have been influenced by the traditional image of the 'passive patient'. Denying users access to their health information and thereby making decisions *for* them without their involvement conflicts with the philosophy underlying the empowerment concept, i.e. that people have the right and ability to choose by and for themselves.

As stated in section 1.4, the participants in paper I were Bachelor and Master students in Media Informatics, hence the generalizability is limited. The results may not be applicable to professional designers with extensive work experience. However, as is presented in the next section, how the control group discussed the prospective users of a DTC genetic testing service is similar to the physician's view of patients in Paper II and III.

4.2   Physician's Perspective

Paper II and III are both based on an interview study conducted with physicians from different medical specialties. Although the two interviews in Paper II were also part of the data set in Paper III, the focus of analysis differed. While Paper II focuses on *Patient Empowerment*, Paper III focuses on *Work Environment*. However, the physicians' framing of the system described in both articles are closely related and influenced by deep concerns related to patients' wellbeing and quality of care.

Patient Empowerment The views relating to patient empowerment of the two oncologist in Paper II could probably not be more oppositional. Oncologist A considers physicians to take on the responsibility for dealing with test results and that patients are supposed to do other things than checking their results online. Oncologist B on the other hand not only encourages her patients to read. She also explains in advance what this could mean in terms of consequences the patient might not think about. Hence, oncologist B enables her patients to make a deliberate decision how to act while facing the possible consequences for these actions.

Oncologist A, considering herself as being the person responsible, even tries to circumvent access to the EHR by not signing or not documenting all information right away. By doing this she prevents patients from reading the notes and thereby retains the information flow preferred by her, i.e. the physician as the source of information who notifies the patient in due time. On the other hand, oncologist B uses the EHR as a communication tool with the patient, e.g. to emphasize a certain activity that she deems necessary for the patient to do.

The technological frames of these two oncologist contrast each other. Their understanding of patient empowerment influences their technological frame and hence the utility they attribute to patients accessing their EHR. While oncologist A seems to see rather disadvantages (e.g. that well-read patients may be more demanding during the visits), oncologist B views it as an advantage that patients may be more informed through accessing the information. Hence, their view on the value of accessing the EHR matches accordingly their positive/negative view towards the system. Oncologist A regards the EHR as a work tool that is not supposed to be for patients but for the HCP only. Oncologist B uses the tool also for communication purposes with her patients, and hence prepares or educates them in advance regarding their responsibility. The framing of an eHealth service that is supposed to contribute to patient empowerment is likely to be incongruent to the technological frames of stakeholders, who have a different or limited understanding of the concept of patient empowerment.

Work Environment The analysis of technological frames with a focus on the work environment revealed four main themes: work tool, control, process, and workload. As discussed in section 2.2, Orlikowski & Gash (1994) identified the three domains *nature of technology*, *technology strategy*, and *technology in use*, which can be used as guidelines to examine and articulate people's interpretations about technology. The identified four main themes in Paper III can be related to the three domains in that work tool refers to the *nature of technology*, control refers to both, *technology strategy* and *technology in use*, and process and workload refer to *technology in use* (Figure 4.1). The four themes are briefly described in the remaining part of this section.
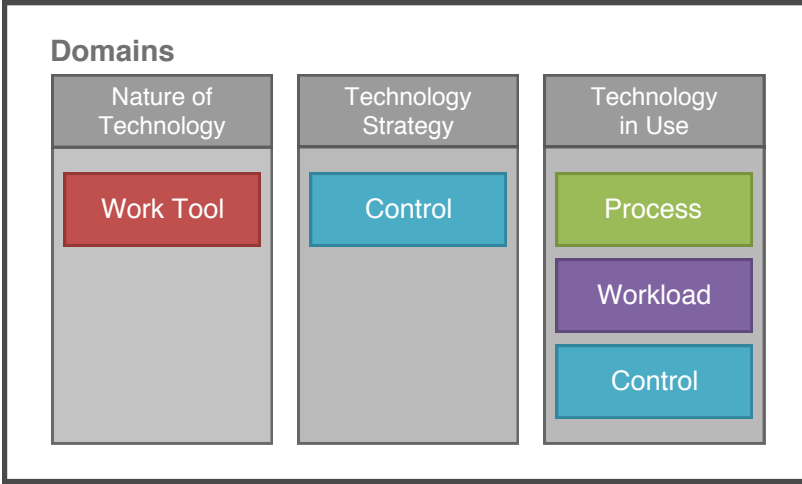
Technological Frames

Figure 4.1: Four main themes related to technological frame domains

The discussions around the EHR as a *work tool* were mainly accompanied by concerns regarding the incomprehensibility for patients due to the initial purpose of the record. It is seen as being a tool for clinical documentation and communication between HCP, hence they include technical terms and suspected diagnosis that would create undue anxiety or confusion in the patient. An anticipated need to change their writing to be comprehensible by patients was instantly regarded as decreasing the efficiency of their work tool and increasing the workload.

In addition to the framing of the EHR as their work tool, the physicians were quite suspicious, that patients' access is a means to *control* and monitor the physician's work. Interestingly, the physicians did not relate this to possible instances, in which for example a patient's neighbor or casual acquaintance who works in health care accesses a record without professional cause. Instead most physicians felt the need to explain that they read the EHR of their patients only out of professional interest, not for fun. The control aspect can be related to the domain *technology in use* in that this is how the technology may be used. It can also be related to *technology strategy*, because this aspect was also seen as possible motivation for implementing the technology. Unfortunately further interpretations or knowledge in relation to the *technology strategy* could not be elicited during the interviews, since none of the physicians could respond to questions regarding the local or national strategies or visions in relation to eHealth services.

Physicians were especially concerned about patients accessing the EHR before they had read the results and/or had informed the patients. Patients' instant access was perceived as a threat to their current *process* in that they expect the need to

catch up in less time, e.g. to read up on the results, consult a colleague, and inform the patient. This concern is also highly associated with the view of a patient, who will get worried when reading the results at home without a HCP present. The examples used were mainly related to exceptional circumstances for the individual patient (e.g. the initial diagnosis of cancer) and not related for example to patients with a chronic disease or those already engaged in self-management.

The expectation of increased *workload* was primarily associated with patients' lack of understanding and thus possible anxiety, which leads patients to call their physicians and demand explanations directly. In addition, it was presumed that patients might request them to change something in the record or demand explanations for alternative treatments that the physicians consider to be inappropriate for their case. Thus, this is regarded as a risk to reduce the already scarce time they are able to spend with the patient and/or increase their workload.

However, few physicians mentioned positive aspects, e.g. that patients can re-read the information they received during a visit, which they perhaps did not understand or forgot. In addition, some physicians had experienced that patients are to some extent already better informed and by reading their EHR they could prepare for the visit. Most physicians reported their lack of experiencing actual consequences of the eHealth service on their work environment at the time of the interviews. However, only few were optimistic that this could have no or even a positive effect. Most physicians were quite negative, did not see any benefit for the patient but rather possible harm, and expected negative effects on their work environment.

Chapter 5

Discussion

In this chapter, the results are discussed in relation to the research question:

> *What are the frames of reference of different stakeholders regarding eHealth services that allow users access to their health information?*

As discussed in section 2.1, this thesis relates to the third paradigm of HCI and focuses on **situated knowledge and meaning making**, that is "entailed by the analytic frame employed by the designers and analysts, and also by the users and other stakeholders in the situation of use" (Harrison et al. 2007, p. 2). The third paradigm acknowledges furthermore that the researcher's knowledge is also situated. Hence, the results will be contextualized with my own frames of reference, which were subject to change during this research.

Frames related to the user

Part of the frames of reference regarding eHealth services entails the view on the target audience, that will make use of the eHealth service in question. As the results illustrated, the participants of the described studies shared the tendency to refer to a generalized or even stereotypic view of future users (customer or patient) as lacking sufficient knowledge or being insufficiently health literate to understand the health information.

My view of users of DTC genetic testing services was quite similar, which was to some extent the motivation for the study design in Paper I. My viewpoint back then regarded the prospective users of these services as potentially health illiterate. Thus they might become unnecessarily anxious about test results, which may just be a predisposition and never lead to a disease anyway. The experiment tried to answer the question, how the design of a platform would change, if designers are aware about the magnitude of possible results and the underlying motivations of the prospective users. Considering empathy as important to learn about patients' experiences of living with a condition, I viewed patients rather as an *information source* during contextual enquiry. Hence, although I considered patients as

"experts" regarding the lived experience with a condition, I nevertheless leaned towards paternalism in that designers should take on responsibility and also to some extent "take care" of what happens after a system has been used.

The stereotypic way the patients / customers were referred to (by participants and researcher) resembles to some extent a problem in the early days of HCI, which implied a "faulty view of users" as being 'naive' or 'passive objects' that others must study or design for, as discussed by Bannon (1991). Bannon called to re-think the concept of users in terms of 'active users', which could serve as an analogy to re-think the concept of patients as well:

> "Just because users do not understand how the machine works, or have difficulty with the system designer's terminology does not imply that they are stupid, as some developers apparently conclude - if we are to judge from the systems that are at times designed." (Bannon 1991)

This also applies to patients, who might have difficulties to understand the medical terminology or may not know all procedures. Even though patients lack some medical knowledge on the one hand, they are on the other hand very knowledgable about their everyday life, their personal condition, and values. Furthermore, Bannon called to "Allow for Active Users":

> "While focussing attention on the user may be a positive step, users are not simply passive objects that others must study and design for, as some accounts would have it. People are, or can become, *active agents.* They often wish to accomplish tasks, to understand what is going on, and are willing to jump ahead and explore the computer system on their own." (Bannon 1991)

This resembles initiatives to increase patient participation. Reading about and following e-patients and patient advocates like Dave deBronkart (2016) aka *ePatient Dave*, Sara Riggare (2016), and many others also made me reflect on my views. Hugo Campos, for example, advocates to "liberate health data" and to make them accessible for patients (Campos & Sebastian 2015). He has an implanted cardiac defibrillator himself that monitors the clinical status of his body, but he has no access to this data yet. Furthermore, patients with diabetes attempt to circumvent these kind of access restrictions by engaging as hackers, and encouraging others to do so as well through the social media campaign *#WeAreNotWaiting* (Hilliard et al. 2015). Overlooking those engaged, enabled, empowered, and equipped patients (i.e. the e-patients) may lead to regulations, albeit well-intended, that can result in lost opportunities and counteract initiatives to increase patient participation.

Participatory approaches in HCI that focus on "multiple, participatorily generated interpretations in concrete, real-world situations" as discussed by Harrison et al. (2011, p. 390) bear the risk to reinforce a generalized and even stereotypic representation if broad ranges of patient groups are not included. The results in this

thesis showed, that not only the students and the researcher, but also the physicians who meet various types of patients in their everyday work referred to a type of patient that is the opposite of an e-patient, i.e. not equipped, enabled, empowered, or engaged. Within participatory design approaches, there might be a need to foster a *reframing* (Kolko 2010). This would be beneficial not only as a method for designers, but also for stakeholders (HCP and patients) to shift their perspective to see things in a new way, e.g. from the perspective of the other stakeholder.

Frames related to changes in health care

The physicians expressed their concerns regarding expected negative effects of the eHealth services on their work. The possible effects were related to changing their work tool and established processes, being controlled by patients, and an increase of their workload. Although the eHealth service in Uppsala are supposed to be for patients and relatives, the work environment of the HCP are likely to be affected or even changed by these services. It has been discussed, e.g. by Karasek & Theorell (1990, p. 251) that "technical and social systems of work must be reorganized together, in an integrated *socio-technical design*." The authors discuss also a group forum method, in which "employers and supervisors can help one another formulate the important problems and find their solution" (Karasek & Theorell 1990, p. 241). Based on the results of this thesis and following this idea of a group forum, the method could be enhanced to include also patient representatives. In other words, in order to foster a change in health care towards patient participation, not only should physicians be included and participate in the redesign of the work processes, but at the same time also patients. This might broaden the view of all involved stakeholders, especially in relation to their concerns, perceived benefits, and values. The collaboration between patients and HCPs is vital, since

> "Just as patients cannot think like health professionals, who have been trained to view medicine with a set of concepts and theories unknown to laypeople, so, likewise, physicians and other health professionals lose the capacity to think like the patient." (Veatch 2008, p. VII)

Including patients on a large scale would also respond to a critique relating to HCI taking the stance of a "self-appointed advocate for users who are said not to be able to speak for themselves", which is seen as a political move with its own problematics (Harrison et al. (2011), with reference to Cooper & Bowers (1995)). This can be related to patients, who indeed are interested and very much able to speak for themselves, as the *Patients Included* charter for conferences suggests (Apostalidis et al. 2016). In addition, the 'utilization' of patients in the experience design process has also been discussed previously in that much can be learned from them (Anderson 2013). However, as Anderson concludes: "Unfortunately, whether you are talking about ePatients or most patients, patients continue to be the most

underutilized resource in the badly needed redesign of healthcare and the patient experience." (Anderson 2013)

Admittedly, including patient representatives also bears a risk, because the stakeholder group 'patients' is quite diverse, let alone their particular conditions and needs. Hence, it is difficult to decide, which patients should represent 'the patient voice' (cf. Thomas 2015).

Frames related to the value of eHealth services

As stated in section 2.3, patient-centeredness is seen as a 'two-person medicine' in which the subjectivity and personality of the doctor is considered to have an impact on diagnosis and treatment. In a similar way, physicians' technological frames which may lead to a resistance or endorsement of the technology can have an impact on the adoption of eHealth services.

The technological frames of the physicians, including the expected consequences influenced their assessment related to the value of the eHealth service for patients. The majority of the interviewed physicians did not see a value for patients to access the EHR. However, the perceived value of a technology or a test might differ between patients and HCP, as has been shown quite recently in a study regarding genomic sequencing (Halverson et al. 2016). Here the authors found that "patients and their family members often do not attribute value in the same way" (Halverson et al. 2016, p. 1). This might be an indication for the existence of not only *incongruent frames* as described by Orlikowski & Gash (1994), but also incongruent *values*. Value-based approaches such as participatory or value-sensitive design could increase our understanding of what it means for systems like the EHR to be 'good' for the different stakeholders, as suggested by (Harrison et al. 2007, p. 8).

Similar to the establishment of a shared understanding between designers and users, the results in this thesis suggest that a shared understanding is also needed between the stakeholders involved in health care. Here, too, the skills and expertise that are brought to the table vary, e.g. medical expertise of HCP and the patients' experiences. However, as Gulliksen & Lantz (2003, p. 17) stated in relation to design in HCI: "respect for other people's expertise and skills is essential for bridging the communication gap."

Chapter 6

Conclusions and Future Research

This thesis investigated the frames of references of different stakeholders in relation to eHealth services, which allow users access to their health information. The results illustrate the underlying reasons for concerns and resistance that accompany the deployment of these services. These concerns, albeit expressed with good intentions, have to be investigated further to elaborate the extent to which they are substantiated.

The contribution of this thesis can be outlined by answering two questions as proposed by Oulasvirta & Hornbæk (2016): a) which problems does it tackle, and b) how does it increase our capacity to solve them. This thesis tackled the problem, that although eHealth services are endorsed by many politicians and patients, it is met with strong resistance by health care professionals. Lacking their support hinders the uptake of the full potential of the service, especially with relation to patient participation and empowerment. This research increased the capacity to solve the problem by an enhanced understanding of the elements of the technological frames related to skepticism and concerns, e.g. a specific view of patients and/or future users of an eHealth system.

Implications for the development of future eHealth services are very difficult to draw. The question remains, how to balance the needs and the requirements of one group of stakeholders against the other, e.g. connected records throughout the county versus safety felt by patients. A feature like the log list that serves the need of one group (patients' control for illegal access), can be interpreted as a threat by the other (physicians feeling monitored). In line with the participatory design approach and the aim to increase technology acceptance, both patients and health care professionals should be included in the design process.

A further question is how to make stakeholders participate in the design who have a strong negative attitude towards the system from the start. Moreover, following a participatory or human-centered design approach would perhaps lead to inertia or a solution that reinforce the current processes instead of initiating a change in terms of patient participation. Balancing assumed concerns with assumed

benefits, and making particular design decisions without the necessary knowledge up front is challenging. However, much can be learned in the future from research in a) how the patients use the system, currently and in the long run, b) the actual effect on the work environment, c) the long-term experience by health care professionals (i.e. including nurses and medical assistants) in order to substantiate or confute the concerns described in the present thesis. In addition, technological frames are subject to change, as well as the meaning ascribed to the technology. Future research may also investigate how technological frames might have changed over time. Research like this would not be possible without the system running, thus much can be learned from this real life project in Uppsala. Taking into account possible regional differences in terms of regulations and work practices and by this acknowledging the limits of generalizability, other counties and countries may nevertheless benefit from this research.

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