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Patient Empowerment and User Experience in eHealth Services

A Design-Oriented Study of eHealth Services in Uppsala County Council

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Abstract

In November 2012 Uppsala County Council (UCC) introduced an eHealth service, 'My Health Record', that gives all inhabitants over age 18 in Uppsala County access to their health records online. However, this service has not been evaluated before this study. We conducted an interview study, based on User Experience (UX) and Patient empowerment, with users of 'My Health Record' to get their opinions, and to see if and how the service can be improved. Our findings shows that the users are positive to the service and the aspects that can be improved mostly concern information and communication. Based on these results, we propose design principles as well as concrete design proposals which can be useful for re-designing the service as well as inspiration for similar projects. Additionally, an interesting finding is that the interviewees had very few opinions and complains on the actual interface, which could mean that the content (the health record) is so interesting that the interface becomes almost "invisible". A conclusion we make is that UX and Patient empowerment is a good fit for each other, and that UX has advantages over traditional usability in services like this.

Keywords: User Experience (UX), Patient Empowerment, eHealth, Electronic Health Records, Uppsala County Council, Landstinget i Uppsala Län (LUL)

Thanks to

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1. Introduction

1.1 Background and Motivation

On 8th of November 2012 Uppsala County Council (UCC), also called Landstinget i Uppsala län (LUL), launched the eHealth service 'Min journal i Uppsala län', from now on referred to as 'My Health Record' or 'the service'. The introduction of 'My Health Record' gave all inhabitants over age 18 in Uppsala county access to their health records online (LUL.se 6/11-2012). UCC are first in Sweden to offer this kind of service, which has given them and the service a lot of attention in media. The service has raised some controversy due to the way it displays who has read ones health record. 'Läkartidningen' wrote that the doctors association are critical to this and mean that it could imply risks for healthcare professionals since patients might argue about why someone has read their health record (Läkartidningen.se 1/2-2013). In another article, the project manager has been interviewed and says that even though there were discussions before implementation, everything has been undramatic and the feedback has been friendly towards both UCC and healthcare (ComputerSweden 25/4-2013).

Inhabitants has also shown a great interest and excitement for the service. In April 2013 the project reported that in total 18 388 persons have read their health record online and that 37 059 persons from other counties gave logged in, even though only health records from Uppsala county exists (Leif Lyttkens, presentation at workshop 26/4 2013). It has now been announced that all counties of Sweden will receive this service and UCC's technical solution will be used as a standard (LUL.se 8/3-2013).

The introduction of this e-health service originate in a research project called SUSTAINS project, short for Support USers To Access INformation and Services, where UCC's implementation has been a pilot project. SUSTAINS is an EU-project that aims to give patients online access to their Electronic Health Records (EHR) with the goals of empowering patients, improving medical results and make healthcare more efficient. The ultimate goal for this is to make patients more active in the management of their health and treatment of possible diseases. To enable this, SUSTAINS is based on the experience from pioneers in this area (Sustains project - Objectives).

DOME is a Swedish action research project connected to SUSTAINS. The project includes University of Lund, University of Skövde and Uppsala University, and collaborates with UCC and Norrbotten County Council. The purpose of the DOME project is to bring forth knowledge and recommendations for introduction of eHealth-services based on studies of eHealth-projects (DOME). Our thesis is situated in this context, with the goal to create design principles and design proposals for EHR-services. We have taken a patient-centered view on how 'My Health Record' and also similar services could be designed and improved. This is done by interviewing users of 'My Health Record' based on concepts of User Experience (UX) and Patient

empowerment. These interviews have been used to inform suggestions of redesign and which functionality is interesting for patients.

1.2 The Current Service: "My Health Record"

Everyone who has a health record in Uppsala County Council can log in to 'My Health Record' using electronic identification. However, not all health records can be accessed via the service. For example health records from private healthcare, psychiatry and those that are not in digital format are currently not available.

'My Health Record' offers patients to get more information connected to their health, for example:

- Read health record entries.
- Read diagnoses.
- Read test results.
- Follow a referral.
- Share the health record with others, for example family.
- Read a log list of all healthcare professionals that have read ones health record.

Figure 1 - Screenshot of Health Record page of 'My Health Record' (Min journal i Uppsala län)

1.3 Research Questions

Here we present questions that this thesis sets out to answer:
1. **How** is 'My Health Record' perceived by users in relation to Patient empowerment and User Experience?
2. **How** can the eHealth services be redesigned to better support Patient empowerment and User Experience?

1.4 Delimitation

We have taken a patient-centered perspective on how 'My Health Record' is perceived and how it can be improved. Therefore, no interviews with healthcare professionals and experts have been conducted, which could have given us a broader understanding. Additionally, we have conducted a qualitative study, focusing on depth over breadth, instead of a quantitative study with more participants.

Due to lack of time a second iteration of interviews for evaluating the design proposals with real users was not performed. This means that we have not been able to study the reception and effects of our design.

1.5 Possible Readers of the Thesis

Participants in projects for introduction of EHR can benefit from reading the problems identified by users and our take our design principles in account when designing their service. As mentioned earlier, all counties in Sweden will receive a service similar to 'My Health Record'. This means that there will be numerous projects for designing and implementing these services.

UCC are interested in the design principles and design proposals as inspiration for future development and implementation. They are also given users opinions on their service.

Since this is an application of User Experience and User Experience design, people interested in those topics can be interested of reading and discussing this thesis.

The thesis also discusses how User Experience and Patient empowerment are related to and benefit each other which can be used for further research and discussion. This is also contribution to how User Experience can be used as a tool for empowering and empowerment in general.

1.6 Overview of the Thesis

In chapter two, the research strategy and scientific approach is presented and discussed.

In chapter three, the theoretical framework is presented and discussed.

In chapter four, results of our interviews are presented and analyzed. This is followed by design principles derived from findings from the interviews and design proposals that demonstrates these design principles.

In chapter five, discussions about the study are presented.

In chapter six, references to literature and articles are presented.

2. Methodological Approach

The chapter on methodological approach gives an overview and discussion of the scientific approach and research strategy used in this thesis.

The research has been made using a design-oriented approach combined with interviews with users of 'My Health Record'. Oates defines a type of research strategy named 'Design and Creation' which is research with focus on developing new IT artifacts. She further presents four types of artifacts that can be the result of this research, these are: (Oates, 2006, p.108-109)

- **Constructs** - Concepts or vocabulary.
- **Models** - Several constructs used as an aid in problem solving.
- **Methods** - Methods for problem solving using IT.
- **Instantiations** - Development of an IT artifact that shows how constructs, models, methods and theories can be implemented.

Even though a complete and working IT artifact or system was not developed in this research, an *instantiation* is what matches the outcome best. This is because the goal was to develop design proposals that shows how theories about Patient empowerment and User Experience can be combined in an IT artifact. We also bring new understanding of the concepts Patient empowerment and User Experience, and how they connect which can be seen as that we also develop a *construct*.

Oates also identifies that this type of research usually consists of five steps, these are: **Awareness -** Identification of the problem, **Suggestion -** An idea for how the problem can be addressed, **Development -** Implementation of the idea, **Evaluation -** Examination of results from development and **Conclusion -** Reflections from what the design process has led to. However, these steps are usually iterative and will not necessarily follow this order (Oates, 2006, p.111-112).

In this thesis the actions was organized as follows:
- **Awareness -** UCC has introduced their EHR service and related e-health services, but the services have not been fully evaluated. Users have contacted UCC with feedback and opinions, which indicates that there is room for improvements. The idea of interviewing users of the services and develop design proposals based on their input was proposed by our supervisor, who is also the coordinator for the DOME research project.
- **Suggestion -** A theoretical framework to be used as a foundation for interview questions and design process was created by reading literature about User Experience, Human-centered design and Patient empowerment. A workshop was attended that gave new and interesting views on e-health services. These were used in interview questions and design

process. Interviews with users were the main source of input for the design process. They helped to identify strengths, weaknesses and problems in the current e-health services that served as a base for developing design proposals.

- **Development -** Development of design principles, or design advices, from what has been found when analyzing the interviews. They were used as basis for design proposals that shows how these can be translated into an interface.
- **Evaluation -** Design proposals were evaluated against the design principles and the overall process was evaluated. This is brought up in more detail in chapter 4.2, where we explain how they implement the design principles.
- **Conclusion -** Discussions and conclusions from our work and design process. This is brought up in more detail in chapter 5, where we discuss the design and our work in a bigger perspective and also discuss the knowledge that has been created.

2.1 Finding the Literature

Literature was collected for defining key concepts: User Experience (UX), Human centered design, UX evaluation and measurement, and Patient empowerment. The literature have primarily consisted of scientific papers by notable and leading researchers in the area. We found that the UX research community seems to be a quite small and well-connected network of researchers, where notable names are e.g. Virpi Roto, Effie Law and Arnold Vermeeren. These researchers also founded the website *'AllAboutUX.com'* which is a site for collecting and sharing findings from the UX community (About - AllAboutUX.com).

In this thesis Patient empowerment has been defined according to SUSTAINS definition and indicators which is the result of a literature review (SUSTAINS, 2012, p.5). The reason for using only their definition is because this thesis focuses on Patient empowerment in a SUSTAINS based service. However, a more critical viewpoint could have been chosen. This definition is presented under Patient empowerment in the theoretical framework, chapter 3.5.

Literature was found using Google Scholar[1] with keywords identified by brainstorming and analysis of keywords in the literature. Keywords used were combinations of the following:

User Experience	Human-centered design	Evaluating
UX	HCD	Measuring

Results was then delimited to better match the research area and key concepts. This was done by reading the abstracts and making sure it was up-to-date. The findings from this has been used as a foundation for formation of interview questions and the design process.

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[1] **Google Scholar** is a freely accessible web search engine that indexes the full text of scholarly literature across an array of publishing formats and disciplines. http://en.wikipedia.org/wiki/Google_Scholar

2.2 Workshop Participation

We attended a workshop with reference groups from the DOME research project on the 26th of April in Stockholm. Attendants were both researchers and practitioners working with either healthcare or e-Health. The workshop gave an overview of the SUSTAINS project, the DOME project and UCC's work with 'My Health Record'. This was followed by group discussions, moderated by the project managers, primarily discussing following questions:

- Are EHR good? For who? In what situation?
- Which e-health services might be requested in the future?
- How does e-health services affect the work in healthcare?
- How does e-health services affect health quality and patient safety/security?
- How can EHR affect the way documenting work is performed? Will the language and structure of health records change because of increased transparency? Will health records become a tool for educating?

The workshop gave the thesis a clearer context by showing its fit among other parts of the research project. It also gave interesting and important thoughts for interview questions.

2.3 Interviews

Interviews were used as the primary source for gathering information about how and why users use 'My Health Record'. Interviews was found as a suitable data generation method to get detailed information containing feelings and experiences, and also asking questions that might seem complex. This is because the person interviewed can be read on additional levels since it is possible to interpret facial expressions and body language (Oates, 2006, p.187). The main downside of using interviews is that it is time consuming and because of this it is also hard to get generalizable results (Oates, 2006, p.198-199).

Interviews were conducted in a semi-structured way. Semi-structured interviews means having chosen themes and questions, however, the order of the questions can be changed depending on the conversation. This method also enables the interviewer to ask follow-up questions that comes to mind during the interview. Another strength is that it makes room for the interviewee to think on his own and also bring forth own questions or themes relevant to the research (Oates, 2006, p.188).

An invitation [Appendix 1] containing information about the study and handling of personal data was sent to the interviewees. At the time of the interview the interviewee was asked to fill in a form to approve of what was written in the invitation and were also asked if they agreed on being recorded. Recordings were used to capture what was not written down and for making quotations possible. Quotations that were used have been modified since the interviews were conducted in

swedish. Therefore, the quotations does not exactly match what the interviewees said. The majority of the interviews were conducted face-to-face and some through Skype because of issues regarding time and place. Group video calls on Skype offered no notable differences compared to face-to-face interviews, however the interviewee may have felt more comfortable by performing the interview in their own home.

2.3.1 Sampling

Interview participants were selected by the project manager for UCC's eHealth services from a collection of users that had contacted UCC with feedback and questions. This relates to purposive sampling, where participants are being picked to meet the purpose of the research (Oates, 2006, p.98). The reason for doing this is making sure that the participants are users of the service and also have opinions about it. In total, nine interviews were conducted with the interviewees equally distributed between genders and in a wide range of age.

Having participants selected by a third party may have affected findings since it is impossible to know the incentives behind the sampling. However, it is reasonable to think that the project managers wish to improve the service is stronger than the fear of negative feedback.

2.3.2 Interview Questions

Interview questions [Appendix 2] derived from Patient empowerment indicators defined by SUSTAINS, combined with conclusions from reading about UX evaluation and design.

To summarize and collect quantifiable data the interviews also contained questions inspired by AttrakDiff. AttrakDiff is a questionnaire-based method for evaluating UX that makes the respondent rate the artifact based on two opposites, for example attractive/unattractive (AttrakDiff - AllAboutUX.com). The interviewee was asked to rate the service based on each set of opposites on a 1-7 scale, where for example 1 is very attractive and 7 is very unattractive, and also briefly motivate their rating. These sets of opposites were selected from the original evaluation method and completed with opposites customized for this service. Some of the original opposite pairs were omitted since they were vague and hard to translate to Swedish. A problem identified with this method was that the interviewee had a hard time to first understand how to answer. This was resolved before the third interview by giving a visual example on a paper instead of just explaining using words.
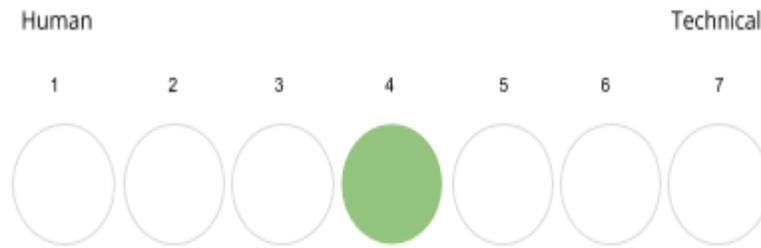
Figure 2 - AttrakDiff example

Participating in the workshop led to identification of new interview questions. These questions primarily regarded future functionality proposed by workshop participants. Examples of this is:

- Do you feel any differences in what is written in the health record and what is being said during encounters with healthcare?
- What do you think about being prompted about wanting to see sensitive information at each log in?
- What do you think about that only health records entries that are signed and approved by doctors are visible? Would you rather get instant access to the entries?
- What do you think about giving healthcare professionals the ability to see if YOU have logged in to the service and read your health records? (So that the health record can be used as a shared source of information for discussions)

Interview questions were improved pre-interview by conducting two pilot interviews where feedback and our findings were used to modify the questions. The questions were continuously improved using findings from interviews, for example questions that were hard to understand was changed and new interesting questions arose during conversations.

2.3.3 Analysing the Interviews

Answers from the interviews were analyzed to try to find patterns and common problems identified by the interview participants. They were grouped and analyzed after the four dimensions of Patient empowerment defined by SUSTAINS, general User Experience measures, identified problems and users opinions and views on future functionality. This analysis was used as suggestions for developing design proposals as well as a foundation for discussions and conclusions.

2.4 Design Approach

Design has been done using Human-centered design (HCD). This means that the design process and decisions was fueled by opinions and stories of humans (users). HCD is explained in more detail in chapter 3.2. In our study this was done by interviewing a set of users and finding out what they think of the service and what they want from the service. From this, design principles were produced covering aspects that the interviewees found that could be improved. These design principles were used to bring forth proposals that show what the service could be. A limitation in the design work is that the design proposals were not tested and evaluated with users.

3. Theoretical Framework

The chapter on theoretical framework gives an overview and discussion of key concepts used in the thesis. This chapter focuses on giving an overview of User Experience (UX), Human Centered Design (HCD), how UX relates to HCD, how UX can be measured and evaluated, Patient empowerment finally and how UX can relate to Patient empowerment.

3.1 User Experience

User Experience (UX) is a buzzword in both industry and academia, even though there is no clear definition of what it really means. The website AllAboutUX has collected 27 definitions of UX (AllAboutUX.com). Most are related, however they have different viewpoints of the scope of UX - what is UX and what goes outside the boundaries of UX. This is also brought up in the article 'Understanding, Scoping and Defining User Experience' (Law et al. 2009 p.1). One could say that UX is a research field that is still being defined. Therefore, this part of the thesis will present literature about UX and how UX is defined and used in this thesis.

The introduction of UX came from researchers finding limitations of the traditional usability framework where focus is mainly on user cognition and user performance (Law et al. 2009, p. 1). ISO defines UX as *"A person's perceptions and responses that result from the use or anticipated use of a product, system or service"* (ISO 9241-210, 2010) which could be understood as it being a complex and broad concept. Usability gurus Jakob Nielsen and Don Norman says that UX *"encompasses all aspects of the end-user's interaction with the company, its services, and its products".* They further mean that first the first requirement for good UX is to meet needs of the user or customer and secondly make sure that the product is a joy to use (Nielsen Norman Group). This has given a brief explanation of what UX is about.

In 'User Experience - A Research Agenda' the authors identify three perspectives in UX literature and also discuss papers on different parts of UX (Hassenzahl and Tractinsky, 2006). These perspectives are as follows:
Beyond the Instrumental[2]
Human-computer interaction (HCI) has for a long time focused primarily on users ability to achieve goals and completing tasks during use. Early UX literature tried to extend this by adding aesthetic beauty as another important aspect. The authors of the article bring forth the concept of emotional usability and the importance of both pragmatic and hedonic aspects of interactive

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[2] Instrumental = helpful/useful/serving a need

products. Pragmatic aspects are related to usefulness and usability, hedonic aspects consists of motivations and stimulating tasks for the users (Ibid, p. 2-3).

Emotion and affect
According to Hassenzahl and Tractinsky, HCI has always considered emotions and affect but has mainly focused on negative emotions and how to prevent them from happening. The concept of UX shares the importance of emotions as something that drives human action, but also considers positive emotions such as joy and fun as important (Ibid, p. 3-4).

The experiential
The authors refer to Forlizzi and Batterbee's (2004) definition of an experience as *"a constant stream of 'self-talk' that happens when we interact with products"*. An experience is created when a product is used in a certain context or situation and is affected by the user and its current mood and motivations. The authors emphasize advantages of experiences, for example; that they are superior in the way that they can affect a person's well being. This is used to accentuate the importance of focusing on the experiential in interactive products (Ibid, p. 4-5).

To summarize the article, the authors speak of UX as *"a consequence of a users internal state, the characteristics of the designed system, and the context within which the interactions occurs"*, and that it is about *"designing for pleasure rather than for absence of pain"* (Ibid, p. 5). Additional important aspects of UX are brought up in 'User Experience White Paper'. The article mentions that even if UX is separate from brand/consumer/customer experience, they still affect each other. It also says that even if UX is mostly about the actual experience of use, experiences before and after use are also important (Roto et al 2011, p. 6-8).

Using this as a background we characterize UX as follows:
- UX is what users experience and feel before, during and after interacting with an interface. It also affects and is affected by surrounding aspects such as brand experience.
- UX is broader than usability, and thus encompasses usability. It also extends this with focus on users stimulations and motivations, and what users perceive as good or bad. This also means that UX focuses on both Do-goals (pragmatic) and Be-goals (hedonic), which means for example, both being able to find information and feel that the use is interesting and engaging.
- UX is dependent of the context of use and the user's internal state.
- UX is about designing for positive emotions and experiences.

In a time where our technology is an integrated part of our lives we think that UX becomes interesting since it goes beyond the functional and focuses on the experiential and emotional quality of a product.

3.2 Human Centered Design

ISO 9241-210 (2010) about 'Human-centred design for interactive systems' include six key principles of HCD. These are:

- The design is based upon an explicit understanding of users, tasks and environments.
- Users are involved throughout design and development.
- The design is driven and refined by user-centered evaluation.
- The process is iterative.
- The design addresses the whole user experience.
- The design team includes multidisciplinary skills and perspectives.

In an article, David Travis, Ph.D in Psychology and an experienced usability contractor talks about ISO 9241-210 as *"the single most important standard in user experience"* and further describes these principles from the standard as follows (Userfocus.co.uk):

The design is based upon an explicit understanding of users, tasks and environments
It is important to understand users, what users want to do and the environment (context) of use. David Travis refers to this as 'the user experience trinity'.

Users are involved throughout design and development
Users should be involved in all design phases, not just in the beginning and in the end. Also, users must be active participants in the design process, demonstrating the design is not enough.

The design is driven and refined by user-centered evaluation
Evaluation and testing with users should be made throughout the design process.

The process is iterative
A user can never know what he wants from a system from the beginning and therefore the process must be iterative and flexible.

The design addresses the whole user experience
The design must go beyond being just simple and easy, perceptual and emotional aspects typically associated with user experience must also be taught of.

The design team includes multidisciplinary skills and perspectives
The design team must feature a wide range of views, from accessibility experts to end users.

Martin Maguire (2001) has also identified similar key principles of HCD: (Maguire 2001, p. 588-589)

- Active involvement of end-users in the development process for the designer to understand their needs and requirements for the system.

- Design should be iterative to be able to continually improve upon feedback from users.
- HCD is a collaborative process that benefits from involvement from various disciplines. The design team should consist of both experts and stakeholders.

Using this as a background we define HCD in this thesis as following:
- The HCD process should deal with input from a wide range of stakeholders, not only end-users but also experts of organisational matters.
- HCD can be implemented not only in interactive systems, it can also be applied to other design processes.
- Focuses on users, what users want to do, and how and where they use it.
- HCD is appropriate for UX design since it allows inquiry into humans experiences, motivations and emotions etc.
- UX can be a part of HCD, but is not dependant on using HCD.

3.3 Measuring and Evaluating User Experience

How can UX be measured and evaluated? As mentioned earlier, UX is broader than traditional usability which means that methods for measuring and evaluating usability are not sufficient for measuring and evaluating UX. Roto et al. (2009) explains this as *"The objective measures such as task execution time and the number of clicks or errors are not valid measures for UX, but we need to understand how the user feels about the system"* (Roto et al. 2009). Measuring the direct experience is hard, as Bevan (2008) puts it. However, Bevan further says *"UX can be measured as the user's satisfaction with achieving pragmatic and hedonic goals, and pleasure"* (Bevan 2008). The author refer to Norman's (2004) definition of pleasure as *"Pleasure will be obtained from both achieving goals, and as a direct visceral reaction to attractive appearance"* (Ibid). This could be interpreted as the user being satisfied with for example, both finding information (pragmatic) and feel that the use is interesting and engaging (hedonic), as well as finding the artifact visually attractive and effective.

In 'UX White Paper' the authors say that no generally accepted measure of UX exists (Roto et al. 2011). However, they say that there are many possible ways to measure UX. You can, for example evaluate if an emotion is positive or negative. There are also methods for evaluating qualities like trust, satisfaction or fun. The authors also point out the importance of choosing evaluation based on experiential goals of the system (Ibid). We understand this as that the evaluation can be customized for goals of the system. Of course, the different interpretations of UX mentioned earlier also mean that UX can be measured and evaluated in different ways and with different scopes.

The website AllAboutUX lists a large number of UX evaluation methods (UX Evaluation Methods - AllAboutUX). A popular method for evaluating UX is AttrakDiff. It is a questionnaire-based method for evaluating UX that makes the respondent rate the artifact based on two opposites, for example attractive/unattractive. This measures both pragmatic and hedonic quality of the system perceived by users (AttrakDiff - AllAboutUX.com). Vermeeren et al. (2010) has conducted a research of the current state and development needs of UX evaluation methods. One of their findings while collecting the methods was that many UX researchers prefer open and qualitative evaluation methods. This is because they find predefined metrics not addressing the whole UX (Vermeeren et al. 2010, p. 528).

We find that UX should be measured and evaluated using multiple sources. Custom-made evaluation and measurement methods derived from goals of the service, system or product should be combined with predefined methods for evaluation and measurement to get a more general view. We think that qualitative methods for depth should be combined with quantitative methods for more breadth. An important aspect is to measure and evaluate both pragmatic and hedonic qualities of a service, system or product since both affects the users experience.

3.4 Patient Empowerment

Patient empowerment is defined based on SUSTAINS literature review of Patient empowerment, which means that this presents SUSTAINS view.

The concept empowerment can shortly be described using Rappaport's (1987) definition *"a process by which people, organizations and communities gain mastery over their affairs"* (SUSTAINS p.8). Patient empowerment emerged in the 70s during the civil rights movement and has grown in popularity ever since. Helmer et al. (2011) defines this as patients ability *"to manage their health care and advocate for themselves as they use healthcare services"* (SUSTAINS, p. 9).

According to SUSTAINS, Patient empowerment should be seen both as a process, focused on developing one's capacity for responsibility, and as an outcome, where one has acquired attributes - such as knowledge, skills, attitudes - that are required to improve their life quality (Ibid, p. 14). An assumption made by the SUSTAINS project is that *"information empowers patients, and that informed and empowered patients take better care of their health"* (Ibid, p. 13).

From this SUSTAINS has derived four indicators of Patient empowerment. These are (Ibid, p. 18-19):

Patient knowledge

The patients understanding of health information and ability to make effective use of it. This also involves the patient being able to find relevant health information.

Patient control
The patients role in managing his health/condition.

Patient participation
The relationship, and change in relationship, between the patient and health professionals.

Patient support
The support the patient receives from health professionals. Healthcare professionals must support the patient for empowerment to occur. This also encaptures the patients satisfaction with his/her relationship with healthcare.

SUSTAINS has formulated their own definition, which we also will use, of Patient empowerment as:

> "*Patients' having the ability to understand health information and make effective use of it, as well as to gain control over and participate in a meaningful way in the disease management process in an equal partnership with healthcare professionals*" (Ibid, p. 14).

3.5 User Experience and Patient Empowerment

This part tries to briefly connect UX and Patient empowerment, and discussing why the concept of UX is a good fit for e-health services for empowering patients.

UX is something that the user experiences before, during and after interaction with an artifact. Empowerment can be a part of this experience. Patient empowerment is an experience and state that can be achieved by use of, for example an e-health service. It can therefore be one of the experiential goals of e-health services that the users feels empowered and experiences empowerment. This is an ongoing process just as user experience is, it can be achieved directly and over time. Depending on what you want to achieve the time perspective is important, whether it is to impress the user or build a long term relationship as we mentioned before. Patient empowerment is something that is experienced both during use and a long time after use. The goal of the IT-artifact is both to empower patients and start the empowering process that leads to more focused and precise health care for that patient.

Both UX and Patient empowerment have pragmatic and hedonic aspects, where it is important to both get something done, e.g. find information about diseases (pragmatic), and the feeling of satisfaction connected to this, e.g. feeling empowered (hedonic).

To get empowered, the patients must be willingly to get empowered in the way they want to. Depending on what experience the users are after, the service can apply different kind of UX for different kind of needs. *"Some patients simply want to be able to understand information they receive about their condition, whilst others want to have full control over and active participation in all medical-related decision-making"* (SUSTAINS, p. 12).

4. Results

In this chapter we will first present the data from the interviews and evaluate 'My Health Record', as it appeared in May 2013, based on dimensions of Patient empowerment defined by SUSTAINS (SUSTAINS, p. 18-20) and ways of measuring and evaluating UX identified in part 3.3. This will be followed with requested functionality from the interviewees and their responses and opinions on suggested functionality and a concluding analysis. Finally we present design principles derived from the evaluation and analysis, and illustrate these with design proposals.

4.1 The Interviewees

The interviewees were all regular users of both computers and 'My Health Record', but none considered themselves as experts. The interviewees were not questioned about their age, hence the information about age are estimations. Additionally, no questions regarding "sickness" and their experience of healthcare were asked, but since the interviewees were users of 'My Health Record' you can conclude that they have interacted with healthcare. Interviews with the interviewees were conducted between the 2th of May 2013 and the 8th of May 2013. The average length of the interviews was 45 minutes, where some were shorter and some were longer.

Number	Gender	Age	Form of interview
1	Man	65+	Face-to-face
2	Woman	31-40	Face-to-face
3	Man	65+	Face-to-face
4	Man	41-50	Skype
5	Woman	21-30	Skype
6	Woman	65+	Face-to-face
7	Man	65+	Face-to-face
8	Woman	41-50	Face-to-face
9	Woman	51-64	Skype

Figure 3 – Table describing the interviewees

4.2 Patient Empowerment and User Experience and the eHealth Services

4.2.1 General Findings

Most of the interviewees have used the service since launch, in November 2012. Interviews were conducted in the beginning of May 2013, meaning that most of the users had used the service for 6-7 months. However, there are differences in the number of times they have used it. It seems that most of them use the service at home, often after a doctors appointment or encounter with health care to check if everything was understood correctly. Main reasons and motivations for beginning using the service among the interviewees was curiosity and timesaving compared to requesting health records and test results on paper. Before launch of the service a few were tempted to request health records on paper, but did not because of inconvenience, or perceived inconvenience. There were also persons that had requested paper health records for a long time. One of the interviewees regularly visited the service to look for new functionality, such as the introduction of the log list[3].

All of the interviewees were positive towards the service. Reasons for use mentioned by the interviewees is quick access to:
- Get information about things they might not have perceived during encounters with healthcare.
- Get information about their medicines and prescriptions.
- The log list, to see which health professional who has accessed their health record.
- Using it as a memo or note of what happened and of what was said.
- Get "Aha-experiences".
- Read test results.
- Managing high-cost protection.

4.2.2 Patient Knowledge

In the theoretical framework Patient knowledge was defined as *"the patients understanding of health information and ability to make effective use of it. This also involves the patient being able to find relevant health information"*. This section will show and discuss how the interviewees are getting knowledge about their healthcare through 'My Health Record'.

The service enables users to see how healthcare professionals work, think and write in the health records. As one interviewee puts it *"When I read the health record i did see that they write a lot more than they might say. It was a good experience and gave me the insight that even if they do not say much during consultations, they might still write things down in the health record"*. The

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[3] A list of all the people in healthcare that has opened the health record.

ones that do not have great knowledge of medical terms uses their relatives or other friends and family to get empowered by them in a way health care professionals could do.

Main reasons why the interviewees used the service was that they wanted to get reminded of what have been said, see what drugs they have been recommended and to see if anything in the health records was incorrect. Especially the ability to refresh ones memory was appreciated by the interviewees, since it earlier took a great effort acquiring health records on paper. The other acknowledgements of test results, reading healthcare records etc could be accessed before the service was available through classic paper health records.

Three interviewees mention that their visits have become more effective since they now can communicate with healthcare professionals directly with real time data contained in the electronic health journals. They mention that when interaction with the health records is in real time it is put in a whole new context, since it is information from the present instead of the past. One interviewee said *"News, good or bad is just old news when you get them after a month or so"*. 'My Health Record' invites the patient to get empowered before a visit and make them available to plan for upcoming conversations with healthcare professionals. All interviewees mentioned that the actual meeting with healthcare professionals was better suited for understanding. This was because the presence of a healthcare professional being able to give guidance while acquiring information about their health.

Depending on what experience you have with healthcare organisations, if you have been a recurring patient or working with related jobs, you understand the information better or worse. This needs to be improved, for this service is not used only by people who possess healthcare vocabulary, but also by people still learning it.

4.2.3 Patient Control

In the theoretical framework Patient control was described as *"the patients role in managing his health/condition"*. Hence this section will present and discuss how the interviewees take control over the management of their health, and how the use of the service affects this.

All of the interviewees use the service to control that the health record matches their view of what happened during the interaction with healthcare. This can be illustrated by what one interviewee said: "*I use the information to check and make sure that I haven't misunderstood something that the doctor said*"**.** The interviewees told us that the service enables them to discover incorrect information in their health records, which they can use for questions and discussion with health professionals. As one interviewee puts it "*I use the service to be able to read, and to spot errors in my health record that I can point out to my doctor*". The fact that a large part of the interviewees says that they read their health records to find incorrect information

could be interpreted as a willingness to be more responsible for management of their health. This is because incorrect information could lead to problems and misinterpretations in the future.

Additionally, the interviewees feel that 'My Health Record' gives them a good overview of healthcare and the healthcare process. One interviewee illustrates this as "*it enables me to see the overall picture more clearly and I see that something is happening after my visit at the hospital*". Another interviewee feel that the service gives an insight in how healthcare professionals are thinking. Connected to the improved interaction that the service gives, one interviewee says "*the service gives another dimension of control, since the information is almost accessible 'live'*". What has been presented above shows that the service can make it easier to control the result of interaction with healthcare. This can make it easier to take a bigger part of managing one's health.

Four of the interviewees are pointing out that the service makes them more independent, in the way that they do not need to adapt to when it is possible to meet with healthcare. This enables them to manage and get information about their health whenever it fits them. One example of this from one interviewee was "*advices from health care are more accessible now which makes it easier for me to take care of my health*". Another example mentioned by several interviewees is that they appreciate the ability to access test results whenever they want, making it easier to follow how they develop. One interviewee also claims that after beginning using the service, he has decided to do continuous health checks. This could mean that by making health advices and test results more accessible and quicker to access, it will be more motivating and easier to take a more active role as a patient.

However, not everyone says that it gives them more control, or make them take more control, than earlier. Two out of nine of the interviewees says that the use of 'My Health Record' has not affected their control, or wish to take control. One of these interviewees claims that she already had an active role in the management of her health before beginning to use the service, and the service does not offer anything extra that would change this.

4.2.4 Patient Participation
In the theoretical framework Patient participation was describes as "*the relationship, and change in relationship, between the patient and health professionals*". This section will bring up how the interviewees feel involved in the healthcare process and how this could be improved.

The interviewees who spoke about receiving information in real time (see section 4.1.2) also points out that when they use the service and take part of the information in this new way also make it more viable to participate with the healthcare. They can now clearly point out results and terms they did not understand and ask questions about them while they are still relevant. Patients would now be able to discuss with healthcare professionals at another level than before, since they now feel more confident in themselves in this particular situation. "*This behavior has been*

there before but now it is possible for everyone, not just the one who really puts effort into it",
says another interviewee.

'My Health Record' has worked as a starting point for more orderliness and structure for patients.
Two patients are now demanding blood tests and pulse tests without any clear symptoms in their
own words. Now they feel they can, for themselves, easily follow up blood values and how they
develop. *"Just to be ensured everything is alright. It is really interesting to see how things can
develop."* says one interviewee.

We conclude that 'My Health Record' seems to be an useful tool for encouraging patient
participation. All interviewees felt much more confident and willing to participate in their health
process after usage of 'My Health Record'. Inviting patients to use the service seems to create
new behaviors which puts them in a new position where they feel more confident to participate.

4.2.5 Patient Support

In the theoretical framework, patient support was described as *"the support the patient receives
from health professionals. Healthcare professionals must support the patient for empowerment
to occur. This also encaptures the patients' satisfaction with his/her relationship with
healthcare"*. Therefore, this section will present and discuss how the interviewees feel about
their relationship with healthcare, and if the use of 'My Health Record' has affected this. This
also includes if the interviewees feel that they are supported by healthcare professionals to use
the service and get empowered.

Only two out of nine interviewees has been encouraged by health professionals to use the service**.**
However, all of the interviewees claim that they have a positive relation towards the healthcare.
A general opinion is that people working in healthcare are professional and trustworthy.

Two interviewees feel that their relation with healthcare has been strengthened after beginning
using 'My Health Record'. One interviewee explains this as *"they write more than you think and
seems to work hard which made me feel positively surprised"*. In contrast to this one interviewee
said *"my opinions and relation towards healthcare are affected by how they treat me during
visits"*. This could be understood as that the service and the information on the service does not
affect how the person feels about healthcare. A few also say that improved possibilities for
communication with healthcare via the service could improve their relationship further.

Some of the interviewees feel worried about the entries in their log list since they do not
understand the reason for why some healthcare professionals have looked at their health record.
They feel that this affects their trust towards healthcare. One interviewee proposed that everyone
that opened and looked at a health record should be required to leave a short comment explaining
why.

To get a more complete picture of this and to be able to improve this aspect more, we feel that health care professionals must also be heard since this is something that lies largely on the organization. SUSTAINS claims that *"Patient empowerment would hardly occur without healthcare professionals' willingness to support the patient throughout the 'empowering process'"* (SUSTAINS, p.12). This has been identified as a problem since, as mentioned earlier, only two of the interviewees had been encouraged by healthcare professionals. This we feel is quite surprising. However, an important notion is that some healthcare professionals might not know that 'My Health Record' exists. Therefore, it is important that all healthcare professionals take notion of the service and begin to appreciate its possibilities, and additionally motivate and support the patients.

4.2.6 User Experience

Large parts about the users experiences of the service has already been covered. The sections above has presented and analyzed how the interviewees perceives 'My Health Record' in relation to the dimensions of Patient empowerment, and also their motivations (how and why) to use the service. This could be applied to what we discussed earlier, in chapter 3.5, *"UX is something that the user experiences before, during and after interaction with an artifact. Empowerment can be a part of this experience. Patient empowerment is an experience and state that can be achieved by use of, for example an e-health service"*. Hence this section could be seen as summarizing some of what has already been covered, but also bringing forth new aspects.

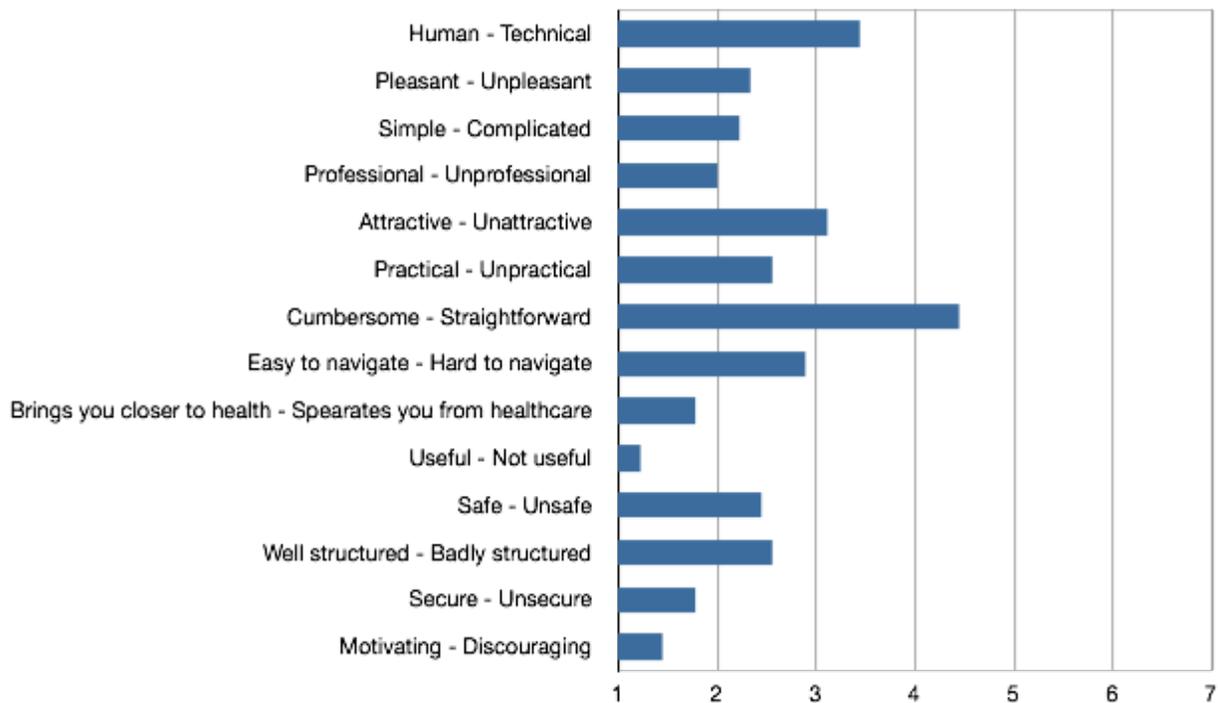The figure below presents results from our AttrakDiff-inspired evaluation.

Figure 4 - AttrakDiff-inspired evaluation

This figure shows arithmetic mean of the grading from the interviewees. The interviewees were asked to grade the service 1-7 based on two opposites and give a short motivation for their grade. One example could be simple/complicated, here a value of 1 should be interpreted as very simple, a value of 7 as very complicated, and a value of 4 as neither simple or complicated. Below, these opposites will be translated and presented further, and assigned whether it is a pragmatic quality (PQ) or a hedonic quality (HQ).

Human - Technical (HQ)
There is a quite equal distribution among the interviewees between finding it human and technical. One finding was that some of them prefered that the service feels human and that some prefer that it feels technical.

Pleasant - Unpleasant (HQ)
Most finds the service pleasant, but says that this depends largely on what the information says. Unpleasant information can make a pleasant service unpleasant to use.

Simple - Complicated (PQ)
The interviewees feel that the service in general is simple. However, a few mentions that the navigation was a bit complicated at the start and that it requires a lot of clicking. One interviewee

says that the service is in reality quite complicated since it contains a lot of health information that has not been adapted for patients.

Attractive - Unattractive (HQ)
Most of the interviewees think that the service is attractive and pleasant to use. One interviewee says that she does not care about this. Three interviewees find the service a bit dull, one think that it is a bit grey and another thinks that it is just a digital health record and nothing extra.

Practical - Unpractical (PQ)
Almost half of the interviewees finds the service practical. Criticisms mostly regard the amount of clicks required to find desired information.

Cumbersome - Straightforward (PQ)
Most of the interviewees thinks that the service lies somewhere in the middle between cumbersome and straightforward. This is mainly because it can be hard to understand what things mean, for example reference values for test results, and that the medical information is not tailored for the patient.

Easy to navigate - Hard to navigate (PQ)
There is a quite equal distribution among the interviewees between finding it easy to navigate and hard to navigate. This has been discussed earlier, but some think that it requires many clicks and that it can be a bit hard to understand the structure in the beginning.

Brings you closer to healthcare - Separates you from healthcare (HQ)
All of the interviewees thinks that the service brings them closer to healthcare in some way. However, one says that it only brings him closer to the medical information but not the healthcare.

Useful - Not useful (PQ/HQ)
All of the interviewees finds the service useful. One feels that it is useful for reading information about ones health but not for deeper and richer interaction.

Safe - Unsafe (HQ)
There is a quite equal distribution among the interviewees between finding it safe and unsafe. Many of the interviewees had a hard time motivating their grading.

Well structured - Badly structured (PQ)
There is a quite equal distribution among the interviewees between finding it well structured and badly structured. This is mostly because of reasons that have been brought up earlier, that it may

require many clicks to reach desired information and that the structure can be a bit hard to understand in the beginning.

Secure - Unsecure (HQ)
The interviewees feels that the service feels secure, mostly because trust for the services that provide electronic identification.

Motivating - Discouraging (Motivating to learn more, take more control, change behaviour etc.) (HQ)
Most of the interviewees finds the service as motivating, mostly because it is interesting to read information connected to ones own health. One interviewee thinks that the service does not really motivate to change ones behavior, however it can be a tool for it.

What can be understood of this evaluation is that most of the interviewees grade the service on the positive end of the scale. This could be understood that they generally are positive to the service, which also go along with what has been said earlier regarding their relation to the service. By looking at the result we see that the service scores a bit higher on hedonic qualities than pragmatic qualities. Most of criticism has been regarding pragmatic qualities such as that it requires a lot of clicking and can be a bit hard to understand.

4.2.7 Suggested Improvements and Functionality by Users
To fulfill everyone's needs and wishes in a service is a difficult task to accomplish. However, most propositions from the interviewees were reasonable and not complex to implement, though some might propose a change to how healthcare works today. For example making it possible to communicate with healthcare professionals in 'My Health Record'. Another example that requires even more organisational change, is the fact that a few of the interviewees feel that it sometimes takes too long for the doctors to sign new health record entries. With this in mind, this section will give an overview of suggestions of missing functionality given by the interviewees and also their opinions on functionality suggested by us.

Eight of the interviewees talks about lack of communication throughout the service. More communication would give them more control and make their relation to healthcare professionals closer. One interviewee feels that the communication option available today is not secure enough since it relies on normal e-mails. Secure communication can be important since it can contain information that the user finds as sensitive and private. Additionally, six interviewees wanted more transparency of whom was responsible for certain divisions of the hospital so that they would know whom to contact in matters of ambiguities. Two interviewees said that it now takes a great effort to find this information.

Moreover some interviewees would like to see scanned documents and radiographs, as in this quote: *"As of today on the service you can not see scanned documents and radiographs, which can be rewarding for us users to be able to get them at any time. And these might say more than words."* One interviewee also says it feels like the service is not complete, as if some information is lacking. A search function was also requested in several interviews, it is a well known function of many web sites and would make it easier to find desired information.

Healthcare professionals can currently not see if the patients have been reading their health records. Seven of nine interviewees thought that it would be a great idea that they could. This might give the caregiver a signal that they also could get a perspective of how the patient has tried to empower him/herself. The other two interviewees who did not like the idea of visits to 'My Health Record' being visible to healthcare professionals said that it was impossible for the healthcare professionals to know if the patients have been processed any of the information given. They further mean that it could lead to confusion between patient and professionals on the next consultation.

Four interviewees requested the possibility to receive email notifications when new information and functionality is available. Now a user of 'My Health Record' must regularly check to see if any changes has made, but does not get a notification of what has been changed or what content that is new.

Two of the interviewees made their own "personalized" health records to match their needs before the service existed. One made his own health care records with short comments about each visit in an Excel spreadsheet, which he could use for refreshing their memory. The other one have been drawing diagrams of his blood tests over the years to make it easier for him/her to follow and see how it develops. For greater ease and understanding, half of the interviewees agreed that a visualisation of blood tests would be a good idea. It is a good way to communicate with users with graphics and images and not only by text one interviewee said. The other half of the interviewees did not have a need for this function as of today, but did not see a problem of implementing it.

In the current version of 'My Health Record' you can print the health record. Some of the interviewees use this functionality to underline certain topics they want to discuss at the next consultation, or to point out errors in the health record. When asked whether they wanted to write their own notes on the health record, accessible for themselves only, they all responded with positively. As mentioned above, one interviewee made wrote own comments in a document after each visit. Other interviewees also said that they wanted to be able to mark things in the health record as incorrect, so that healthcare professionals can see this and maybe correct it at their next consultation.

One issue of great debate in media has been the access of signed or unsigned records. Signed health record notes was of interest for six out of nine interviewees, they said that the information given should be consistent and precise therefore not containing unreliable information about their health. Only three thinks it is a good idea to get unsigned information, but marked with a warning sign saying that the information given could be wrong and should not be taken seriously. But they all agreed that the problem would not be existing if healthcare professionals did sign them more quickly than of today.

To clarify special terms and words that are used by healthcare professionals, several interviewees mentions an information icon assigned the term/word they did not understand. This icon is provided with an hovering effect that brings forth a popup that contains an explanation of the term/word so users can get empowered within the borders of the service. Today several services gives users the opportunity to get empowered in this fast and appropriate way. For example pharmacists use a service called FASS[4] daily that have the same functionality and is appreciated by the interviewee and his/her colleagues

To keep users who does not want sensitive information in the journal pleased, users are asked if they agree or disagree to receive sensitive information that could be e.g a blood samples confirming they have a severe diseases. Seven out of nine interviewees said that it would be a better idea to have a checkbox saying "save this answer for later" and be able to change this in preferences. Receiving this popup every time was confusing for one interviewee, who told us that it *"can create confusion and feel like you might have done something wrong"*.

A larger part of the interviewees gave input about that health records contains information that to them feels irrelevant to read each time. They wanted an option to mark them as hidden, which would increase the efficiency of their use of 'My Health Record'.

One interviewee wanted better correlations connecting the different areas of the health records in 'My Health Record' to make it easier to follow and see relations. Along with this three of the interviewees also points out that the navigation of today's service is not the best, it takes too long for them to get to the part they want to. It takes an effort to learn where everything is and for first time users this can be hard one interviewee says, especially when they are not used to these types of interaction.

Only four interviewees had opinions about graphic design or interaction design and the majority of interviewees did not feel that the lack of graphic elements on 'My Health Record' is a problem. *"But for the ones who need it, it's not there. Some interpret images a lot better than text, its good for people that remembers images better than text"*, one interviewee said.

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[4] www.fass.se

In this chapter we can clearly see that even though the interviewees have a positive experience of the service, there is still room for improvements and additional functionality. This functionality should be integrated smoothly and not be forced upon the users, so it does not disturb the existing user base and their usage patterns. It might be hard to predict the impact of the implementation of further functionality. For example, how communication within the service would impact the healthcare professionals today.

4.2.8 Concluding Analysis

In general, the interviewed users of 'My Health Record' are very satisfied with the service. From our interviews it also seems that the service would lead to better Patient empowerment as defined in SUSTAINS' definitions and indicators. Though, it should be noted that we have only addressed experiences after interaction and reflections on experiences before and during use. However, during the AttrakDiff-inspired questions interviewees told us that it was a bit cumbersome to navigate, a bit grey and dull, and that it required some effort to learn.

Problems and wishes identified by the interviewees are mostly regarding the information given by the service. A few thinks that the information is hard to understand, a few want more information such as x-ray images, a few want more explanation of test results. Another issue with the service is that it does not give sufficient possibilities for communication with healthcare. Following is a summarizing list of problems and wishes identified from the interviews. These should be seen as beyond basic demands such as be given access to information. The interviewees feel that this would enhance experiences of using the service, even if many finds that only access to information is engaging and exciting on its own.

- Communication via the service.
- Hard to understand the information given.
- Takes time to navigate throughout the service.
- There is no good overview of recent activities.
- The service is a bit grey and dull, and readability could be improved.
- There is no visualization of test results, only text. This could be used to see how values develop and also see correlations between different values.
- To be available to write your own notes for yourself in health records
- Let functionality be optional to use and configurable at preferences.
- There is no way of searching and filtering information.
- Does not offer functionality to retrieve notifications via for example e-mail when new information is available.

4.3 Recommendations for Redesign of the eHealth Services

These design principles come from interviews with users and reflect what they want. These should be understood as what is wanted beyond the basic functionality, providing health records in a structured way.

A: Electronic health records should speak both language of patients and health professionals
Notes written by health professionals can sometimes be hard to understand because of specialist language. Also, health professionals can be patients and therefore information in electronic health records must be explained so that everyone can make good use of it. It is stated in Swedish law that health records should be written in swedish and be understandable for patients[5]. However, this can be improved further by providing using tooltips that explains certain words, and not force them to search further in some other way.

B: Focus on accessibility and readability
These services has potentially a high amount of elderly users. Therefore good accessibility and readability is something that should be focused on. This can be done by making sure that the service works for visually impaired and making sure that the text has a carefully chosen font, font size, line height and letter spacing.

C: Provide quick access to the most recent information on the index page
Providing quick access to the most recent information directly on the index page makes it easier for the users to navigate.

D: Provide the ability to write own notes in the health record
Some patients like to write notes for their own memory. Giving them the ability to this on the side of the health record entry, giving the right context, could make these more valuable.

F: Provide the ability to search and filter health records and test results
Many have a long list of entries and many of these may come from just simple visits. Therefore it is important to provide the ability to effectively search and filter.

G: Provide the ability to receive notifications
Providing the users the ability to receive notifications, for example an e-mail, when new information is available gives a feeling of "live"-interaction. Also, users would not need to log in to see if new information has arrived.

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[5] Chapter 3; §13 - http://www.notisum.se/rnp/sls/lag/20080355.HTM

H: Have optional functionality so patients can configure the service their own way
All users have different relations to their health and in what way they want information. Providing the ability to configure functionality can be used to satisfy needs of different users, for example giving the ability to choose whether only health record entries attested by doctors should be visible or that all health record entries should be visible.

I: Visualize test results
Test results can be difficult to understand and see correlations between one value and another. It can be hard to get an overview of how readings develop over time. Visualizations is a good tool for making this easier.

J: Choose a color scheme that fits healthcare
Colors have meanings, pick a color scheme with colors relating to healthcare. For example, different hues of blue or green. This also means that color scheme could be chosen to fit branding of the service provider.

K: Enabling communication through the service makes it more focused
Enabling communication between patients and healthcare professionals via the service could have a positive impact on their relation and it could also provide an easier medium for healthcare professionals to communicate with the patients. To communicate this way could also empower patients, make them more willingly to participate, give them more control and make the healthcare support more effectively.

L: Help patients get reminded
Patients that are up to date can lead to better participation, empowerment and more patient control at consultations. Patients aware of their own health can be a source of knowledge about the themselves for healthcare professionals.

M: Clarify to the users how to the information on the service should be used
To reduce the misinterpretations of how to use the information given, the service should contain an explanation of how to use the information. For example providing a tutorial for the service. Everyone should strive to use information in the same way while communicating and consulting with each other. Especially for users which does not have the knowledge that others might possess.

N: Point the information on the service to the users
Instead of using healthcare terms like "Patientuppgifter" (Patient data) you should use "Mina Uppgifter". Direct the information given to patients so they feel it is theirs and not just some information they are allowed to look at.

O: Use images and icons as complements to text

To make the service appropriate for everyone it should contain both images and text for presentation of information. It should also provide icons and images to help users navigate throughout the service.

4.3.1 The Index Page

Figure 5 - Our recommendation for the Index page

The service have been given a new and more appealing visual design with a green color that is appropriate for healthcare, according to design principle **J.** This will be consistent throughout the service.

1. 'Patientuppgifter' (Patient data) has been renamed to 'Mina uppgifter' (My data). This is in line with design principle **N,** which say that the language should be aimed at the patient/user, not the healthcare.

2. Instead of receiving a popup every time you login to Min Journal you get a notification bar that informs you that you have/have not accepted the terms of getting sensitive results in the records. This bar can be hidden for one session if the close button is clicked and a link to configuration is also available where you can change the setting. This is more unobtrusive than a popup.

3. The user can receive notifications when new information is available on the service, this follows design principle **G.**

4. Recent activities let users access recent activities in a quick way, as mentioned in design principle **C.**

5. Providing the ability to get a tour of the service that explains how it can be used. This shows an example of how design principle **M** can be implemented.

4.3.2 The Health Record Entry Page

Figure 6 - Our recommendation for the Health Record Entry page

The Health Record Entry page have been redesigned with a better way of searching throughout the service and in health records. It is now also clearer that you should click on an entry in the list to view more information by adding "Visa mer" (View more) to the right. The new design also have images and icons according to design principle **O** which make it to easier navigate and remembering.

1. This allows searching and filtering of health record entries, which has been brought up as important in design principle **F.**
2. The information circle helps users understand words and terms they might not understand. It can be used to empower users so they does not need to get empowered by someone/something else but can be that directly in the service according to principle **A**.
3. Here users can write notes, both for them as reminders and explanations and to healthcare for mentions and questions. The notes will be shown to the right of the health record entry. This follows design principles **D** and also **K.**
4. The bottom bar enables communication inside the service by providing the functionality "Ställ en fråga" (Ask a question), according to design principle **K**. A picture and contact information to doctors responsible for this particular health record entry enables recognition and reliability.

4.3.3 The Test Result Page

Figure 7 - Our recommendation for the Test Result page, showing the readings from one test

Figure 8 - Our recommendation for the Test Result page, showing readings over time

The test result page have now been visualized and delivers data to users in a clearer way, with both text and graphs. According to design principles **I** this helps patients overall to understand the information given better. Functionality has been improved by showing both the reading from the current test [Figure 6] and also "Värden över tid" (Values over time) where users can plot how one or more readings develop over time [Figure 7].

1. This illustrates design principle **F,** providing the same functionality for searching and filtering as on the Health Record Entry page.
2. The visualization of data given helps, according to design principle **I,** users to follow development of certain values over time. The reference value is also available in the graph and it gives the users an option to choose between which dates to show and what values in the tests to follow.

5. Discussion

Answers were found to our research questions and we found a clear connection between Patient empowerment and User Experience. User Experience seems to be a good tool for achieving system/service goals of a complex character such as Patient empowerment since it enables inquiry into a person's motivations and emotions. Traditional usability measures such as number of clicks and task execution times does not feel sufficient since many of our interviewees said that it do not matter that it required many clicks and was a bit cumbersome to navigate. Even though the service has these problems, all interviewees actually enjoyed using the service. Evaluating the service based on these traditional measurements would probably have led to another result, that might not necessarily have affected the empowerment of patients as much.

We can recommend using UX for design and evaluation of eHealth-services, we feel that we got rich information that gave us a good understanding of what users want, and how and why they use the service. This is in line with Gustafson & Wyatt (Gustafson & Wyatt 2004, p. 1-2; p. 2), who argue that important aspects for evaluating eHealth services are qualitative studies that captures what users feel when using the service and its affect on their lives, as well as how people use the service. For these services, it is more important to understand how users feel, not that it takes two seconds shorter to find the information provided. Similar arguments are stated by Hesse and Schneiderman who states that improving lives is the most important metric from a user perspective (Hesse & Shneiderman 2007, p. 11).

One could argue that our design process is not fully "human-centered" and iterative since it does not include several iterations of interviews and user testing of our proposals. However, since we set out to redesign an already implemented service this cannot be seen as the first iteration. User testing our proposals would have enabled us to refine them and the "design principles" even more since it can be a lot easier to discuss around pictures. But because of short of amount of time, we are satisfied with our results and feel that they could be used to improve the service.

The interviewees were in a broad spectrum of age and had different experience of computers, some working with computers on a daily basis and some still learning to interact with them. An unexpected aspect was that that the interviewees did not have many opinions and complaints about the actual user interface of 'My Health Record', in spite of their various age and computer knowledge. A walkthrough of the service where the interviewee could interact with it, think out loud and allow us to observe their usage would maybe have given us more feedback on the interface itself. Our method of interviewing users after use requires reflections on use, which might mostly be about the parts of 'My Health Record' that has made the biggest impression on them, maybe the actual health record. This could mean that the user interface becomes almost invisible to users because they find the information to be very interesting and exciting. The cause of why they begun using the service was in most cases curiosity of what had been written in the

health records, not because they were early adopters of technology. An old study with 200 patients shows that almost 80 percent thinks that patients should be given access to their medical records (Michael & Bordley 1982, p. 433). This can be interpreted as health records being of big importance to a person and therefore made the biggest impression to them, which could explain why this is what interviewees focused most on. What we have found could be compared to the very popular website Craigslist[6] which has an interface that could be found as ugly, boring and ineffective. Its popularity comes mainly from the content. Another reason to this "interface transparency" could be that users have no experience of another similar service, giving them nothing to compare it to. This could mean that an improved interface and improved functionality would still be well received and appreciated.

Because of this we have chosen to be "visionary" in our design by proposing things that might also require change on an organizational or programmatic level. The design is based on what users/patients said during the interviews and are not limited to what is possible at the moment. Additionally, in our design we have not changed headings and navigation even though a few interviewees pointed this out as a problem. We find that this could interfere with patterns of navigation that users have learned, and improvements could require further tests such as card sorting for finding a more logical structure. Instead we chose to give easier and quicker access to points of interest on the service, such as health record entries and test results to satisfy those who find it cumbersome to navigate.

The interviewees were all users of 'My Health Record' and therefore the design principles are defined customized for this specific service. But they could also be useful and interesting for others looking to implement a similar service, which will happen since it has been announced that all counties in Sweden will receive a similar service. The design principles should be improved and validated by more studies. Additionally, we only conducted nine interviews and there are almost 21 000 users. A similar study, with 231 respondents, about how patients use their access received results similar to ours. They found that most users report a positive experience and that main reasons for use are: looking at test results, satisfying curiosity and to see what doctors have written (Bhavnani et al. 2010, p. 4-5). However, this study has been made in another country and studies a different service. It would be interesting to conduct more interviews and also quantitative studies giving a more general view and opinions on 'My Health Record' in particular.

The interviewees were all active users of 'My Health Record' and there are still a lot of people who interact with healthcare but does not use this service. It would truly be interesting to see why they are not using it and what is required to motivate them to start using 'My Health Record'. Since more counties in Sweden are planning on also launching a similar service it

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[6] http://www.craigslist.org/about/sites

would be interesting in the future to interview these users to be able to compare and make a more complex analysis.

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Appendixes

Appendix 1 - Invitation

Inbjudan till studie angående E-hälsotjänster

Personuppgiftsansvarig

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Angående projektet

Vi är två studenter som gör vårt examensarbete vid institutionen för informationsteknologi på Uppsala universitet. Arbetet handlar om hur E-hälsotjänster bör utformas för att vara givande för användarna/patienterna. Som grund för detta ska vi undersöka Landstinget i Uppsala läns E-hälsotjänster (främst patientjournaler på nätet) och intervjua användare av dessa. Resultatet av detta är en C-uppsats, en akademisk uppsats på kandidatnivå, som publiceras på internet.

Angående intervjun

Under intervjun kommer vi att ställa frågor om hur ni har använt Mina vårdkontakter, hur ni upplevt användandet och hur det har påverkat er. Frågorna berör inte sjukdomar, vi är intresserade av hur tjänsten används och hur den kan påverka patienters inflytande och kunskap. Intervjun omfattar ca 45-60 minuter.

Hantering av personuppgifter

Personuppgifterna hanteras i enighet med PUL (Personuppgiftslagen). Personuppgifterna kommer endast att hanteras av oss som genomför studien och lämnas inte ut till någon annan part.

Typ av personuppgifter och ändamål för insamling

De personuppgifter som samlas in är namn, kontaktuppgifter och anteckningar samt eventuella inspelningar från intervjuer innehållande känslig information. Detta då den intervjuade kan nämna information om sin hälsa när den svarar på intervjufrågorna. Namn och kontaktuppgifter separeras från intervjuerna genom att varje intervju får ett nummer som svarar mot dessa uppgifter i ett separat dokument.

Förvaring av personuppgifter

Personuppgifterna kommer lagras på ett krypterat USB-minne tills dess att arbetet är klart, den 20/6-2013, och kommer sedan att raderas. Krypteringsnyckeln till USB-minnet förvaras i ett kassaskåp på institutionen för IT vid Uppsala universitet. Detta gör att obehöriga inte får tillgång till uppgifterna.

Registerutdrag

Den intervjuade har rätten att begära ett registerutdrag innehållande alla personuppgifter som behandlas om personen. Upptäcker den felaktiga personuppgifter har den rätt att begära ändringar av dem.

Deltagande

Att delta i intervjun är frivilligt och ingen ersättning erhålls. I samband med intervjutillfället skriver den intervjuade under ett samtyckesformulär där den godkänner deltagande i studien samt lagring och behandling av personuppgifter i enighet med detta dokument.

Det skulle vara roligt och givande om ni vill ställa upp.

Hälsningar Johan Andersson och Viktor Kjerrman

Appendix 2 - Interview questions

Intervjufrågor

Inledande

Informera om vilken funktionalitet som finns:
* Läsa sin journal
* Läsa diagnoser
* Läsa provsvar
* Följa en remiss
* Dela sin journal så att andra kan läsa den.
* Läsa logglistan
* Låsa journalen så att ingen kan se den via Min Journal

Hur länge och hur många gånger ungefär har du använt tjänsten?

Hur var dina förväntningar på tjänsten före användandet?

När kollar du? När skulle du vilja kolla?

Varför använder du tjänsten? (Inte fokuserat på sjukdomar)

Hur mycket av informationen förstår du?

Hur använder du informationen?

Hur mycket av informationen tycker du känns relevant för dig, för att du ska få mer kunskap och kunna vara mer delaktig i din behandling, är informationen överflödig eller vill du ha mer eller annan information?

Hur påverkar användandet av tjänsten hur du ser på dina valmöjligheter för behandling/sjukvård/hälsovård?

Eventuell följdfråga till ovan - Vilken nytta ger tjänsten dig/vad får du ut av användandet?

Berätta fritt om hur du upplever användandet. Följ upp med Kunskap? Kontroll? Trygghet? Integritet? Något negativt? efter en stund

Ev följdfråga till ovan - Vilka känslor upplever du vid användandet och vilka känslor kopplar du till tjänsten? Vilka adjektiv förknippar du med tjänsten? Hur menar du då?

Hur har tjänsten påverkat ditt intresse/ansvar för din egen hälsa? Ev. följdfråga: Gör den så at du också läser vidare på t.ex. vårdguiden?

Hur känner du att informationen som ges ger dig kontroll över din hälsa? Ev. följdfråga: Påverkar det den grad av kontroll och ansvar du vill ta/ha?

Hur har det påverkat din relation/åsikter till sjukvårdare/sjukvården?

Känner du att sjukvårdspersonalen uppmuntrar till att du använder tjänsten?

För att sammanfatta den nuvarande tjänsten och gå in på att prata om förbättringar:
Vad är bra med tjänsten?

Vad är dåligt?

Förslag på förbättringar

Hur skulle informationen kunna göras lättare att förstå?

Vilken ytterligare information vill du att det ska finnas? [Har frågats tidigare, fråga igen om otydligt svar]

Upplever du någon skillnad i det som står journalen och det som sägs vid besöket?

Vad vill du mer veta för att bli mer delaktig i din behandlingsprocess?

Hur kan tjänsten utformas för att förbättra/stärka din relation till sjukvårdare/sjukvården?

Skulle du vilja kunna ta del av din vårdplan? (t.ex. en individuell vårdplan som möjliggörför patienten att aktivt delta i planeringen av vården samt vid behandlingsbeslut.)

Skulle du vilja att själv kunna skriva kommentarer i din journal för din egen skull?

Tror du att visualisering av provresultat skulle hjälpa dig eller vill du göra den bedömningen själv?

Vad tycker du om att man får välja om man vill se känslig information varje gång du loggar in?

Borde man kunna spärra vissa journalanteckningar och inte bara hela journalen?

Vad tycker du om att det endast visas vidimerade och signerade journalanteckningar och provresultat (detta betyder att en läkare måste ha läst och godkänt innan den visas)? Detta betyder att tex provresultat dröjer innan man kan se.

Vad skulle du tycka som patient att vårdpersonal kan se att du varit inne på tjänsten och tagit del av informationen? (Så man kan använda journalen som gemensam grund för diskussion)

Avslutande fråga

Är det något mer som du vill berätta i relation till intervjun som vi har missat att fråga om?

AttrakDiff

Betygsätt 1 - 7 och ge en kort motivering

Mänsklig (vänlig, hjälpande, varfim) - teknisk (hård, svår, kall)?

Behaglig - obehaglig?

Enkel - komplicerad?

Professionell - oprofessionell?

Attraktiv - oattraktiv?

Praktisk - opraktisk?

Krånglig - rakt på sak?

Lättnavigerad - svårnavigerad?

För dig närmare sjukvården - distansierar dig från sjukvården?

Användbar - icke användbar?

Trygg - otrygg?

Bra strukturerad - dåligt strukturerad?

Stimulerande - icke stimulerande?