



Project
EARTH

EXTENDING ACCESS TO MEDICAL RECORDS
AND TEST RESULTS IN HEALTHCARE

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COMPUTING IN A GLOBAL SOCIETY - CSSE241
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Abstract

With the development of technology in today's society there are many new ways to change the healthcare system. Due to this and the fact that more and more people want to be able to access their medical data, Online Health Records(OHR) is a possible extension. On the 8th of November 2012, Uppsala County Council launched an OHR service for all its citizens. This system is the first in Sweden and has been met with criticism.

This research project aims to investigate the OHR service and suggest changes that might lead to increased usability and accesability and thus increased usage. The research is based on interviews, surveys and a comparative study. In our paper we propose features that will increase the usability and accesability of the system. We investigate in detail the possibilities of adding features such as self-testing and masking sensitive information as well as the advantage of extending the OHR system to handheld devices.

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Chapter 1

Introduction

The IT in Society course at Uppsala University is run as a collaborative course with the Computing in a Global Society course at Rose-Hulman Institute of Technology. Uppsala University is located in Uppsala County in Sweden and is one of Sweden's largest universities and the oldest university in Scandinavia. Rose-Hulman Institute of Technology is one of the United States' most prestigious institutions of technology and is located in Terre Haute, Indiana. The course is focused on a single, open-ended project for an external client that involves developing IT solutions in society.

An open-ended project is one in which the client explains a situation or a context and the students will then define the problem description and what they want to deliver from that. The description is then checked with the client to see if this is what the client wanted. For the last six years Uppsala County Council has been the client. This year the client is Benny Eklund who is the IT Strategist at Uppsala County Council.

Previous work done by the IT in Society course for the Uppsala County Council has dealt with issues in health care such as securing health care data by efficient and intelligent log file analysis, enabling patients on-line access to their health records, increasing interoperability, and unifying electronic health care records[1].

This year the project group is composed of 21 students from Uppsala University and 9 students from Rose-Hulman Institute of Technology. The majority of students have a background in IT and computer science in areas such as software engineering, socio-technical systems engineering, and human-computer interaction. The students' broad range of backgrounds and perspectives gives a comprehensive approach to the project. Further on the project group will be referred to as the EARTH group or the EARTH project.

Chapter 2

Background

2.1 Health Care in Sweden

In Sweden today, there is no standard system for health records. This is mostly because health care in Sweden is decentralized. This means that each county might have a different system for handling health records, thus leaving them unable to share medical records in an efficient way. As a result, whenever a patient is being treated in a new area, a new medical health record will be created and the hospital that is currently treating the patient will have to contact the other hospitals to find information about the patient. Some counties do have the same underlying system but different versions or procedures for working in the system which still leaves them unable to share health records efficiently. The political climate varies between different counties, which affects their ability to adopt different policies and implement changes in the existing system. This leads to fragmentation within the health care system, which also means that some problems that occur in certain health care institutions might be non-issues in others.

2.2 Uppsala County's System for Medical Records Online and the SUSTAINS Project

With the development of technology, there have been new possibilities for different kinds of communication. One of the possibilities is Online Health Records (OHR). Uppsala County Council is leading an EU project called SUSTAINS. The SUSTAINS (Support USers To Access INformation and Services) project is a European Union project run collaboratively with eleven pilot programs in nine different EU countries and it focuses on three issues in health care^[2]:

1. Empowerment of patients: There is a growing tendency by patients and the public to question information from the health system, ask for a second opinion, demand respect and dignity in their treatment, expect convenience, etc.
2. Quality of care: New progress in health care means that patients demand, and health care professionals want to offer, the best quality of care.

3. Efficiency and economy: There is a growing demand from patients/citizens for improved efficiency and economy.

The contact person for the SUSTAINS project is Benny Eklund, our client. With the help of SUSTAINS, Uppsala County Council has launched a system for patients in Uppsala County that allows them to see their medical records online. This system was launched on the 8th of November, 2012. This means that any person that has been treated in Uppsala County since this date will have their medical records available online. The OHR will contain things such as diagnosis, information about visits to local health care facilities, and information about prescribed medications and test results. Some things are intentionally left out from the OHR, such as psychiatric information, information from the department of genetics, information from the women's clinic and unsigned records. The system can be accessed by logging in to www.minavardkontakter.se and clicking on "Min Journal".

2.3 The DOME Project

DOME, Deployment of Online Medical records and E-health services, is a collaboration between the Faculties of Engineering at Lund University, the University of Skövde, and Uppsala University. The purpose of the DOME project is to build knowledge and understanding of the adoption and use of e-health services by utilizing studies of various e-health projects. The research team from the DOME project sent out a survey with questions regarding the opinions about a system that displays health records for end users. The survey focuses on the general opinion of accessing the information online, what people think about searching for information about their physical health on their own, and how they currently get the information about their health.[3]

2.4 Estonia's Online Health Record System

Estonia has a system where patients can view their health record online which was launched in December 2008. The Estonian Ministry of Social Affairs began the e-health concept by phasing in four projects: EHR, Digital Image, Digital Registration, and Digital Prescription[30, p. 9]. Additionally, they created a new organization to oversee the system, the Estonian eHealth Foundation. This organization was composed of the three largest hospitals in Estonia, the Ministry of Social Affairs, the Estonian Society of Family Doctors, the Estonian Hospital Union, and the Association of Ambulance Doctors. By bringing all these groups together to administrate the system, it unified all major stakeholders in Estonian health care. This encourages all members of the system to cooperate and govern the system fairly. Such an organization does not exist for the OHR system in Uppsala.

Additionally, the Estonian OHR system does not replace existing local systems[30, p. 9]. Internal systems which are local to individual institutions must still be used in Estonia, but they are required to interface with the central system to share data with patients and other institutions. In the scope of Uppsala county, the OHR is intended to act as the

primary system for health records and related documents, rather than being a separate, central system with which local systems must interface.

2.5 Laws Dealing with Medical Records

Swedish law states how, when, and by whom health record data can be used and managed in the process of the medical treatment of patients. The law also governs communication between different users of the health records, and requires that all accesses be logged. County councils are obliged to check the access log to patient data at regular intervals[4, 4kap 3§].

Health records are not only a tool for communication between doctors and other health care personnel (although, it is often seen as the primary purpose) but also it is a tool for medical personnel to convey information to patients. Today, every patient can request to pick up his or her health record even though the health record is formally owned by the hospital. Thus, doctors have been trained to express themselves in a way that is understandable by patients. There are also several laws regulating doctors, their work and how the health record should be handled. Patientdatalagen[4] and Hälso- och sjukvårdslagen[5] are examples of these laws. All combined, it has, over many years, formed and developed how the health care system works and how the communication between patients and the system is performed.

The Swedish patient data law(Patientdatalagen) states that the health record should be in Swedish and the text should be written as clearly as possible for the patient[4, 3kap 13§]. It is not a new problem which arises within the Online Health Record context[13].

Chapter 3

Project Requirement

The project is open-ended which means that there were no set requirements at the start of the project except that the end product should be a report. The project group, together with the client, decided which areas the project team would research.

3.1 Client Requirements

In the beginning of the project, Benny Eklund held a presentation in which he detailed the current state of the system and some areas of improvement that he recommended that the project group look into. He also mentioned several criticisms that people had with the current system which the project team should take into account. From the information that was presented, the project group chose to focus on the accessibility and usability of the system.

3.2 Our Vision

The purpose of this project is to create a report for the client that will be used as a basis for further research and development of these systems. The goal in the long run is to aid the process of every patient having easy access to their full medical history, independently of where they are stationed, without endangering the patient or the medical personnel and at the same time improving the level of care.

The purpose of allowing the patients access to their medical records is to make patients more involved in their own care. The intended result is a higher level of care for the patient with a reduced workload for the medical personnel. The main focus would be usability and accessibility concerning the patients' access to their own medical records.

Chapter 4

Method

6 The majority of the information used in this report was gathered by analyzing the current system and questioning potential users about their opinions to compose a list of proposed features. Proposed features are presented in Chapter 6. The investigation has gathered information from different sources on the Internet, reports in the OHR field and old surveys made by other organizations. The information has then been used for collecting more information with both a qualitative approach and a quantitative approach for a more deep and all-around understanding. Different approaches have been investigated in parallel during the project.

4.1 Qualitative Approach

The EARTH group interviewed seven people in this study and the interviews were between one to two hours in length. Leif Lyttkens at Uppsala County Council was interviewed because he is one of the leading figures in the project of making online health records available. He was also in charge of introducing the Cosmic EHR system to Uppsala which is the system used by the medical personnel to handle health records. The aim was to get a bigger picture of what has happened but also to ask more detailed questions.

The project group also interviewed Ture Ålander, a general practice physician. Ture has used a similar system with his clients, where they could access their medical record online. Ture has the experience of the consequences of using an online system.

Ulf Högberg was interviewed because he works at a women's clinic and at Uppsala Academic Hospital, and he could give us another picture, since he is working with different things than Ture. This bring us back to the observation that the Swedish health care system is fragmented and complex and it is hard to get a whole picture of it and what different parts think about the OHR system.

The project group also interviewed Anna Rask-Andersen who is the chief safety representative of doctors in Uppsala. Anna has another perspective and she is not involved in the DOME project. Anna is critical of the process of the SUSTAINS project and could bring up some other perspectives and flaws with this OHR system.

Interviews with Rajja Eloranta who is a nurse at the 1177.se service were conducted because of her experience with self testing people with questions about their health. Khalid Hussein, who is a doctor at the hospital of Arvika, was interviewed because of his experience with health care outside of Uppsala County. The others the EARTH project interviewed are, in general, advocates of the system. The interviewed people were chosen to get a broad and varied view of the problems and possibilities of OHR. To get another view, the EARTH group also interviewed Rebecca Palmstierna, who is a patient with close contact to health care. All group members have also been a patient at some time, and the EARTH project also has some members who have a close relationship with health care.

4.2 Quantitative Approach

This report uses data from two surveys made by the EARTH team. One survey has been focusing on patients and the other on medical personnel. Backgrounds for each survey are presented below. Final design and results from the surveys are presented as appendices.

4.2.1 Patient Survey

The strategy for constructing the patient survey was to first look at three surveys that were already done and then complement them with a new survey. The three surveys that were used were made by Inera AB, the DOME project and Ture Ålander.

Survey made by Inera AB

Inera is one of many organizations working together to implement a system to make health care information more accessible and available in a safe way online. Inera is owned by the county councils and regions of Sweden and have no commercial interests at all. They get jobs from the Swedish government, municipalities and other private customers. Inera has about 135 employees and had 2011 turnover of 378 MSEK[6] and can therefore be seen as a serious performer.

In 2011 Inera made a pilot study about how to make it possible for patients to access their medical health records online. The pilot study investigated which ethical, medical, technical and legal conditions must be fulfilled to make this possible. One part of the pilot study was a survey addressed to patients to discover their needs and opinions. The survey was available online together with explanatory text at Inera.se and 1177.se[7].

The survey from Inera is a credible source since it has a wide range of relevant questions and is driven without any commercial interests. However, one downside is that it surveys a narrow group of people. The majority of people who answered are employees and only 2% of the answers came from students. In addition, the gender distribution of the received answers is very uneven: as many as 72% of the group surveyed were women.

Survey made by DOME project

The survey from the DOME project is a valuable source since it was answered by people that had requested their medical health records and also had regular contact with health care. The EARTH project chose to look deeper into the questions regarding what people think about getting information about their health records and medical records online. This decision was made because the project thought the answers to these questions could make it possible for us to get an insight into peoples' attitude towards what is already in the current system and laid a foundation for our survey, adapted to how the system could be extended to meet the user's needs.

Something that should be highlighted is that the target group for this survey was people who have a lot of contact with health care. For instance, 42% are working or have worked in the health care industry and 56% visit health centers or secondary care givers at least four times a year. These are both high numbers and could affect the result.

Survey made by Ture Ålander

The survey was made by a primary health care clinic in Uppsala in 2005. In 2003, this particular clinic used something they called Health Care Account, where the users could read their medical records from primary care online. The OHR system had to be temporarily put on hold because of legal issues, but could later on continue as a research project in 2005. Ture's patients had access to this system for ten years and therefore many of the patients who answered this survey have valuable experiences.

The survey was sent out as a part of the research, about how many people would be interested in using a Health Care Account. Those who had an account in 2003 also got some specific questions about how they used the old account and how it affected their contact with their health care providers[9].

There are a few things that the EARTH project can use from this survey. One of the things that was used was to look at what people thought about having a health care account several years ago, and also maybe get some data from people who actually had an account almost ten years ago. This data could be examined and some conclusions may be drawn from it. The answers may differ from today and nine years ago, and that could be an advantage. The EARTH project can try to draw conclusions from the changes in the answers, and these conclusions could give us a hint about how people's opinions about this kind of technology changes.

Survey made by EARTH project

From our studies on the surveys from the Inera project, the DOME project and Ture Ålander, the EARTH project got an idea of people's opinions toward a system for getting their own health information online. Since these studies show that people are agreeable to accessing their medical health records online, the EARTH project wants to explore what additional features can be added to the system and in what way they can be developed to expand the system in a way that users would want it to expand. Because the studies

were based on answers from a target group with a high average age the EARTH project chose to focus on a younger target group. This target group can also be used for a long time evaluation on what the system should contain, because the younger target group in general are more technical aware than the older.

Our survey will be more into detail of what kind of features the users wish that the OHR will include. The EARTH project wants to reach as widespread a user group as possible but will be focusing on a younger and more technical experienced group. The reason for focusing on younger people is to complement the other surveys: the survey made by Ture Ålander had an average age of 55 and the survey made by DOME had an average age of 46. It makes sense to focus on younger people because when the EARTH project is looking at all the surveys together the project will be able to get a sense of what as many people as possible want from this system.

The questions in this survey were designed by taking questions from all the students included in the IT in Society course. The EARTH project then tried to minimize the number of questions by merging similar questions, and simplified some while trying to keep the information each question brought to the table. The project wanted the survey to be as small and simple as possible, while at the same time bringing good feedback. The reason for this is that the EARTH project wants as many people as possible to answer the survey.

The first part of the survey was designed in a way that it is possible to divide the results in different subgroups. This is important - to be able to more easily find needs of a certain subgroup which might have gone unnoticed if you look at the whole group at the same time. It is possible to divide people into different groups depending on their age, sex, education, technical knowledge and the amount of contact each user has with health care. You might also want to prioritize different groups' wishes differently depending, for example, on how much contact they have with health care.

After these questions the "real" survey starts by asking the question "Did you know that you could access your health record on the net?" This question does not necessarily give much information to the survey but it is aimed to introduce the user to what the survey is about as well as in the same time informing them about the availability of their health record on the net.

All other questions have one common direction: what features can be implemented in this system to maximize the number of people using the system? Many of the questions are multiple choice questions with a lot of choices; this might seem like a lot of information to take in for the users at each question. But the project really needed all the choices and the alternative would be to have a text field where each user could list all their needs. The project thinks this would hurt the survey more in regards to how many people answered the survey, not to mention how much harder it would be to analyze the results.

4.2.2 Medical Personnel Survey

It is important to review all different opinions about the OHR system from the different stakeholders' point of view. Since Uppsala is the first county in Sweden to publish health records online[10], the investigation needs to include all stakeholders' opinions.

The medical personnel's opinions are very important since it is essentially their work that other people will view in the OHR-system. This will, most likely, affect how people work but to what extent is hard to say without a dialogue with the medical personnel. Medical personnel consists of a diverse group of people, they can both be the end users and be responsible for the information in the system. The medical personnel do not directly use OHRs in their work, but their work will end up in the system. They write in a different health record system, and users can see their health record in the online health record system.

The EARTH project did not find any old surveys in the medical personnel field. Because of that the project decided to design a medical personnel survey without any statistical background. Instead, questions were made from different aspects that were found in the pre-study.

Design

The survey for the medical personnel is designed to gather sufficient information to be able to draw conclusions from the medical personnel's opinions regarding OHRs and further development towards a more usable and accessible online record system. Since handling health care records is a sensitive matter and regulated by law, the survey is anonymous. The survey is online, both to make it easier for people to answer and to make it easier to collect and compile the information to get faster results.

To ensure that the survey is as precise as possible it was reviewed both by representatives from Uppsala County Council and the DOME project (the Deployment of Online Medical records and E-health services). The time of the medical personnel is valuable and thus the survey should not take more time than necessary to complete.

4.3 Comparative Study

In an effort to gain a better approach to the OHR system in Uppsala and to be informed of what exists in OHR systems outside of Sweden, the team studied a report from an OHR system in Estonia. This report "reflects the results of the scientific work carried out during the project 'The Development of a Methodology for Assessing the Influences of the Electronic Health care Message Exchange System in Estonia' (DIGIMPACT)." While it focuses primarily on the economic effects of the system, which was only one of many investigated aspects in the EARTH report, it was primarily used for comparing and contrasting approaches to administration, design, and system features. Overall, there were many similarities in approaches and features; however, there was some variance,

often due to differences in legislation and governmental organization between Estonia and Sweden.

4.4 Validation of Sources

The EARTH project interviewed three people who are involved within the development of the OHR system in some way, but the EARTH project also interviewed one person who is not involved and also was critical about the development of the system. That means that the project group got opinions from both sides of the OHR system development process. One thing to notice is that Ture Ålander is the only person with experience with an OHR system. Ture has used a similar OHR system with his patients which makes him a valuable source of information.

The strategy to complement old surveys with collecting patients' opinions has one potential weakness. If the results from the old surveys are out of date then the studies are working with data from two different time domains when the old data is complemented with the new. It could be the case with the survey made by Ture Ålander. First of all, the report is quite old by now, about seven years. Technology advances at a rapid pace, and also people's knowledge about technology. Someone who felt secure about using this system seven years ago may not do so anymore, knowing what he or she knows now. Much has changed during this time, which could change peoples' opinions and answers. Another disadvantage is that the survey is made with too few people. According to the report, Uppsala County had 183,308 inhabitants at the end of 2004[9]. The health care clinic had 2,437 people listed and 2,213 people received the survey; 205 of those had a health care account in 2003. This means that about 1.2% of the population received the survey, and only 0.11% of the population had an account before.

The survey for medical personnel has not given us the results the EARTH project wanted, mainly because of the lack of respondents. Neither the union for medical personnel nor the Uppsala academic hospital has been able to help us to send the survey. Of the 33 responses that the survey provided, over 90% were from medical students, which will make it impossible to draw any conclusions regarding what medical personnel think about patients' access to their health records online.

Chapter 5

Challenges

In order to fulfil the aim of the report, an understanding of the current situation is needed. Overall, the Swedish health care system is fragmented in many ways. Different counties use different health care systems and are controlled by different political climates. A consequence of this is that there are no easy answers to questions in this field. Sometimes, there is a possibility to implement a system in the view of the technical aspects but not according to the economical or even the ethical view. People have different opinions, which are often connected to their backgrounds and professions.

The health care fragmentation, the different aspect of every question and people's views on the OHR system are also parts of a major change that is already happening in Sweden. The change means that a part of the health care communication is offered to the patient in a digital way. Besides the change that could be very challenging itself, all the perspectives and views must be taken into account when forming and extending the current OHR system that is in use now. This project has recognized some parts of all the current challenges in the work with the OHR system.

The general development of technology and politics will probably increase the use of OHRs and it is likely that the new technology will change the communication and how the health care system works with patients. That will raise some new questions, and one of them is how can the medical information online be made more understandable. Making medical information more understandable is not just a national problem for Sweden, it is also a worldwide problem because there are more countries trying to develop similar OHR systems. One example is Estonia. Experience from other countries has shown that support systems to OHRs are very important for the overall success of the OHR system. Support systems could make some information confidential for some individuals if the patient wants to make certain information in their health record confidential. The problem here is that doctors want to see the whole picture of a patient's health record when they take a look. For example, consider the case where a former drug user's parents are doctors and can therefore access the health record without his consent and see information that he would prefer to not allow them to see.

Beside masking information about patients it is possible that individuals would like to prevent certain doctors from being able to learn about aspects of their medical history.

Right now, the only way to block a doctor is to apply for the health record to be blocked at the health care clinic at which the patient has been treated. With the advancement of technology, one would have believed that this feature should exist on the Internet-based health care service.

The advancement of technology will also provide more advanced medical technology for home use, e.g. long-term oxygen treatment, dialysis and ventilator treatment. Is it possible to integrate the use of such technology along with the OHR to improve the treatment for a patient? This can also raise the question about having the ability to keep track of a patient's location in the hospital and informing the patient's relatives when the patient has been discharged. This would of course make it easier for the visitors, although presenting information about a patient's whereabouts on the Internet to someone who is neither the patient nor the patient's doctor is not entirely trivial when it comes to both legal and technical issues. There will also be possibilities for presenting the information on several different platforms. Making health records available online is a substantial step to making them more accessible for the patients. Taking the system to the handheld devices, such as smart phones and tablets, makes it even more accessible and also extends the potential of the system. As the market for handheld devices is growing bigger every day, taking the system to this new platform becomes more and more interesting but with new features and possibilities new issues will arise.

Chapter 6

Proposed Features

6.1 Chat and E-mail Function

The inclusion of a system that would allow patients to ask a doctor questions using a chat function would allow patients to improve their understanding of the medical information that they access. The chat function would be connected between the patient and the doctors that have been written in the OHR. It would be a convenient way for a patient to ask questions and for a doctor to respond to the question when it is convenient for him or her. Another potential benefit is that if the responsible doctor does not have the opportunity to respond in a timely manner, another suitably trained professional could do it. Having another trained professional perform this role should not present a problem since they are trained to read one another's writings. This feature could also be implemented using e-mail.

E-mailing questions and chat functions have already been tested in a small scale and the results were very good. Patients got answers to their questions without having to book a new appointment with the doctor, and the doctor got more time to do other things as well as more flexible time at work[11]. If a chat function was implemented, it would be necessary to keep a record of the exchange. The Swedish patient data law says that all patient contact should be recorded[4, 3kap 6§.5]The system must be implemented to be in compliance with the law, which means that every chat session would need to be saved. Otherwise the law would need to be changed in order to allow for the use of new technologies and new methods of operation for doctors.

6.2 Encyclopedia Links

Doctors and people working in health care have been educated to write health records in a way so that patients can understand the content. But this does not eliminate the difficulty that many people will have in interpreting the record due to the inclusion of medical terms. It is difficult for people with no education in the medical field to understand the terms, many of which are Latin or Hebrew[11]. Presently, patients can use Google to find definitions and descriptions, but the results of a search can be intimidating[12]. This problem could be solved by including a links to an appropriate medical encyclopedia. The

addition of this system would allow users to quickly receive an explanation by clicking or hovering over the term they wish to be explained. The explanations do not have to be limited to definitions, but also include pictures of the object that may improve a user's understanding. This would give patients more control of their situation and treatment in the comfortable environment of their own home.

Patients can always ask trained personnel about information they do not understand, but with a linking system in place, many of these questions could be answered by users themselves. However, not all users will have the capability to make meaning of all the information relevant to their affliction preventing this solution from eliminating all questions that patients will have. A factor to consider when looking at how much information people are able to understand is that patients may find themselves under heavy stress when looking at their own health conditions. There are already examples when patients misunderstood the information and thought they were seriously ill, with a suicide attempt as consequence, when they in fact were healthy[13].

Another aspect of an encyclopedia is that the information in it must be correct and developed in a way so as to promote understanding. The development of a linking system and an encyclopedia would cost a lot of money which means that it must be approved by politicians. The implementation of these elements would also take a considerable amount of time. The time in money required to implement these designs could potentially be reduced by using a database that has already been developed. Presently, there are already examples of databases with medical information connected to home pages, such as 1177[14]. Results from a survey made for this report showed that 53% favored this solution to assist them if they did not understand the information in their OHR. The respondents to the survey had five additional options to chose from for this scenario.

6.3 Blocking of Medical Personnel

It is possible that individuals would like to prevent certain doctors from being able to learn about aspects of their medical record. Right now the only way to block a doctor is to apply for the medical record to be blocked at the health care clinic at which you have been treated[15]. In case of emergency, the Swedish law says that the doctor can overrule blocking of health records when the patient is not in the condition to decide, but not all the information is presented, only relevant information[4, 4kap 5§]. According to the law, the parents are not entitled to block their child's medical record[4, 6kap 2§]. The reason is that health professionals should be able to detect if a child is mistreated and assess whether the matter should be reported to social services committee. The law puts more emphasis on child protection than privacy.

People under the age of 18 can block their records in some cases if they are deemed mature enough, which means that there are no specific age restrictions. In the survey made by EARTH-group, there were about 30% of the people that said that they wanted a function that could block medical personnel[16]. Another point of view is that the patients has a trust for the medical personnel and that this feature is not necessary[12].

An extension of this feature would be the implementation of a log system that would allow a patient to view who has accessed their medical records. This blocking and/or logging feature could exist in the OHR system as long as it does not conflict with current laws.

6.4 Self-Testing

Self-testing could be a crucial method for reducing the workload for medical personnel. The collection of self-test data is a growing trend in medicine. Test kits are available to allow individuals to check if they are positive for certain conditions. However, there are also widely available devices to measure vital signs and characteristics such as blood pressure and blood sugar levels[17]. These are the types of information that the system would be setup to record, since these vital signs are generally held at a stable condition, variations from which are often signs of some sort of trouble. Therefore, the collection of data can be used to search for these anomalies and behaviours. Trained personnel can identify the trends and variances that represent certain ailments. What more, it is possible that patients can use information available online in order to identify signs for themselves.

Today databases with medical information are available online which allows patients to seek information with help of a guide. These databases consist of information that could help patients to gain knowledge of different diseases and their different symptoms and common ailments, this database can also provide suggestions for treatment or recommendations for seeking further assistance[14]. The patients can ask for advice by sending an anonymous e-mail with answer within 7 work days. During the call, the patient can describe their symptoms to the nurse on the line that will diagnose the patient and decide if the patient needs to seek further care at the hospital or not. With the introduction of this functionality to the OHR-site, the patient shall be able to do the diagnosis themselves. It is important to note that this functionality is not meant to replace a patient's reliance on the hospital care, but is meant to reduce the number of patients that are diagnosed by health professionals due to common illness and help people determine what actions best to take[15].

For self-testing, there are several ways that new technology can improve the benefits of self-testing. One is simply the development of more user friendly devices. Simplicity of use in testing would improve the likelihood that people would actually use self-test systems. Additionally, if a device could link directly to the information database or use another device to connect to the database, would further improve the usage of the database. Another advancement that could improve the benefits of self-testing is software capable of making diagnosis based on information given to it. These systems are called Expert Machines. An Expert Machine has an index of knowledge – in this case of medical information – and can use information provided to it in order to make determinations through a process simulating human decision making. Since the system the EARTH project are currently looking at is an OHR system, the inclusion of Expert Machines is not appropriate: an OHR system is meant to allow for the collection and retrieval of medical information. However, this technology could use the information gathered by the system,

either through forms or raw self-test data to improve the treatment of patients[20].

This could allow patients to record the results of tests taken at home on a regular basis and record that to an online database. The benefit of this system is that doctors looking to diagnose a patient will be able to look for trends and variations as an additional resource to base their diagnosis on. The reason to implement self-testing is to reduce the burden on health care and to improve the level of care a patient receives. It should also improve the patients life quality by eliminating time, travelling to the hospitals and time spent at the hospitals. Implementing this service will have to come with requirements of qualification to use the service. This means that the patient, or a close relative that takes care of the patient, will have to go through some form of education or introduction from the caregiver. There should also be a service or possibility for the service-user to chat or video chat with an online support for immediately help which should always be available.

6.5 Information Masking

A patient might want to make certain information in their medical record confidential. The problem here is that doctors want to see the whole picture of a patients record. If patients are given the ability to mask certain information, the information that they choose to mask might happen to be information that the doctor could have used to determine an easier and faster diagnose when the patient is sick.

Some doctors want to be able to use information masking the other way around as well, sometimes a doctor might want to hide sensitive information from the patient. For example, if a patient is tested for cancer and the result turns out to be positive, the doctor should present this to the patient personally before the patient can read about it in their OHR. Allowing the patient to find out about such critical information might result in a very traumatic experience that could have been eased by having an expert explaining the whole situation and the patients options.

Another situation that might arise is where an underage patient wants to mask information about hospital visits from the patients parents. For example, an underage patient might want to visit a doctor to receive contraception pills without having her parents or legal guardians reading about it in her health record.

6.5.1 Patient's Ability to Access Information from their EHR

Being able to view your medical records online brings up a lot of questions, one of these is if the patient should be able to see everything in their records. Should the patient be able to see the notes the doctors make? Should they be able to see the lab results from their last test which shows a fatal form of cancer? These are examples of a few of the questions that need to be carefully examined and considered during the development of these functionalities online.

The main reason to let the patient see everything in their medical record is to empower the patient to have more control of their own medical care. This is something that has been, and is changing in many countries, including Sweden. One of the Swedish health care systems goals is to empower the patients to be a bigger part of their own health care, and this could be a huge leap towards that goal.

But what do the patients themselves think of this? There are two interesting results from the report[18, Delrapport 1]. In this report, one of the questions asked to the study group was *“If you could read your patient journal online, would you want to take part of medical data that could be worrying, for example a suspicion of a serious illness?”*. About 60% of the asked answered *“Yes, I want to read everything right away”*. 17% answered *“Yes, but only if there is medical personnel to contact if I get worried”*. 9% answered *“No”*.

The result from this question shows that about 77% of the asked is positive about viewing medical data online, even though the results could be worrying, where not even one in ten did not want to take part of worrying medical data online.

Another question that was asked was *“If you could read your patient journal online, would you want to take part of the lab results as soon as they are finished, even if the result shows an elevated risk of a serious illness?”*, here only 48% answered *“Yes, always”*, 25% answered *“Yes, but only if I soon will have a conversation with a doctor to interpret and discuss the results”*.

The answers show that there seems to be important to not deliver bad news online without making sure the patient will have someone to talk to soon, since the patient will have that need. Given that the patient will have a doctor to talk to soon after the lab result arrives, the study group seems to be positive to the possibility of getting their results, with almost 75% of the asked being positive.

What could the implications be if patients would be able to take part of results showing a serious illness, without anyone near them to speak with? Even if there is no good way to inform a patient of their serious illness, doctors are professional and educated to deliver this information and help the patient deal with it and answer questions the patient may have.

What do doctors think of giving the patients the possibility to view all information from their medical record? According to the survey the EARTH project made, it seems that a lot of the main worries doctors have about showing all medical data to the patients is:

- Patients do not understand medical terms good enough, can cause confusion.
- The doctors don't have enough time to try to write more easily understood medical notes.
- Worrying results should be presented in a better way than online

- Increased misunderstanding between patients and medical personnel.
- Increased workload for medical personnel.

The doctors seem to agree on the fact that the medical records is one of their work tools, and they use medical terms which are more precise and increases efficiency and decreases misunderstandings between the medical personnel. To write in a more easily understandable manner would make them write with a more imprecise language, which is suboptimal for the medical personnel, and indirectly the medical care of the patients.

Of the asked doctors in our survey, only 32% thinks the patients should be able to see all information in their medical record. They were extra negative to show mental patients their medical records, since this could, according to the doctors, be contra productive for the medical care of the patient.

But there is not only negative responses from the doctors. The doctors do understand the patients need and request for more transparency and influence of their own medical care. Many of the doctors think that transparency should try to be maximized, as they think it is not right to hide medical information from the patient, although they acknowledge problems that may arise with this transparency if it is driven too far.

There may arise problems with giving patients total control of all medical data online. This could cause increased unnecessary worries among the patients, increased workload amongst the doctors and ethical issues.

Empowering the patients to have more power over their records is something to strive towards, but only as long as it does not affect the medical care in a negative way. It seems as a compromise, where the patients can view a subset of their medical records, or the whole record but with a time delay so the doctors themselves can talk with the patients first, would be the best solution to this question.

6.5.2 Patient's Ability to Mask Information in their Health Record

In some cases a patient might want to hide specific information in their medical record from medical personnel. This is possible to do today but then you have to inform your doctor in person that you wish to do so. It is possible to include this feature in the OHR system, which would give the possibility for patients to mask information from home.

If patients hide information online they should get a warning that their doctor will not see the information and that they might have to forward the information to your doctor in person. When patients have hidden information in their OHR it should be clearly displayed that medical personnel won't be able to see that information, thus it is easy for the patient to see what information the patient might have to inform the doctor about.

If there is hidden information in a medical record, medical personnel who view the medical record will see a text that there is some information in the medical record they can't

see. If a patient is in a state where it cannot give a doctor all information the doctor might need to treat the patient the doctor can bypass the information block. By doing so an investigation will be launched to determine if it was justified.

In a survey made by Inera the question *"be able to block some of my medical records from being accessed by other health professionals"* was asked. The answer showed that 28% chose the option "very useful" and 12% chose "quite beneficial". This shows that this feature is requested by the public[18].

If patients have the possibility to block information in their medical record it would most likely lead to more people blocking information. Doctors that the EARTH project has interviewed have raised concerns about not getting all information when treating a patient and that it is easier for a doctor to treat a patient if they see the whole picture. In a survey the project conducted, the doctors raised the same concerns and they also said that it is hard for patients to know what information is relevant for doctors in different situations[16].

6.5.3 Patient's Ability to View Access Logs

According to the conditions for electronic access in Patientdatalagen and the social services regulations considering active choice when accessing patient records[19, 2kap 7§], user activities involving access to patient records shall be logged. This function could be implemented in the OHR system. One of the questions in the online survey "e-consultation, medicines and vaccinations wanted" was about the opportunity to take part of log information and was described as the ability to *"see which care units and staff groups that have been in my journal to edit or read it"*. 45% of the correspondents chose to answer "very useful" and 15% chose "quite beneficial". The results show that this function is something that the patients are interested in[18, p.19].

The patient records are protected by privacy laws, which means that only authorized personnel are entitled to read or distribute the content. The system keeps a log of who has read the health record and when it was read. The County council or the private health care provider should check that no unauthorized access to the records has occurred by sampling the logs. If it has occurred, the patient has the right to know about it. Every care unit, such as a health care center or a hospital, is responsible for the health record and the permissions that are assigned to the personnel.[4, 4kap]

Having logs in the OHR system might cause some patients to call the hospital and ask why some doctor has read their medical record. If many patients do this, it will cost money and resources for the hospital to double check if the doctor should have had access to the medical record or not.

6.6 Patient Tracking

Patient tracking is about having the ability to keep track of a patient's location in the hospital and informing the patients' close relatives about where and when the patient will be discharged. For example, when a patient who suffers from dementia is released from the hospital, some chosen close relatives should be notified in order to avoid putting the patient in danger. Another example is where close relatives are able to access information about which hospital room the patient is located in without having to consult the hospital staff. This would of course make it easier for both the hospital and the visitors, although presenting information about a patient's whereabouts on the Internet to someone who is neither the patient nor the patients doctor is not entirely trivial when it comes to both legal and technical issues. This is why the EARTH project has conducted our research to find some possible solutions to this problem.

In today's system, every patients location is stored digitally in the medical record system. So presenting this to close relatives in the OHR would be fairly easy from a technical point of view. The patients location could be presented on the OHR that is available to the close relatives as either a room number and the name of the ward where the patient is resting, in surgery etc. or the place where the patient will be released from the hospital. The problem in this case is from a legal and ethical point of view.

In the survey that was aimed towards doctors, a lot of negative critique was received when asking about their opinion on being able to let close relatives see where a patient is located and when the patient will be discharged. Many doctors thought that this would compromise the patient's integrity and that it would probably be better if the close relatives were informed via telephone instead[16].

6.7 Extending the System to Handheld Devices

Since the launch of the iPhone in 2007, the popularity of smartphones has risen exponentially in the consumer market, and during the last few years tablets and other handheld consumer electronics have become increasingly prevalent. During 2011, the number of smartphones sold outnumbered PC sales for the first time, and Sweden was ranked as the fourth top smartphone using country, tied with the United States. The use of handheld devices is advancing in many fields, and in every age demographic. Today, two million Swedish people own smartphones, and use them daily. This is only predicted to continue growing during the coming years[21].

The data mentioned above makes the possibility of a smartphone extension of the current system an interesting prospect, but naturally there is a strong possibility that a significant portion of the end users will be elderly. This affects the strategic decisions that have to be made if such an extension will be implemented. The usage of smartphones is growing in every age group though, according to [22], and many tablets have proven to be easy to use by elderly and disabled users[23]. Although handheld touch-based devices are a relatively new phenomenon using the latest advancements in technology they are also much easier to use than conventional personal computers to new users. There are

also many possible features outside of medical records and records that would alleviate and facilitate medical care for elderly patients in a smartphone or tablet context. For instance, notifications to remember taking medication, prescriptions, contact information and the possible “patient tracking” feature.

Elderly patients are not the only probable demographic of such an application though. There are also many young patients and people without medical conditions who could use the features of an application like this to access important information, schedule appointments, list nearby medical facilities, etc. When taking into consideration the complete set of possible features this extension of the current system could make possible, a larger part of the demographic who are already smartphone users will find this system more relevant and helpful.

6.7.1 Related Survey Results

As discussed in other parts of this report, two surveys were conducted toward both end users of the system and medical personnel respectively. Part of these surveys were about the introduction of a handheld interface.

End user Survey

The end users survey included in this project includes some questions about how if people feel that a mobile application would be a good complement to the current system.

For the peoples who answered the survey almost 90% answered that they have a smartphone, given the young age of the people answering the survey this result was quite expected. 52% of the respondents answered that they did not want access to their medical record from a mobile application. The main reasons why people do not want access to their medical record from a mobile application is that they did not think that this would be interesting. The second most common answerer is the belief that the security would not be high enough. This number may seams a little high but considering that most of the people answering the survey are not directly under special medical care, and would not need to use this kind of services that often.

From the people that wanted to have access to a mobile application for viewing their patient data, this is a list of the most requested features sorted by popularity starting with the highest ranked, unlimited number of features where possible.

1. Schedule appointments - 96%
2. Request renewal of prescriptions - 81%
3. Find the location for the closes clinic - 74%
4. Reminders for taking medication - 68%
5. Overview of vaccination and needed vaccination - 67%

6. Fill in the health declaration before a clinic visit - 60%
7. Contact information to health care - 58%
8. Order doctor's note or other medical certificates - 56%
9. Simple self diagnostics (measuring blood pressure etc.) - 39%
10. Functionality to ask questions about specific journal entries - 35%
11. Functionality to point out incorrect journal entries - 33%
12. Order self testes - 30%
13. Use the services as a guardian - 28%
14. Use the services for elderly relatives - 28%
15. Grant access for relatives to your journal - 26%
16. Block specific personal from accessing your journal - 21%
17. Other - 5%

Medical Personnel Survey

In the survey for medical personnel the question “*What do you think about the possibility of medical records available on mobile devices?*” was asked. About 80% of the participants answered that such application would introduce security risks. 40% thought that the application would lead to increased availability and 25% thought that it would lead to increased usage. Some of the participants also provided comments on the question. For example, one person wrote that it could cause anxiety if information about oneself gets in the wrong hands and the person also reflected that the security worked in the mobile applications that banks use, but that the information in medical records is more sensitive.

6.7.2 Technical Challenges with Handheld Devices

Of course there are some differences between the existing medical record system and a potential mobile application. The biggest difference between the systems is the portability. Handheld devices are, most often, smaller and easier to carry with you than computers and a mobile application would lead to extended availability. This might be an advantage comparing to the current system which requires the users to visit the Uppsala county OHR system using a computer.

One possible disadvantage in having all information in this application is that it might get to cluttered, but if the data is presented in a structured and user-friendly way this should not be a problem.

6.7.3 Possible Implementations

Besides the features and information present in the current system there are some new features that could be implemented on handheld platforms that would take advantage of the new capabilities that comes with the technological assets. However, including all of the suggested features below in the same application may be a bit cluttered, thus rendering the system even less usable. One should entertain the option of constructing a closed application programming interface, or API, [27] to the current system that requires developers and publishers to authenticate themselves. That way it would be possible to create additional applications with more focused and specialized fields of use. There are pros and cons with both options; creating a single highly integrated application, or divide the features into a series of applications.

Since the data is already accessible from through a web browser there should not be any ethical issues since the information is already accessible as long as the security in the handheld device is at least the same as for the current system.

Emergency Features

One possible new feature on the handheld devices is the addition of emergency services that could in some sense be a lifesaver. The emergency feature on the handheld device would be like a digital version of the analog Medical Emergency Information Card that contains the most important information about the card holder, that may be needed in a situation where the card holder is unconscious. This information includes blood type, current medication and other important data about the card holder. A portion of this information could be too personal to be accessibly for anyone that get hold of the device, but having access to the information could be critical for the medical personnel in some situations. Finding a good solution means finding answers to the following questions:

- What information would be of use in a critical situation?
- Do we need to protect the information or could it be public accessible in some way?
- Are there similar emergency applications on the market? What features do they offer, and how reliable are they?
- Are emergency applications trusted by doctors in critical situations?
- Is there any medical information we would like to show, but cannot because of technical, ethical, religious or juridical reasons?

Information about the holders blood type could come to use if the holder needs extra blood fast in a critical situation also information about current medication, allergies and intolerance could be crucial. Contact information to close relatives and instructions about how the patient would like to be treated like donor status is other information that could be of use. Insurance information would not be that interesting in Sweden, but in the US it would be crucial to have in some in some situations.

Some smartphone applications that solve this problem already exist like the Android application, “ICE: In Case of Emergency” [28]. One problem with this type of application is that the user has to input one’s information by themselves, and therefore the medical personnel cannot know if they can rely on the provided information. If the application would fetch the information directly from the patient’s medical record the medical personnel would know that they can trust that the information that the application provides is correct, since it is the same information they would have got if they had access to the patient’s medical record. Additionally, it should be noted that if all medical record systems could exchange information with each other this kind of emergency information would be accessible everywhere to begin with. Users would need to authenticate in some way to get the information into the device for the first time after that storing the information local on the device for fast and easy access. If the information is stored local on the device the information would also be accessible when the smartphone is offline, for example it is rare for users’ Internet access enabled on their smartphone in foreign countries. One problem with storing the information local would be that the data needs to be updated by some interval to be sure that the data is up to date.

Drug Store Services

If the system should be built on a closed API, cooperation could be arranged with different drug stores to enable services related to buying prescription drugs, renewing prescriptions, etc. This could be accompanied by services related to the store chain, like locating nearby stores, inventory and products right in your phone, perhaps a numbered queue system to spare the usual paper tickets, etc. These applications could be made by third party developers hired by the stores themselves, but more in-depth services could be added if allowed access to the API of this system.

Medication Reminder

A new feature that really would make use of the mobile platform and that users carry the devices with them almost all the time is the functionality of reminders for taking medication. One way of giving these reminders would be to automatically send so-called push notifications when it is time to take medication with information about which drugs to take and in what dosage. This feature would be very useful for people with bad memory.

This feature does not exist in the current system, but information about which medication a patient is using exists, which means that the system would not have to be modified that much.

Nearest Health Centre and Instructions

The feature to find the nearest health center should definitely be in a potential mobile application. That functionality would be really useful if you need to visit a clinic in an area that you are not familiar with. Functionality to find the nearest health center is not present in the current system, but it would not be too hard to implement since the only new information you need is the coordinates to the health clinics. The application could

also help you find drugstores in your immediate area.

One could also incorporate a list of contact information, such as visit addresses and telephone numbers, both for local clinics and national hotlines. Different instructions for on-the-spot emergency help could also help end users in many situations.

Appointment Scheduling

In such an application, it could be possible to view scheduled appointments, and possibly even cancel them as well as make new appointments. Physicians could also show changes in scheduling immediately to patients with this feature. Implementing this service would probably require working with other parts of the County Council's existing booking system.

6.7.4 Potential Risks with the Mobile Application

In a potential mobile application the authentication should be at least the same as for the current system, that is that the user has to authenticate itself with some type of electronic ID. This would prevent that others can log in to your account without your permission. The problem is when you temporarily close the application. Should you automatically be logged out or should you remain logged in until you log out by yourself. If you have to log out by yourself, unauthorized will be able to access your data if they have the possibility to use your device. On the other hand, if you are logged out every time the application is not active, it would be annoying if you are browsing your medical record and receive a text message that you want to respond to and then continue to browse your medical records. The best solution to this would be to have a timeout value and when the user has been inactive for that specified time it is logged out.

Another risk is if users are able to fill in emergency information by themselves. If faulty information is filled in and used by people treating the user, things might go really bad. This could easily be solved as stated above by fetching the data from the medical records and not allow the user to modify this data in the mobile application. Some data would be good to be able to modify, for example telephone numbers to close relatives and other people that are good to contact if something happens.

6.7.5 Mobile Security Considerations

There are many technical measures that can be taken to increase security and protect privacy. For example data encryption can prevent outside access, passwords or security questions can help secure a profile, CAPTCHA [25] can prevent robot ID fraud, and then electronic identification services like BankID [26] to provide simple secure verification. However, robot ID fraud will not be possible since no new profiles will be created from the end user side. This renders the benefits of implementing things like CAPTCHA unclear unless in the context of some third party application.

To maintain accessibility and usability without giving into security flaws many things need to be considered. Usability and accessibility are not direct enemies with security;

they are in the end just as much about the end users satisfaction as actual implementation. While a perfectly secure system is inaccessible, an easily used system can be properly secured. The middle ground for this lies around the area where the smartphone being used to access the information is verified in the following way: once on initial application install, then a sign in with both a single user passcode that verifies for a specific period of time, and an established password. The password could be circumvented with an ID login: the initial verification would only occur once, and then access to the single use passcode is still be needed, making it very hard for someone other than the account owner to access it, but giving the owner only one code to enter.

Some users may feel they need more control over the access of their profile, and would in turn have a more secure entry. For this the single use passcode would be needed, while other users could opt to have that passcode last for a certain amount of time. This option to add an additional level of security by trading off accessibility is common in smartphones, and is often used by the operating system itself.

For security reasons keeping the information stored locally is ill-advised. In the case of a stolen phone it would be possible to access the data without having to connect out to the server, they would only need to take the time to decrypt it. If a phone is stolen and a user believes their account has been compromised they should be able to access the system from another location (such as a computer) and temporarily disable all account access or simply mobile account access for a specific device.

With sensitive information needing to be accessed with each check, the data masking would need to be very secure. Encryption algorithms that provide an encryption so secure that at current levels it would take 100 years' worth of computing time just to break special testing keys that are designed to be easily broken down exists[29]. This kind of encryption would make the data unreachable without a verified log in granting access.

There are questions about how much data should be shown, and to whom, and how users can protect this data from those they do not want to verify while having others able to see it. From this comes a basic standard about who should have access to sensitive information. Access to a person's information should be available to their primary physician without restriction; treatment information should be available to anyone treating them in cases of multiple doctors/nurses, with no one else able to access information without emergency access in the most secure base case. Patients should be able to attain this level of security, with a normal level being all medically trained staff able to access their records, with the possibility of restrictions against specific doctors/nurses, and having the general population blocked, with the possibility of certain people being allowed access. In both cases special cases would likely come in with the emergency information system.

The production of such application for mobile devices would result in one similar to those used to access bank accounts, which need thorough verification to log on to protect finances and unauthorized transfers. Electronic Medical Records are just as important. With proper execution this security will be more than enough to protect any user from those wishing to gain their information by trickery or force.

Chapter 7

Comparison with Estonia's OHR System

It is not only Sweden that is developing an OHR system. Estonia launched an OHR system in December 2008 and we base our comparison on a report on that system[30]. Experiences from Estonia are an asset for working with the Swedish OHR system and could grant different perspectives for the creation of future features.

7.1 Common Features

There are many implemented and suggested features which are common between the Estonia and Uppsala systems. The Uppsala system already supports basic functionality, such as checking your health record from any internet connection, which the Estonian OHR also offers. Other more advanced features in the Estonian OHR are not currently implemented in the Uppsala OHR, but are proposed within this report. These include recording results of patient self-testing and blocking certain information from being viewed on your health record.

7.2 Estonian Features

The Estonian system, being nationwide and launched in 2008, has had a head start on the system developed for Uppsala. Naturally, this results in more implemented features with a greater degree of polish. Specifically of note is the Decision Support Service in the Estonian OHR. This service comprises a set of features which uses patient health record data combined with both known, catalogued historical data and pools of expert knowledge to aid the patient in his or her condition. This aid includes treatment and lifestyle recommendations, notifications of relevant knowledge or treatment changes, and “health-related calculators”. Health-related calculators are tools which can be used to calculate outcomes or values related to a patient’s condition. An example of their use could be calculating blood sugar levels given a patient’s data and providing of possible example dietary options.

7.3 Uppsala Features

Of course, developing an OHR system for Uppsala is different than developing one for Estonia due to its small scope (county vs. national) and the difference in local and federal laws. One proposed feature which is very unique to the Uppsala county OHR is the idea of blocking certain health care personnel from viewing a patient's record. This is starkly different from Estonia where only the current, attending physician can view the patient's record, thus removing the need for blocking certain personnel. For Sweden this is not the case, since it is possible for any licensed medical personnel to access health records in general, making the blocking of medical personnel a potentially important feature. This feature is discussed in greater detail in the Proposed Features section above.

7.4 Benefits

Similarly to the EARTH project team, the Estonian team recognized the opportunity for many benefits to be gained from an OHR service. The Estonian team compiled a detailed list of benefits, not only for the health care providers, but also for their society and to individual patients. From this list the team determined benefits that could be seen used concrete benchmarks of progress in these fields.

Benefits were broken down into five key areas of improvement with each area indicating what needed to be improved to result in its assigned benefits. These areas of improvement included communication, access to patient data, access to medical knowledge and experts, more motivated personnel, and ease of creation of new services. Some key benefits from each of these areas are discussed below, but in general, the improvement in these areas was linked to higher patient satisfaction, fewer complaints, reduced visits and stays, and fewer complications. This also caused improvements to motivation, productivity, and time management.

In terms of personnel-patient communication, the team found that patients would be more informed of their condition and could communicate with their health care providers better with an OHR system in place. These patients would be more likely to be satisfied by the level of communication and to comply with their physician's treatments and requests. With a compliant patient, treatment is much easier and can be done more efficiently. Additionally, greater communication between patient and doctor would reduce the likelihood of medical errors due to miscommunication.

Access to patient and institute data provides some distinct benefits as well. With easy access to health records, health care providers can more easily give accurate diagnoses and assignments for treatment. This results in fewer errors and more effective treatments. As a result, fewer visits may be necessary for the patient. Patients viewing their own data also cuts down on visits made specifically for checking their own records, and the electronic record keeping means that less time is spent by personnel maintaining, adding, and transferring documents in the system.

Access to this data also results in increased efficiency for doctors, as they can more quickly pull up information about their patients. Additionally, doctors can find resources such as specific services or equipment in the OHR system and schedule use of these facilities. By managing these resources with the OHR, it allows for more efficient scheduling and optimization of the use of these resources. It also allows providers to easily track the usage of these resources to calculate or forecast costs or the need of more or fewer resources.

Access to a medical knowledge pool and to expert opinions helps to better inform physicians on their diagnoses and treatments, and they can make their decisions more quickly. If all physicians use this resource, it allows known best practices to become the standard treatment. Patients can also access some of this knowledge, which helps him or her to better understand their condition on their own, and reduces the number of unnecessary visits.

The Estonian team also found benefits due to more motivated personnel. Specifically, due to the fact that an OHR system allows for closer monitoring of data and performance, personnel are more motivated to perform well. Additionally, OHR-utilizing incentive programs have been discussed, which would reward high performing personnel. Overall, the increased motivation leads to higher productivity, better performance, and fewer errors.

Finally, the existence of a central OHR system eases the creation of new and maintenance of existing e-Health services. These services may provide revenue to health care providers. Additionally, the central system allows easier management of smaller providers, which may provide unique services or offer a specialization. Maintaining these smaller providers increases capacity and efficiency of the overall health care system.

Chapter 8

Conclusion

To strive toward the goal that every patient should have easy access to their full medical history, the EARTH project group suggests to extend the system with new features. These features would make the system more accessible and usable. By making the system more accessible and usable it will probably attract more people to use OHRs and therefore more people will be more involved in their own health care. To increase the usage even more, one should make sure that medical personnel approve of this OHR system. The EARTH group believes that in order to make the system more successful the involvement of medical personnel is important. If the medical personnel promote the system, the patients will probably be more inclined to use it. However, if they do not agree with all stakeholders on the purpose of the system, medical personnel might not promote the OHR system.

The workload for medical personnel is probably going to change in some way after the implementation of OHR. There are some indications that the workload could decrease because there will be less administrative work due to the OHR's existence than handling the health records manually. The EARTH group cannot draw any conclusions on whether or not the workload will decrease for individual doctors as there are different opinions on how the patients will react. On one hand there is a worry that patients will ask a lot of questions when they have access to their health records, but on the other hand some think that the patients will be more informed which will lead to less time needed in discussion with the doctor.

Chapter 9

Discussion

The EARTH group has examined possible extensions to the OHR system. Since the OHR system is the first of its kind in Sweden and because it concerns the general public there are not only technological and economical issues to consider but also political ones. That means that development is done in a complex context. Such an environment demands a lot from those involved regarding corporations and communication.

The overall impression the EARTH group has gotten is that the cooperation between the developers of the system and the medical personnel is lacking. Both sides have their own perspectives in the development of the new OHR system. The perspectives are not always matching and the manner of communication has not eased the situation over the last years.

It will be important for the future and the success rate of the OHR system that both sides find a way to compromise and develop a common understanding on the purpose of the system.

Communication is also important in situations where patients think they understand the medical record while doctors are skeptical of it. Their skepticism lies in their years of understanding the underlying message in different areas in the medical record whereas the patient might only understand basic parts of the record. The EARTH group has not found any evidence pointing either way. It is likely that research will be needed in this field in order to improve the understanding between doctor and patient.

The Swedish patient data law[4, 3kap 2§] says that the health records should contribute to a good and safe care for the patient and that it should also function as an information source for the patient. This part can be interpreted in different ways, either that the health records should mainly be used by the medical personnel as a tool for communication and that the patient simply has a right to view it or that it is a tool for conveying information to the patient. The different opinions on how to interpret this law could be one deciding factor on why some people think that it is a bad idea for patients to be able to see their full medical record. One way of solving this would be to change this legal paragraph in order to clarify the use of health records.

With OHR, the patient can view their health record for free. Before, patients had to pay for the administrative work when printing and sending the health records by mail to the patient. By accessing the health record without paying for it, patients overcome one barrier that could hold them back in their commitment to be more involved in their own health care.

Chapter 10

Acknowledgements

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Anna Rask-Andersen
Ture Ålander

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Appendices

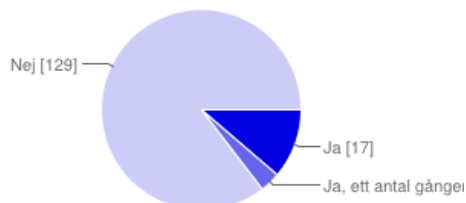
Appendix A

End User Survey

151 [responses](#)

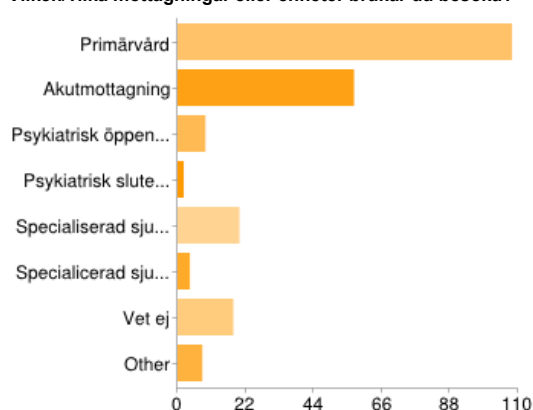
Summary [See complete responses](#)

Har du beställt din journal från vårdgivare någon gång?



| | | |
|----------------------|-----|-----|
| Ja | 17 | 11% |
| Ja, ett antal gånger | 5 | 3% |
| Nej | 129 | 85% |

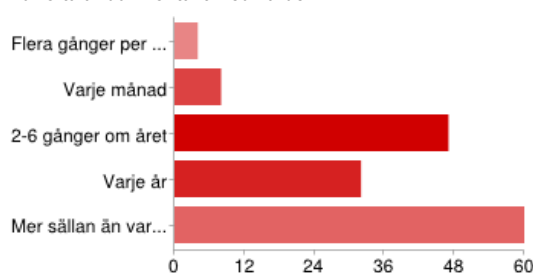
Vilken/vilka mottagningar eller enheter brukar du besöka?



| | | |
|---------------------------------|-----|-----|
| Primärvård | 108 | 73% |
| Akutmottagning | 57 | 39% |
| Psykiatrisk öppenvård | 9 | 6% |
| Psykiatrisk slutenvård | 2 | 1% |
| Specialiserad sjukhusvård öppen | 20 | 14% |
| Specialicerad sjukhusvård slut | 4 | 3% |
| Vet ej | 18 | 12% |
| Other | 8 | 5% |

People may select more than one checkbox, so percentages may add up to more than 100%.

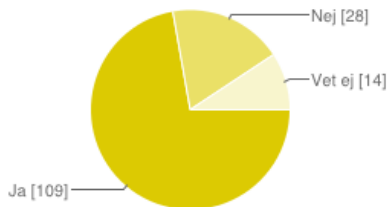
Hur ofta är du i kontakt med vården?



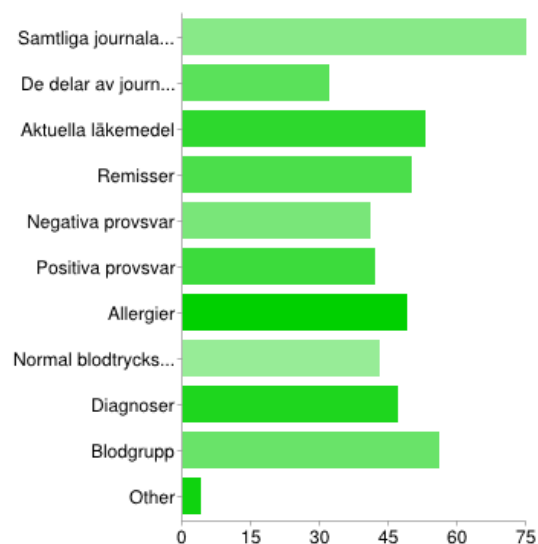
| | | |
|------------------------|----|-----|
| Flera gånger per månad | 4 | 3% |
| Varje månad | 8 | 5% |
| 2-6 gånger om året | 47 | 31% |
| Varje år | 32 | 21% |
| Mer sällan än varje år | 60 | 40% |

Om möjligheten fanns, skulle du vilja ta del av dina journaluppgifter via Internet?

| | | |
|--------|-----|-----|
| Ja | 109 | 72% |
| Nej | 28 | 19% |
| Vet ej | 14 | 9% |



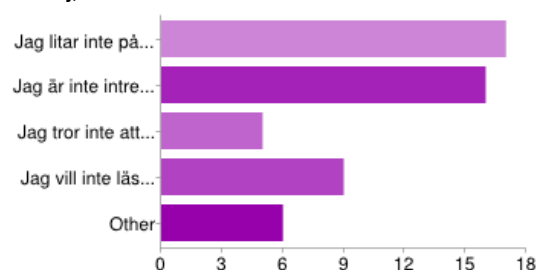
Om ja, vilken information vill du ta del av på Internet?



| | | |
|--|----|-----|
| Samtliga journalanteckningar | 75 | 65% |
| De delar av journalanteckningarna som läkaren bedömer att du förstår | 32 | 28% |
| Aktuella läkemedel | 53 | 46% |
| Remisser | 50 | 43% |
| Negativa provsvar | 41 | 36% |
| Positiva provsvar | 42 | 37% |
| Allergier | 49 | 43% |
| Normal blodtrycksnivå | 43 | 37% |
| Diagnoser | 47 | 41% |
| Blodgrupp | 56 | 49% |
| Other | 4 | 3% |

People may select more than one checkbox, so percentages may add up to more than 100%.

Om nej, varför inte?



| | |
|--|----|
| Jag litar inte på säkerheten via Internet | 17 |
| Jag är inte intresserad av att läsa min journal på internet | 16 |
| Jag tror inte att jag skulle förstå vad som stod | 5 |
| Jag vill inte läsa min journal utan att tala med en läkare eller annan vårdpersonal istället | 9 |
| Other | 6 |

People may select more than one checkbox, so percentages may add up to more than 100%.

Vilka funktioner skulle du vilja ha i ett journalsystem på Internet?

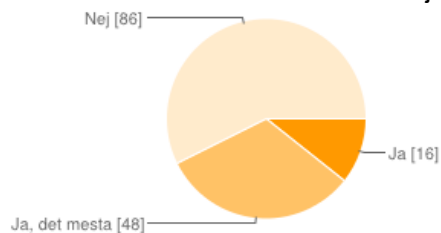
| | | |
|---|-----|-----|
| Boka läkarbesök | 124 | 87% |
| Skicka förfrågan om att förnya recept | 120 | 84% |
| Beställa olika hemmatest | 59 | 41% |
| Enkel självdiagnostisering (mäta blodtryck, etc) | 49 | 34% |
| Funktion för att ställa frågor om specifika journalanteckningar | 57 | 40% |
| Få en överblick över vilka vaccinationer jag tagit och behöver ta | 113 | 79% |
| Beställa sjukintyg och andra intyg | 96 | 67% |
| Fylla i hälsodeklaration inför läkarbesök | 98 | 69% |
| Kunna spärra specifik personal från att ta del av din information | 46 | 32% |
| Kunna se vilka som har tittat på din journalinformation | 78 | 55% |
| Hantera tjänster som målsman | 56 | 39% |
| Hantera tjänster för äldre anhöriga | 57 | 40% |
| Kunna godkänna att dina anhöriga kan se din journal | 58 | 41% |
| Få kontaktinformation till sjukvården | 97 | 68% |



| | | |
|---|-----------|-----|
| Kunna påpeka felaktigheter jag hittat i min sjukjournal | 74 | 52% |
| Other | 2 | 1% |

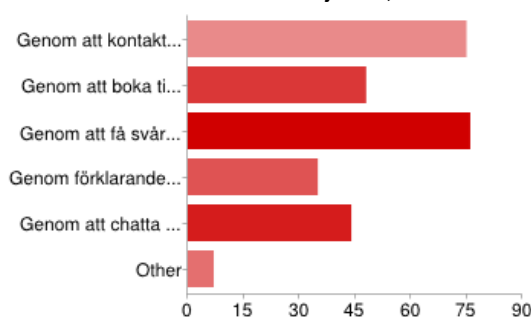
People may select more than one checkbox, so percentages may add up to more than 100%.

Är det ett krav att du ska förstå allt innehåll i din journal?



| | | |
|---------------|-----------|-----|
| Ja | 16 | 11% |
| Ja, det mesta | 48 | 32% |
| Nej | 86 | 57% |

Om du inte förstår allt som står i din journal, hur skulle du vilja få hjälp att förstå innehållet?

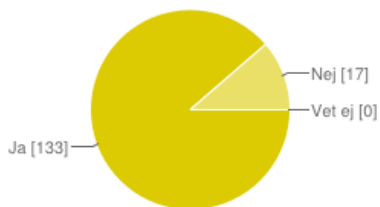


| | | |
|--|-----------|-----|
| Genom att kontakta vårdpersonal via telefon | 75 | 54% |
| Genom att boka tid för samtal på vårdcentral eller annan vårdenhet | 48 | 34% |
| Genom att få svåra facktermer förklarade bredvid journalen | 76 | 54% |
| Genom förklarande bilder eller illustrationer | 35 | 25% |
| Genom att chatta med vårdpersonal över Internet | 44 | 31% |
| Other | 7 | 5% |

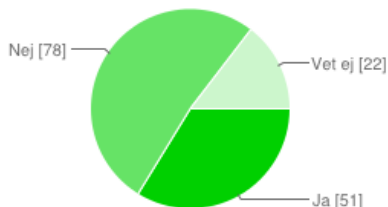
People may select more than one checkbox, so percentages may add up to more than 100%.

Har du en smartphone?

| | | |
|--------|------------|-----|
| Ja | 133 | 88% |
| Nej | 17 | 11% |
| Vet ej | 0 | 0% |



Om möjligheten fanns skulle du vilja ha tillgång till din sjukjournal i en mobilapplikation?



| | | |
|--------|-----------|-----|
| Ja | 51 | 34% |
| Nej | 78 | 52% |
| Vet ej | 22 | 15% |

Om ja, vilka funktioner skulle du vilja ha tillgång till?



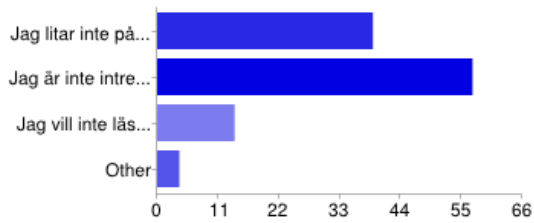
| | | |
|---|-----------|-----|
| Boka läkarbesök | 56 | 97% |
| Skicka förfrågan om att förnya recept | 47 | 81% |
| Beställa olika hemmatest | 17 | 29% |
| Enkel självdiagnostisering (mäta blodtryck, etc) | 22 | 38% |
| Funktion för att ställa frågor om specifika journalanteckningar | 21 | 36% |
| Få en överblick över vilka vaccinationer jag har tagit och behöver ta | 39 | 67% |
| Beställa sjukintyg och andra intyg | 33 | 57% |
| Fylla i hälsodeklaration inför läkarbesök | 35 | 60% |
| Kunna spärra specifik personal från att ta del av din information | 13 | 22% |
| Hantera tjänster som målsman | 17 | 29% |
| Hantera tjänster för äldre anhöriga | 17 | 29% |
| Kunna godkänna att dina anhöriga kan se din journal | 16 | 28% |
| Få kontaktinformation till sjukvården | 34 | 59% |
| Kunna påpeka felaktigheter jag hittat i min journalinformation | 20 | 34% |
| Få information om var närmaste vårdcentral ligger | 43 | 74% |
| Få påminnelse om att ta medicin | 39 | 67% |
| Other | 3 | 5% |

People may select more than one checkbox, so percentages may add up to more than 100%.

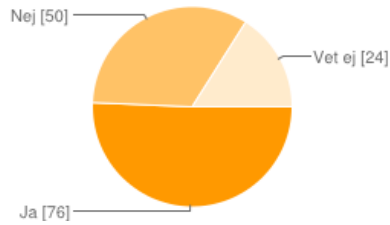
Om nej, varför inte?

| | | |
|--|-----------|-----|
| Jag litar inte på att säkerheten är tillräckligt hög | 39 | 46% |
| Jag är inte intresserad av dessa funktioner i en mobilapplikation | 57 | 67% |
| Jag vill inte läsa min journal utan tala med en läkare eller annan vårdpersonal istället | 14 | 16% |
| Other | 4 | 5% |

People may select more than one checkbox, so percentages may add up to more than 100%.

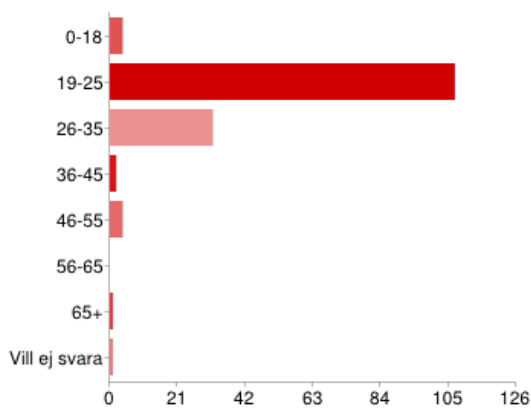


Skulle du, utan att behöva logga in, vilja ha åtkomst till akut hälsoinformation (blodgrupp allergier, läkemedel, etc) i telefonen?



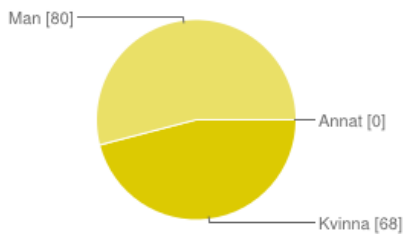
| | | |
|--------|----|-----|
| Ja | 76 | 50% |
| Nej | 50 | 33% |
| Vet ej | 24 | 16% |

Alder



| | | |
|---------------|-----|-----|
| 0-18 | 4 | 3% |
| 19-25 | 107 | 71% |
| 26-35 | 32 | 21% |
| 36-45 | 2 | 1% |
| 46-55 | 4 | 3% |
| 56-65 | 0 | 0% |
| 65+ | 1 | 1% |
| Vill ej svara | 1 | 1% |

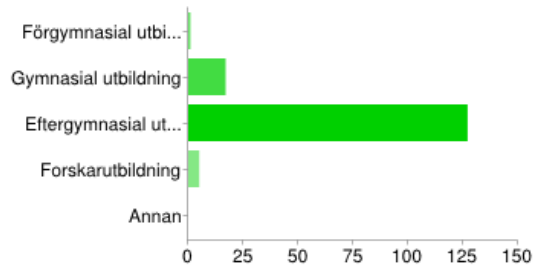
Kön



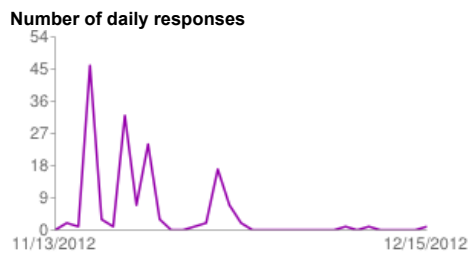
| | | |
|--------|----|-----|
| Kvinna | 68 | 45% |
| Man | 80 | 53% |
| Annat | 0 | 0% |

Utbildningsnivå

| | | |
|---------------------------|-----|-----|
| Förgymnasial utbildning | 1 | 1% |
| Gymnasial utbildning | 17 | 11% |
| Eftergymnasial utbildning | 127 | 84% |
| Forskarutbildning | 5 | 3% |
| Annan | 0 | 0% |



Tack för att du tog dig tid att svara på denna enkät!



Appendix B

Medical Personnel Survey

Enkätundersökning bland sjukvårdspersonal vid Akademiska sjukhuset i Uppsala

Vi är fjärdeårsstudenter på civilingenjörsprogrammet inom informationsteknologi vid Uppsala Universitet. Vi läser projektkursen *IT i samhället* som är en kurs där vi bland annat samarbetar med Landstinget Uppsala Län och forskningsprojektet DOME (Deployment of Online Medical records and E-health services). Den här enkäten är sammanställd som en del i vår undersökning och utvärdering av patienters tillgång till journaler på nätet, *Min journal*.

Projektet syftar till att ge kunskap och förståelse för vilka möjligheter patienters tillgång till journaler på nätet ger, hur tjänsten kan förbättras samt hur den kan göras mer tillgängligt för patienter. Enkäten riktar sig till Er som sjukvårdspersonal för att få Era synpunkter på hur journaler på nätet bör användas och vad systemet bör innehålla.

Vi vill få med så många aspekter som möjligt i vår kartläggning och därför hoppas vi att Ni vill ta Er tid att svara på våra frågor. Skriv gärna fritext om befintliga svarsalternativ inte täcker in Era åsikter. Resultatet av denna undersökning kommer att ingå i den rapport som vid kurens slut kommer att lämnas över till representanter för Landstinget i Uppsala Län.

Alla enkätsvar är anonyma och kan därmed inte spåras till uppgiftslämnare. Data kommer inte att överlåtas till tredje part eller användas för kommersiella syften.

Vi svarar gärna på frågor gällande projektet och enkäten.

Daniel Persson

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+46704 162914

Vänligen

Daniel Persson, Emma Rangert, Daniel Wedin

Enkät om patienters tillgång till journaler på nätet

A. Bakgrundsfrågor

1. Födelseår

År: _____

2. Kön

- Kvinna
- Man

3. Yrke

- Överläkare
- Underläkare
- AT-läkare
- ST-läkare
- Sjuksköterska
- Undersköterska
- Studerande
- Sekreterare
- Annat: _____

4. Är du specialist, i så fall inom vilket område?

Specialistområde: _____

5. Hur länge har du praktiserat ditt yrke?

_____ år.

B. Huvuddel

6. Känner du till att patienter kan få tillgång till sin journal på nätet?

- Ja
- Nej

7. Vad anser du om patienter får tillgång till sina journaler på Internet?

Kryssa i de alternativ du tycker passar in samt fyll i fritext:

- Bättre informerade patienter inför läkarbesök
- Snabbare återkoppling till patienter (exempelvis provsvar)
- Minskad arbetsbelastning för vårdpersonal
- Kortare mötestid med patienterna
- Ökad oro hos hypokondriker
- Missförstånd mellan patienter och vårdpersonal
- Ökad arbetsbelastning för vårdpersonal
- Patienter tror att de vet mer än vårdpersonalen
- Viss information bör utelämnas ur journalen
- Annat: _____

Kommentar: _____

8. När nu patienter kan läsa sin journal på Internet, kommer du då för patienten skriva tydligare journaler?

- Ja
- Nej

Kommentar: _____

9. Är det i dagsläget ett problem om patienter ej förstår innehållet i sin journal?

- Ja
- Nej

Kommentar: _____

10. Tycker du att patienterna skall kunna se all information i sin journal?

- Ja
- Nej

Om nej vilken information tycker du ej att de ska ha tillgång till: _____

11. Vad anser du om att låta patienter dela sin journal på nätet, med t. ex familj eller förmyndare?

Kryssa i de alternativ du tycker passar in samt fyll i fritext

- Minskad oro för anhöriga
- Risk att känslig information görs lättillgänglig
- Minskad arbetsbelastning för sjukvårdspersonal
- Ökad arbetsbelastning för sjukvårdspersonal
- Annat: _____

Kommentar: _____

12. Vad anser du om möjligheten att låta anhöriga se var en patient befinner sig och tidpunkt för när patienten skrivs ut från sjukhuset?

- Minskad oro för anhöriga
- Minskad arbetsbelastning för sjukvårdspersonal
- Ökad arbetsbelastning för sjukvårdspersonal
- Risk att informationen visas för obehöriga
- Annat: _____

Kommentar: _____

13. Vad anser du om möjligheten att *Min journal* finns tillgänglig på mobila enheter?

Kryssa i de alternativ du tycker passar in samt fyll i fritext:

- Ökad användning
- Ökad tillgänglighet
- Säkerhetsrisker
- Annat: _____

Kommentar: _____

C. Informationsblockering

Det här avsnittet handlar om möjligheten för patienter att kunna dölja eventuell känslig information i sina journaler från viss sjukvårdspersonal. Informationen kan exempelvis innefatta missbruk, våld i hemmet etc.

14. Tror du att det kan bli problem genom att patienter döljer känslig information för att viss sjukvårdspersonal inte ska få tillgång till den?

- Ja
- Nej

Kommentar: _____

15. Finns det viss sorts information som går att dölja från sjukvårdspersonal utan att problem kan uppstå, förutsatt att informationen visas i nödfall?

- Ja
- Nej

Kommentar: _____

D. Intervju

För att ska kunna få en fördjupande förståelse skulle vi uppskatta om du kunde ställa upp på en intervju. Observera att dina svar ej garanterad kan förbli anonyma om du väljer att ställa upp på en intervju.

16. Kan du tänka dig ställa upp på en intervju?

Om du svarar Ja på denna fråga kan din anonymitet inte längre garanteras.

- Ja, ange dina uppgifter nedan
- Nej

Mail: _____

Tel (Valfritt): _____



Enkät om patienters tillgång till journaler på nätet

1. 1. Födelseår

Antal svarande: 32

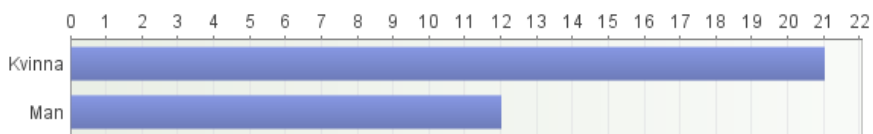
 Dölj

År:

- 1990
- 1987
- 1987
- 1991
- 1987
- 1991
- 1986
- 1991
- 1984
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- 1986
- 983
- 1990
- 1980
- 1986
- 1987
- 1985
- 1984
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- 1971
- 85
- 89
- 1987
- 1980
- 1965
- 1982
- 1990
- 1984
- 1985
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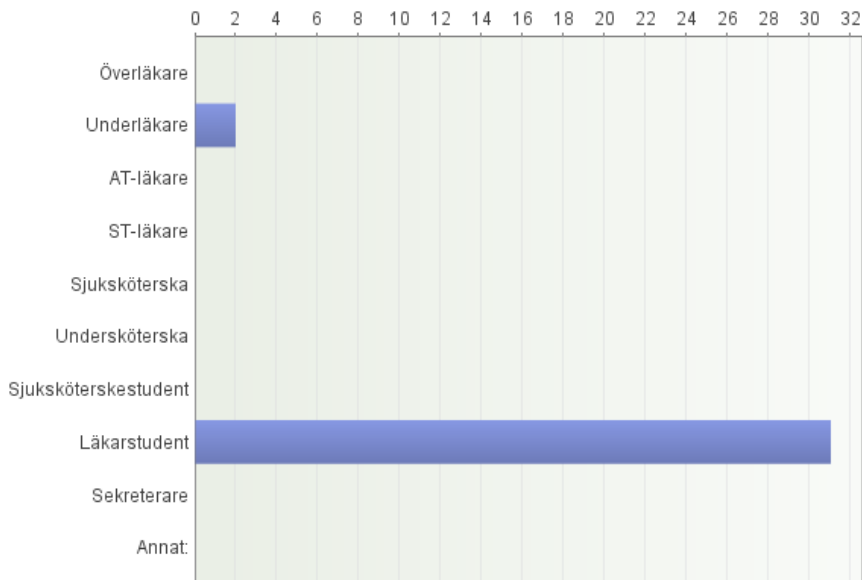
2. 2. Kön

Antal svarande: 33



3. 3. Yrke

Antal svarande: 33



4. 4. Är du specialist, i så fall inom vilket område?

Inga svar.

5. Hur länge har du praktiserat ditt yrke?

Antal svarande: 12

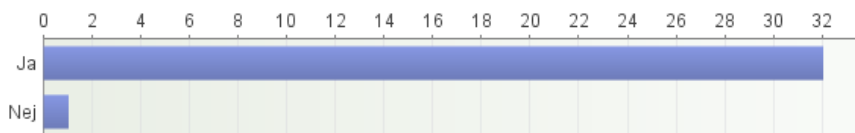
Dölj

år

- 5
- 5
- 2,5
- 0
- 0
- 1
- 5
- 3
- 0,5
- 0
- 2
- 5

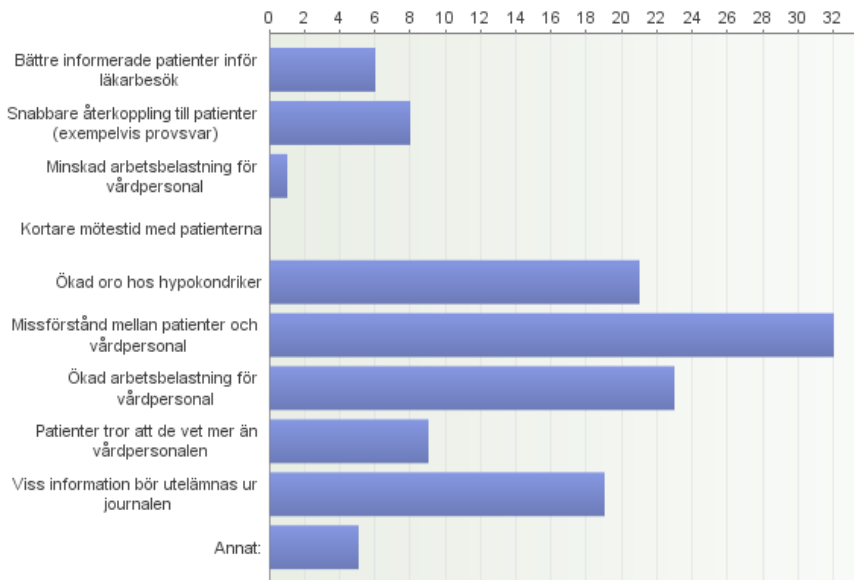
6. 6. Känner du till att patienter kan få tillgång till sin journal på nätet?

Antal svarande: 33



7. 7. Vad anser du om patienter får tillgång till sina journaler på Internet? Kryssa i de alternativ du tycker passar in samt fyll i fritext:

Antal svarande: 33



Fritextsvar

Annat:

- Försämrad information mellan vårdgivare
- Det finns en rättighetsaspekt också. Man kan ju redan få ut sina journaler, då kan de ligga på nätet också
- Risk för merarbete, behöva uttrycka sig så att gemene man ska kunna läsa en journal som egentligen är menat som medicinskt verktyg, utarbetat av och för vårdpersonal för att kunna utföra /underlätta arbetet.
- värnar patientens integritet

8. Kommentarer:

Antal svarande: 15

Döj

- Språket som används i journaler är väldigt byråkratiskt och väldigt svårt att förstå för den som inte har de kunskaperna. Det är inte för att låta smart utan för att det gör det väldigt mycket lättare att kommunicera inom sjukvården
- Cancerbesked får idag ej lämnas per mail eller telefon, ett mottagningsbesök bokas alltid in för att hantera eventuella frågor. Basaliom och liknande oftast ofarliga cancersorter kan orsaka missförstånd. Det blir även en ökad arbetsbelastning att förklara vad alla provsvar, röntgenutlåtanden etc. betyder i detalj. Det är bättre att patienten får koncentrerad och förenklad information, dels för att minska missförstånd och dels för att undvika tidsödande förklaringar av oväsentlig information. Journalen bör vara ett arbetsredskap för kvalitetssäkring och underlätta vårdpersonalens vardag i första hand.
- Både bra och dåligt.
- Tycker att vissa delar av journalen ska ges ut, tar man det hela för långt måste läkare börja anpassa journalskrivandet vilket kommer förstöra mycket av den interna kommunikationen. Dock är jag klart emot e-journal då jag tvivlar starkt på att ett webbaserat system som är säkert kommer uppnås.
- Jag är helt emot detta.
- journalerna måste skrivas på "svenska" så att patienterna förstår och då går poängen med medicinska termerna, och deras mer talande och beskrivande innebörd, om intet.
- Journalen är ett arbetsverktyg.
- Tror det finns få positiva saker med detta. Även att vårdpersonal ständigt måste tänka på vad de skriver i journalen på ett helt annat sätt.
- Jag ser journalen främst som ett arbetsverktyg för vårdpersonalen och är osäker på ifall patienter skulle vara betjänt av allt som står där.
- Kommer nog vara mest negativt och ge ökad arbetsbelastning i början, men bli ett bra verktyg med tiden och med rätt säkerhet.
- Risk för merarbete, behöva uttrycka sig så att gemene man ska kunna läsa en journal som egentligen är menat som medicinskt verktyg, utarbetat av och för vårdpersonal för att kunna utföra /underlätta arbetet.
- Jag tycker det är mycket positivt med en öppnare hållning kring patientens journal.
- Tror dels att vissa kommer att ha många frågor kring det de läst. Vårre är dock att om man överväger en allvarlig diagnos men vill bekräfta den med prover/uns så kan man inte skriva i journalen hur mycket man sagt till patienten så att nästa läkare vet det. Kan inte heller skriva dessa differentialdiagnoser/misstankar för då blir det onödigt oroad. Personal/studenter byts mer än folk tror, ex nya AT-läkare, studenter av olika slag, ST-läk som randar. Överläkaren kanske är samma, men då ska den ha allt i huvudet i stället för att skriva ner ex. diff. diagnoser.
- Svårt för patienter som inte har medicinsk utbildning att tolka allt som står i journalen då det förekommer mycket fackuttryck. Är t.ex. ett provsvar som är positivt något bra eller dåligt?
- Jag tror att det kommer leda till ökad arbetsbelastning då patienter kommer höra av sig och fråga kring saker i sin journal, t ex vad olika labbsvar innebär. Detta kan i sin tur leda till en mängd onödiga utredningar. Ett rätt labbsvar innebär inte sjukdom per definition, det innebär att man inte håller sig inom den 95%iga normalfördelningen. Jag tror det leder till ökad arbetsbelastning då personal inte kan lämna spekulativ information kring pågående utredningar som skulle kunna misstolkas av patienter. Detta gör att personal måste informera annan personal mera muntligt vilket är en stor risk för att information ska gå förlorad.

9. 8. När nu patienter kan läsa sin journal på Internet, kommer du då för patienten skriva tydligare journaler?

Antal svarande: 33



10. Kommentar:

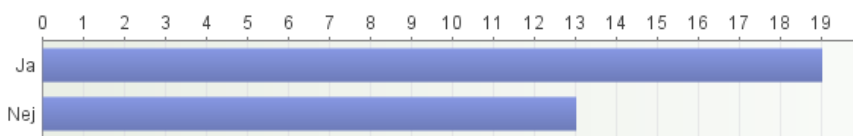
Antal svarande: 16

👤 Döj

- Se förra kommentaren
- Jag vill kunna använda mitt fackspråk som är ett utav mina arbetsredskap. Det tar mycket längre tid att skriva på vanlig svenska och blir mindre precist.
- Administrationsbördan är redan så pass hög på vårdpersonalen att förkortningar och medicinska termer behövs för att hålla ner tiden som dels läggs på att föra in information, men även för en annan behandlande medarbetare att snabbt få ut koncis information. Journalföring fungerar inte som löpande text, med liknelser, förenklingar och omständiga förklaringar. Det behövs ett mått av förkunskap för att skriva och läsa en journal där relevant information fås fram på en liten yta.
- Journalen är till för att underlätta vårdarbetet. Tar redan alldeles för mycket tid i anspråk.
- absolut inte. jag kommer att använda ett extra avancerat medicinskt språk
- Strävar alltid efter att skriva tydligt. Vill kunna använda mig av medicinska termer utan att behöva skriva långa, krångliga förklaringar
- Inte tydligare kanske men tänka på vad som skrivs, kanske utelämnar vissa saker/formuleringar
- En svår fråga, spontant tror jag dels att det är svårt att lära gamla hundar sitta, dvs lägga om typ all nuvarande vårdpersonal. Dessutom tror jag att det i många fall kan bli för förenklat och i viss fall rent felaktigt information om man skrivet på "svenska". Vården har ju ett eget språk av en anledning (oftast). Där kanske läkarsekreterarna kan ta en ny roll och utforma någon slags översättningstjänst, privat eller inom landstinget, de är ju oroliga för skråets framtida överlevnad vad jag förstår.
- Men egentligen inte för att de får tillgång utan för att jag för närvarande inte efterföljer Patientdatalag(2008:355) 3 kap. 13§
- Vill pat läsa sina journaler obehindrat får de sätta sig in i medicinsk nomenklatur. Finns ej tid att sitta och översätta till icke-medicinska termer.
- Journalen är ett arbetsmaterial för sjukvården som patienten skall ha full tillgång till, men patienten ska inte använda sin journal på nätet för att få information om sitt hälsotillstånd, den informationen får patienten av mig som läkare i våra möten.
- Försöker redan skriva enkelt.
- Journalen är mitt och kollegornas arbetsredskap, är den dålig blir vården sämre. I så fall bättre att pat frågar om de inte förstår.
- Jag anser inte att journalen är ett kommunikationsverktyg mot patienten utan mellan vårdpersonal. Formuleringar i journalen är i nuläget inte anpassad för att en icke-medicinskt utbildad person skall läsa den.
- Tycker redan jag skriver relativt tydligt. Journalen är dessutom i första hand ett arbetsverktyg för sjukvårdspersonalen och inte en självbiografi för patienten...
- Kommer nog passa mig väldigt nogga för att använda termer som "cancer kan ej uteslutas", vilket är ganska vanligt att skriva i en journal för att förmedla till nästa läkare i utredningsledet att dom ska ta hänsyn till detta. Man kanske måste skriva "cancer är högst osannolikt med tanke på detta och detta, men det är bra att utesluta". Hypokondri är en av de absolut största kostnadsfaktorerna inom svensk sjukvård.

11. 9. Är det i dagsläget ett problem om patienter ej förstår innehållet i sin journal?

Antal svarande: 32



12. Kommentar:

Antal svarande: 15

👤 Döj

- Om patienten inte förstår sin journal så får de ta kontakt med någon som gör det; ex sin husläkare, distriktsläkare eller bekanta med läkarkunskaper. Möjligtvis kan man googla vissa ord.
- De som hämtar ut sin journal har nog ofta svårt att förstå den, och behöver då förklaring för att kunna tolka den.
- Jag har än så länge inte mött så många patienter som läst sin journal.
- Så länge dialogen med behandlande vårdpersonal, medicinister patientorienterad medicinsk information (en lekmanamässig skriven text som behandlar vårdförloppet och kompletteras med medicinlista) vid utskrivningar fungerar är journaltexten överflödigt för patienten.
- Nej. De som är intresserade kollar väl upp vad saker betyder. Men det kanske kommer att bli ett problem.
- Journalen är ett sätt att föra över relevant information till vårdgivaren i nästa vårdtillfälle. Den ska då inte behöva anpassas för patienten.
- journalen är ett arbetsredskap för läkare (och övrig vårdpersonal). bara bra om patienten inte förstår vad som står. det bevisar väl bara att journalen inte bör ligga online, när patienten uppenbarligen inte förstår innehållet
- Inte nödvändigtvis alltid, beror på patienten. Tror dock att det är ett problem i det stora hela. Kan skapa onödig oro och frustration hos en del patienter.
- Onödig oro för patienter. De kommer förmodligen att känna ett behov av att få vissa journaldata förklarade för sig. Vem ska göra det?
- Missförstånd och onödig oro! Ta bara ordet tumor, som dels betyder cancer, men ibland bara svullnad eller knö!l
- Frågor , merarbete och tid måste läggas på att förklara journaluppg istället för att under läkarbesöket fokusera på aktuellt problem. Risk för ännu mer tidspress.
- Både och. Jag kan inte förstå det som står om min skorsten i "sotarjournalen", jag förstår inte vad som står i polisens register och jag förstår inte tandläkarjournaler (fullt ut). Sjukhusjournaler är arbetsdokument ämnade för sjukvården, det är viktigt att patienter förstår.
- Har dock liten erfarenhet
- Det kan väcka mycket oro och funderingar hos en del patienter är jag rädd, och vem ska då fånga upp dessa individers frågor?
- Man måste fundera över vad som är syftet med journaler, är det för att patienten ska få ett kvitto på deras sjukdom och att utredning gjorts på ett korrekt sätt eller är det ett verktyg för sjukvårdspersonal att effektivisera arbetet kring patienterna med avseende på utredningar. Jag tycker det senare. Men vi som sjukvårdspersonal har en skyldighet att förklara för patienten det dom inte förstår. Edukation för patienten är nog tyvärr det som fått stryka mest på foten i och med den minskade patienttiden. Alldeles för lite av den varan.

13. 10. Tycker du att patienterna skall kunna se all information i sin journal?

Antal svarande: 31



14. Om nej vilken information tycker du ej att de ska ha tillgång till:

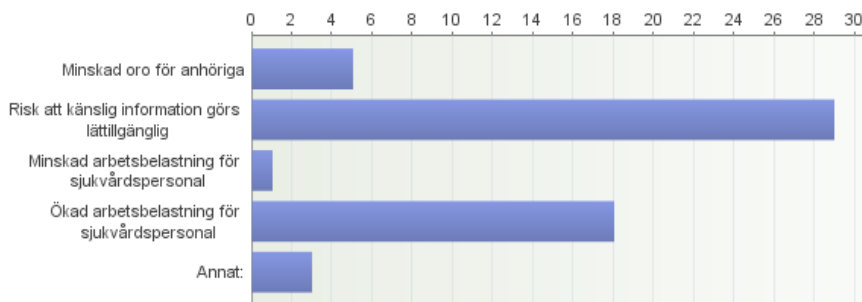
Antal svarande: 21

Dölj

- Nej, inte vissa uppgiftslämnare. Ex om ett barn berättar att deras mamma blir misshandlad av pappan, så är det ju olämpligt om pappan får tillgång till detta genom journalen.
- Men undantag från vissa psykiska grejer...
- Vid vård av psykiater är det ofta kontraproduktivt för vården att pat. läser sin egen journal. Det borde även sättas åtminstone en tidspärr på allvarliga undersökningar så att patienten får träffa behandlande läkare och får besked därifrån i förstälaget. Detta kan sedan läsas upp om patienten behöver ha tillgång till det.
- Psykuppgifter kan tex vara mycket känslig information och leda till en försämring i sjukdomsförloppet om personen får ta del av informationen (Suicid etc).
- Exempelvis i vissa fall inom psykiatri, kan vara bra om patienten inte sitter hemma och läser själv, om detta ska ske bättre om patient gör tillsammans med vårdpersonal. I vissa fall röntgensvar, provsvar, biopsi etc exempelvis vid cancerutredning tycker jag att patienten ska få information av sin läkare och inte läsa själv på nätet.
- Information som snarare kan skada eller förvärpa patienten ännu mer. Tex för psykiskt sjuka patienter, schizofreni etc
- ingen information alls. de får beställa en läkartid om de vill diskutera vad som sades på tidigare besök/mottagning/inläggning. däremot tycker jag att de ska kunna begära ut sin journal och att menprövning skall göras
- Möjliga laboratoriesvar (i sifferform, utan beställarens eller mottagarens kommentarer)
- Ej osignerat eller sista månadens besök.
- Exempelvis tunga besked som bör lämnas på ett bättre sätt.
- Ingen om de ej begär det
- Tveksamt. I framtiden ja, men i nuläget skulle det nog bli en jobb omställning för vårdpersonal, även om man redan nu vet att de kan begära ut sin journal. Till en början skulle man t.ex. när man signerar en anteckning eller provsvar få klicka i "ja, redo för att patienten får tillgång till detta", så att det kan användas tex som kommunikation av provsvar efter överenskommelse med patienten.
- Labsvar. Rtg-svar. Viss journaltext.
- Psykjournals
- Bilddiagnostik Psyk
- Kan inte svara på frågan då den är så otydlig, menas t.ex. icke-signerade poster? De ska inte pat se, bl.a för det kan faktiskt vara fel där. Senast denna vecka menade jag hypo- (under-) och sa fel alt. sekreteraren hörde fel så det blev hyper- (över-).
- osignerade provsvar. de flesta anteckningarna.
- Är tveksam till att de ska ha tillgång till journalen överhuvudtaget när de saknar hjälp med tolkning av densamma. Däremot tycker jag absolut att de ska få möjlighet att gå igenom vad som står i deras journal tillsammans med vägledande sjukvårdspersonal vid behov.
- provsvar, röntgensvar
- Samma som gäller nu. Patienterna har tillgång till sina journaler, med undantag för vissa psykiatriska journaler. Det är latenstiden och chansen att få förklara för patienten som är det viktiga i frågan. Sjukvårdspersonal måste få chansen att förklara patientens eventuella sjukdom före dom läser det själva på internet. Jag ser bara bekymmer med detta system och tycker att vi har tillgång till våra journaler som systemet ser ut idag. Det som är bra är om man kan boka tider och möten via internet, se sina recept m.m.
- Misstankar om diagnoser som måste utredas, det kan vara väldigt liten misstanke men som man ändå måste utesluta och om patienten läser det kan de bli onödigt oroliga Psykiatri

15. 11. Vad anser du om att låta patienter dela sin journal på nätet, med t. ex familj eller förmyndare? Kryssa i de alternativ du tycker passar in samt fyll i fritext.

Antal svarande: 33



Fritextsvar

Annat:

- Både minskad och ökad (både befogad och icke-befogad) oro för anhöriga.
- Ingen åsikt
- Risk för brott mot sekretessen

16. Kommentar:

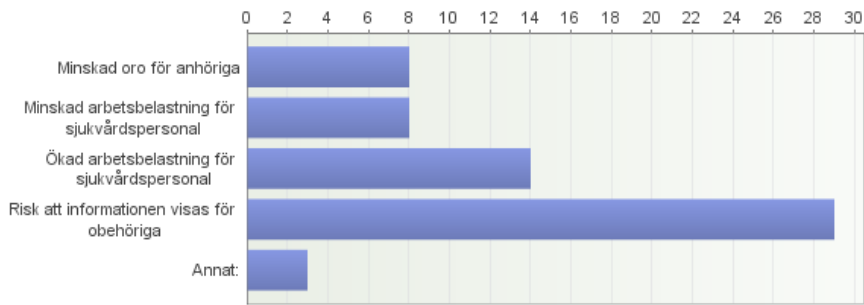
Antal svarande: 6

Dölj

- Osäker på att människan i dagsläget är tillräckligt "mogen" för att kunna hantera något sådant. Eventuellt riskerar det endast till att öka stressen.
- I vissa fall kommer säkert anhöriga ringa extra mycket ang inläggande patienter, och i andra fall ner. Svårt att förutse.
- Missnöje, ifrågasättande, följdfrågor
- Misshandlande partner kan ju innebära ett problem för den som söker hjälp för det t ex, likaså "dåliga" föräldrar, barn, gode män osv
- Risk att anhöriga, utöver patienten, feltolkar journalinnehåll med påföljande oro, krav på åtgärder, etc.
- Otroligt korkat. Detta kommer skapa incitament och press på patienten för att dela med sig av sina journaler till myndigheter, familj eller t o m arbetsgivare för att de i det senare fallet ska kunna se sjuklighet hos den anställde.

17. 12. Vad anser du om möjligheten att låta anhöriga se var en patient befinner sig och tidpunkt för när patienten skrivs ut från sjukhuset? Kryssa i de alternativ du tycker passar in samt fyll i fritext.

Antal svarande: 33



Fritextsvar

Annat:

- Risk för missförstånd
- Risk för brott mot sekretess
- integritetskränkande

18. Kommentar:

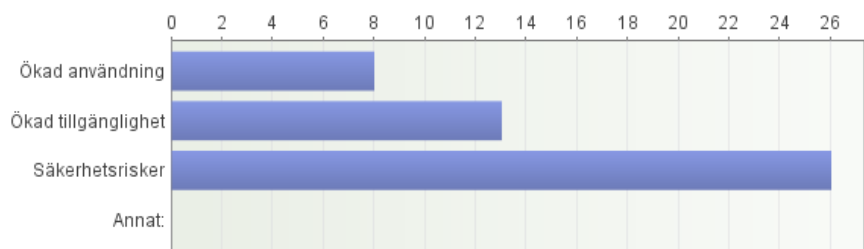
Antal svarande: 7

Dölj

- Finns risk att det bryter någon lag, men jag är inte hundra
- Om patient vill förmedla till anhöriga när de lämnar sjukhus är det bättre med telefonkontakt mellan patient och anhörig, alternativt att vårdpersonal hjälper patienten med detta om denne inte kan kontakta anhöriga på egen hand
- Känns som ett "storebrorssamhälle"/nytt Östtyskland, vilket jag inte tycker om.
- Det låter Integritetskränkande.
- Visste inte ens om detta förslag
- Det kan väl berörd sjukvårdspersonal/patienten själv meddela dem som behöver veta det om/när de behöver veta det.
- Tja skulle det funka som så att man kommer överens med patienten att idag skrivs du ut, så kan man på något enkelt sätt förmedla detta till anhöriga kanske man slipper ordna med sjukresor. Men sjukdom är en dynamisk process och sjukhus är inga fabriker, om man kommer överens på silttronden att denna patienten skrivs ut idag, sedan när man träffar patienten på gårdonden så är det helt plötsligt inte alls tal på utskrivning, ska du anhöriga kunna kräva utskrivning för att detta angavs vid en tidigare tidpunkt?

19. 13. Vad anser du om möjligheten att Min journal finns tillgänglig på mobila enheter? Kryssa i de alternativ du tycker passar in samt fyll i fritext:

Antal svarande: 32



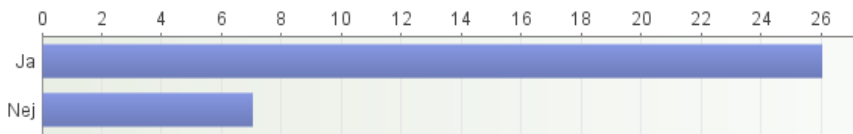
20. Kommentar:

Antal svarande: 5

- Fördel att patient och läkare kan läsa journalen samtidigt på den mobila enheten eftersom läkarnas datorer ofta är stationära och i arbetsrum med andra läkare, vilket gör att man inte kan ta med patienten dit hursomhelst.
- Kan skapa oro att information om en själv hamnar i orätta händer. Förvisso tycks det fungera med banktjänster etc, men patientjournaler känns lite känsligare.
- Vad är en mobil enhet? folks telefoner? Kan tyvärr inte tycka nåt när jag inte fattar
- Möjlighet till dataintrång. Lättare att man tappar bort/blir bestulen på en mobil än en dator.
- Tror det kommer vara oerhört lätt att hacka sig till patientjournaler, mobiltelefoner saknar idag ofta brandväggar.

21. 14. Tror du att det kan bli problem genom att patienter döljer känslig information för att viss sjukvårdspersonal inte ska få tillgång till den?

Antal svarande: 33



22. Kommentar:

Antal svarande: 16

[Dölj](#)

- Tycker att det är en självklar rättighet.
- Problemen kan uppstå om patienten tar läkemedel som interagerar med varandra men som läkaren inte känner till, har andra pågående behandlingar/terapi som kan påverka den aktuella behandlingen, risk att missa vissa skador som är förenliga med missbruk och våld i hemmet så som skallskador.
- Det ju redan att göra det, och jag har förstått att det kan bli bökigt och kanske även farlig. Men självklart ska man få göra det men det ska vara en av en orsak och inte bara att man får för sig framför datorn att man inte vill att ens läkare ska veta att man röker, eller vad det nu kan vara som kan påverka behandling. Dåligt exempel, för undrar man det så frågar man ju. Men ni kanske förstår hur jag menar
- För att förstå patientens hälsoproblem såväl fysiska som psykiska är det viktigt att som vårdgivare få ta del av hela bilden. Ex missbruk påverkar i allra högsta grad båda dessa och att inte känna till det kan avsevärt försvåra diagnostisering och behandling. Läkemedelslistor bör aldrig vara dolda.
- Pat. kan redan spärra sin journal.
- Men det finns nog fördelar också
- Det är svårt för läkare att bedöma vad som är relevant för ett visst vårdtillfälle, att patienten ska göra denna bedömning är idioti, viktig information kan gå förlorad.
- I de flesta fall tror jag inte det blir problem men i de fall där det riskerar uppstå problem kan det få negativa konsekvenser
- Journalerna ska vara en hjälp för sjukvårdspersonalen att hjälpa patienten på bästa sätt. Givetvis tråkigt om känslig information utnyttjas på fel sätt men jag anser att det är en risk man får ta i strävan efter att se till patientens bästa. Det är ju inte Expressen eller Aftonbladet.
- Definitivt
- Patienten kan inte avgöra vad som är relevant för olika vårdpersonal. Information som kan vara viktig för både patientens och personalens liv och hälsa kan gå förlorad!
- Journal är ett arbetsredskap. Att inte få "hela bilden" kan påverka handläggning och ev försvåra i arbetet.
- Men vill folk göra det så har dom rätt till det.
- Enklare när hela psykjournalen är spärrad för då vet man det. Enstaka uppgifter verkar mycket mer godtyckligt.
- Integritet är visserligen viktig men inte på bekostnad av patientsäkerheten. Det är ju absurt att man som behandlande läkare inte ska ha möjlighet att få hela sjukdomsbilden, det blir så oerhört svårt att göra en vettig bedömning då i vissa fall.
- Det kan bli ett problem, men jag tycker man har rätt att dölja information som inte ingår inom säkerhetsinformation, ex. om patienten bär på en blodsmitta som kan vara en fara för övrig personal. Däremot ska man ha rätt att häva blockeringen i akuta situationer, men detta ska då motiveras.

23. 15. Finns det viss sorts information som går att dölja från sjukvårdspersonal utan att problem kan uppstå, förutsatt att informationen visas i nödfall?

Antal svarande: 32



24. Kommentar:

Antal svarande: 12

[Dölj](#)

- Ja, alla detaljer är ju sällan helt nödvändiga.
- Lättare psykiska besvär, och viss mån fysiska.
- Jag tycker personligen att det vid några tillfällen kommer upp information som kan vara känslig för patienten och som jag ej är i behov av för patientens nuvarande besvär.
- Vet inte om jag riktigt förstått frågan rätt, men det finns ju vissa journaler (ex. beträffande barnmisshandel etc.) som endast behörig personal kommer åt och det tycker jag känns riktigt.
- Kanske dy, viss info från psyk tex, men det bör inte vara patienten som bestämmer det pga ovan.
- Vet ej
- Ex gynjournal (aborter etc) , psykiatrisk journal (går att "forcera" och ta sig in i på begäran mha lösenord vid behov i vissa län)
- Både och här också. All information behövs ibland och det är svårt att säga vilken information det är, när den behövs och hur stora problem som skapas om den döljs.
- Gyn, vissa psyk, annat som kan vara känsligt
- Mycket perifer information, ex fritidssysselsättning, motionsvanor (som kan vara viktigt ur förebyggande hälsovårdssynpunkt o.dyl.)
- Det gör det säkert, men jag ser inte vitsen. All sjukvårdspersonal ska följa sekretessbestämmelserna och bara ta del av det som är adekvat för den aktuella behandlingen. Men all information bör finnas tillgänglig vid behov.
- All sjukvårdspersonal behöver absolut inte ha tillgång till all information kring patienten, detta tycker jag man kan se över. Jag tycker dock att PAL (patientansvarig läkare) ska ha tillgång till all information, då ska också patienten ha något att säga till om vem som ska vara dess PAL.

25. 16. Kan du tänka dig ställa upp på en intervju? Om du svarar Ja på denna fråga kan din anonymitet inte längre garanteras.

Antal svarande: 32

Appendix C

Interview Questions

Patientfrågor

Dessa frågor ställdes till vårdtagare som ofta är i kontakt med vården. Intervjuerna var semistrukturerade. Vissa följdfrågor kan även ha ställts som inte finns med i frågorna nedan.

- Vad tycker du om helt allmänt om att du ska kunna läsa din journal på internet?
- Har du beställt hem din journal någon gång?
- Förstod du vad som stod i din journal när du läste den?
- Vilka funktioner skulle du vilja att ett sådan här system skulle innehålla?
- Vad skulle du tycka om möjligheten att ansöka om förnyande av recept?
- Skulle du vilja kunna ge anhöriga tillgång till din journal?
- Vad tycker du om att du skulle kunna självdiagnostisera dig och skriva in saker som du tror är relevanta för läkare?
- Skulle du vilja läsa provsvar på ett sådant här system?
- Hur tror du att du skulle påverkas av att läsa exakt hur sjuk du är?

Interview questions

These questions were asked when interviewing people that have medical experience and work with health records in one way or another. The interviews were semi structured. Some followup questions that were asked might not be present.

- How big is the problem with people not understanding the health record?
- Will all kind of medical journals (e.g serious diseases) be available on the system?
- Will medical journals containing information that can lead to serious concerns of the patient be treated in another way than regular medical journals?
- Will people contact the hospital more and ask if they can get access to their health record or explanation of their journal?
- Can all kind of medical information be available on the system?
- If the language of the medical records did not involve the medical terms, would it lead to misunderstandings for doctors?
- Is there a suggested solution available on how to make the understanding better in form of language?
- What do you think people don't understand? Is it the medical terms or the language structure? How it can be improved?
- Will the medical journals on the web look exactly the same as the medical journals the doctors use in their everyday work?
- Is it an option to allocate doctors/medical personnel more time to write more clear and understandable records for the patients?
- Would a wiki (like clicking on a term and get more information) help the understanding?