

IT AND SOCIETY

Healthcare Guide: Improvements to the Healthcare Information Network

Supervisors

Åsa Cajander Mats Daniels Anne-Kathrin Peters Nanna Lagerqvist
Steve Frezza Cary Laxer Can Kultur



UPPSALA
UNIVERSITET



Joakim Andersson
Rayan Brouwer
Linus Eriksson
Marcus Henricsson
Evmorfia Kalogiannidou
Marianna Kapari
Yassar Nader
Adam Olevall
Elin Parsjö
Tilda Pentikäinen
Stina Richard
Dawn Richardson
Jonas Rosenlind
Nadia Röning
Linnea Sandelin
Kristin Schläpfer
Maria Svensson
Sven Wildermann

Nicholas Allen
Gabriel Glenn
Aaron Golliver
Jack Petry
Jordon Phillips

Scott Conrad
Brett Schultz

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Abstract

In Swedish healthcare, communication and accountability are issues that are becoming increasingly significant as the level of specialization for physicians continues to rise. Patients who are simultaneously under the care of a variety of specialists require a high level of communication between physicians in order to receive the best care possible. When patients are moving between a multitude of different specialists with no single party responsible for their overall care, some overall responsibility for the patient may be lost. This report proposes the introduction of a healthcare guide within the Swedish healthcare system, focusing on Uppsala County Council, to improve the communication and transparency between a patient and their physician. The healthcare guide would incorporate a number of communication improvements and information delivery techniques. The concept builds upon a number of required qualities and can be a combination of healthcare personnel, information technology, or other means for information sharing.

Abstract

Kommunikation och vem som är ansvarig för en patients vård är frågor som får större betydelse när nivån av specialisering fortsätter att öka bland läkare. När patienter vårdas av flera specialister samtidigt krävs en tydlig kommunikation läkare emellan. Behandlas patienter av många olika specialister uppstår problem om vem som har det övergripande ansvaret. Denna rapport introducerar en sjukvårdsguide i det svenska sjukvårdssystemet, där fokus ligger på Uppsala Läns Landsting, för att förbättra kommunikationen och klarheten mellan patient och läkare. Sjukvårdsguiden skulle förbättra kommunikationen och spridningen av information. Konceptet bygger på ett flertal rekommenderade kvalifikationer och lösningen kan vara en kombination av sjukvårdspersonal, informationsteknologi och andra källor för informations-spridning.

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1 Introduction

How can the Swedish healthcare system be refined to bridge the communication gap between physicians and patients? Communication and accountability are issues that are becoming increasingly significant as the level of specialization for physicians continues to increase. While specialization improves skill levels, it also reduces the overall area for which a specialist physician feels responsible. As a result, recent years have begun to see a lack of involvement for patients and an absence of accountability for their physicians. It is clear communication and accountability are influential in healthcare, with both issues being the target of ongoing research, legislation and media coverage. Sweden's unique healthcare landscape presents a complex system, changes to which must fit within the cultural and legislative limitations of the country.

This report aims to examine the interplay of a number of critical issues within the healthcare systems today and how a new concept, a healthcare guide, could potentially provide a way to reduce some of these ongoing concerns. The findings presented have been obtained as part of a course run as a global collaboration between Sweden and the United States, involving participation from the three universities: Uppsala University, Rose-Hulman Institute of Technology and Gannon University. The project concept was defined by the County Council of Uppsala, who has been a involved in a long-term collaboration with Uppsala University. The collaboration aims to give students the opportunity to investigate and work on real issues within healthcare information technology in Sweden and worldwide.

The research presented here will examine the landscape of the Swedish healthcare system, including the current structure, organization and IT systems it utilizes. The report will then look at existing work that aims to overcome some of these issues and evaluate the successes and failures of each. The concept of a healthcare guide will then be presented as a potential solution to these issues. The concept will be analyzed alongside the potential problems and acceptance issues. Recommendations for utilizing the healthcare guide as a method of improving healthcare systems will then be presented. Finally, a number of further issues surrounding these findings and their implications will be discussed.

The proposal of a healthcare guide aims to combine a number of efforts to improve communication and transparency between a patient and the healthcare system. The healthcare guide concept would incorporate a number of communication improvements and information delivery techniques. As well as this, a person, or group of people could be introduced to act as a link between a patient and their physician to improve patient care by increasing the level of patient involvement.

There is little doubt that healthcare is a complex issue, and the Swedish healthcare system is no exception. While the system in Sweden contains many strengths, particularly relative to those worldwide, there is still a number of influential issues and discrepancies in communication and accountability between segregated healthcare departments. This report aims to enhance some of these mechanisms and improve the Swedish healthcare system as a whole. The recommendations and healthcare guide concept presented in this report are part of the web of an intensively complex system, changes to which are a challenging job. While the implementation of a healthcare guide is no minor task, it is the hope of the authors of this report to present recommendations to contribute to

and guide future work in this area in years to come.

1.1 Problem Description

The advancement of specialized medicine has left new opportunities within the medical profession for improvement. As healthcare advances and requires more sophisticated medicines and procedures, there are more different types of physicians involved and patients are seeing more specialists. This is beneficial to the extent that it allows them to get accurate information on very specific subfields of medicine. However, there are two major issues with specialized medicine that are discussed within this report. Firstly, patients who are simultaneously under the care of a variety of specialists require a high level of communication between physicians. Secondly, when patients are moving between a multitude of different specialists with no single party responsible for their overall care, some overall responsibility for the patient may be lost.

1.1.1 Communication

Communication between physicians can be absolutely critical for the treatment of their patients. The intended outcome of a variety of different medications, procedures, and other treatments can depend upon other treatments the patient is presently undergoing and how they reacted to previous treatments. Presently, doctors can only view this information via the meeting notes for each of the different visits on the e-health system. However, this system lacks a section with information that could be critical to other doctors treating the patient. Some improvement to the communication could improve the system as it increases the amount of information shared and by reducing the amount of time overhead in communicating between different doctors.

1.1.2 Accountability

Accountability can be a very complicated and controversial issue in the healthcare system. There are three main facets of accountability:

- The party responsible for the different health outcomes
- The domains of that accountability
- The procedures by which that accountability is upheld

Different accountability structures can radically shift the efficiency, effectiveness, and success rates within the healthcare system and can shift the entire structure of the healthcare system[1]. One of the primary concerns raised about specialized medicine is that as a patient is passed between different doctors, there is no party accountable for the overall care of the patient. Each healthcare professional is responsible for specific tasks, but no one is responsible for the overall care of the patient and something valuable may be lost. [2, 3]

2 Methodology

The project was received from Uppsala County Council with the focus of investigating if the overall responsibility for a patient's medical situation can be

improved. For a deeper understanding of what problems exist in this area today, see section 1.1.

When investigating this, seven main areas to consider were pointed out by the county council. Four of these aspects were considered throughout the project when exploring improvements and suggesting solutions, these were:

- Efficiency
- Security
- Privacy
- Ethics

Besides these four aspects, three other questions were also pointed out as important to consider in order for a solution to actually be possible:

- Acceptance by healthcare professionals
- Missing information for patients or physicians
- Funding

In order to find one or several possible solutions to this problem, interviews were conducted, demonstrations were attended, surveys were sent out and a lot of information related to healthcare and similar work has been studied. Throughout all of these processes, the seven areas described above were considered in order to reach a solution that would satisfy the county council and would be possible to implement.

Interviews were conducted with a variety of people related to Swedish healthcare. Physicians, nurses, security experts, technicians, patients, relatives to patients and many others that are in some way related to healthcare in Sweden today. Many of these open-ended interviews performed are referenced throughout the report. The interviews can be viewed with the interviewee's profession and the date of the interview in appendix A. Each interview is referenced with a letter and these letters will be used throughout the report to refer to results and input received from the interviews. To some of these roles, surveys have also been sent out in order to get input from several people in the same situation and to better understand what a larger group of people think about different matters.

A demonstration of the technical systems used within Uppsala County Council was also reviewed. The demonstration showed how the systems work, the connections between different systems and functionalities that exist today. This was done in order to get a better understanding of how technical aspects can help the healthcare guide.

Besides this, a lot of research has been done to get a better understanding of how Swedish healthcare works today and to understand what limitations, problems and options must be considered.

The information received from these different processes has then been summarized and analyzed to suggest solutions to the county council that are believed to be possible and appropriate. How information has been processed and the associated reasons can be seen in section 2.1.

2.1 Formal Methods Used

Throughout the project, *qualitative research* has been conducted by collecting data from a smaller number of focused interviews and questionnaires, doing content analysis and reporting the findings. Qualitative research aims to understand the experiences and attitudes of different interviewees and to answer the questions *how* or *why* rather than *how many* or *how much*[4]. *Qualitative data analysis* was performed on the data collected from the interviews. Words, sentences or paragraphs were highlighted and given labels to find key issues. After reflecting on the results, sections of the report were formed around these key issues. The interviews and data analysis were done collectively by groups of two to four people to get different points of view. Collective discussion in larger groups was also done as a part of the data analysis to compare and derive results.

Interviews performed during the research were *semi-structured*. Semi-structured interviews have a reasonably open framework which allows conversational, two-way communication where information is both given and received[5]. Topics and questions used during interviews were prepared and then discussed freely during the interviews.

2.2 Main Research Areas

When investigating if it would be possible to implement the concept of a healthcare guide, four areas were chosen to focus on. These four parts were considered necessary to research in order to cover the factors that have to be considered when introducing the concept of a healthcare guide. The four different parts were:

- **Healthcare Guide:** The main focus in this part was to find out what person or which role would be best suited to be a healthcare guide. Subareas to consider for this were, for example, what tasks the healthcare guide will perform and what level of education is needed.
- **Prospective Patients:** The important thing in this part was to find which patients would benefit most from having a healthcare guide.
- **Health Information Technology:** This part mainly focused on looking into technical systems and tools that exist today, how these can be used by a healthcare guide and what new technical solutions are possible to develop in order for a healthcare guide to perform a good job.
- **Medical System Integration:** This part of the project mainly focused on finding information about how systems have been accepted in healthcare historically. Also how systems in general can be implemented in a good way to get accepted and how these two factors could be used in order to suggest a healthcare guide concept that can be accepted within Swedish healthcare.

3 Healthcare in Sweden

In the Swedish healthcare system, responsibility is shared between the government, county councils and municipalities. Swedish healthcare builds upon a

decentralized system with many independent counties and municipalities each being responsible for prioritizing their region's healthcare. [6] Figure 1 illustrates these levels and shows where different instances are located in the structure.

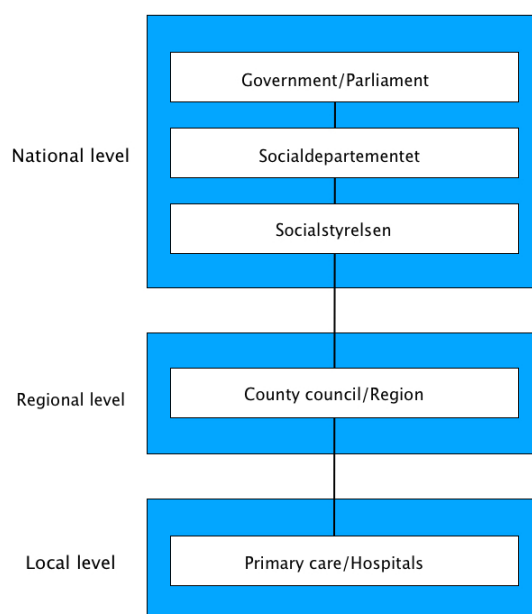


Figure 1: The three levels that defines healthcare in Sweden: national, regional and local. [7]

In Sweden there are seven regional hospitals, approximately 70 county hospitals and over 1000 healthcare centers. Together these create and represent three different kinds of care: *regional healthcare*, *county healthcare* and *primary care*. More complicated cases are addressed on the regional healthcare level, which includes rare injuries and diseases. This care is practiced throughout those regional hospitals in Sweden which have more specialized care and knowledge than other health facilities. [8] County healthcare includes the county hospitals that are spread throughout the country. Primary care is practiced at the healthcare facilities that are not on a regional or county level, it is the instance in Sweden that provides first step care for patients before going to more specialized hospitals. [9] Separated from these three levels, private healthcare facilities do also exist in Sweden.

On the national level, the government is responsible for the political aspects regarding healthcare, including state rules and guidelines for counties and municipalities to follow[6]. Together with *Socialstyrelsen* and *Socialdepartementet*, the government supervises the care in Sweden. On a regional level, the county councils are responsible for organizing healthcare within each county with the goal of ensuring that all citizens receive adequate care. Municipalities are then responsible for caring for the elderly and people who have been discharged from

hospitals. The local level is responsible for the primary care in Sweden. [10]

The Swedish healthcare system is dynamic and consists of an extensive network of interconnected parties. New organizations and operators enter the healthcare system often, leading to constant restructuring of healthcare organizations. Due to the constantly changing nature of the system and the regional differences, it is challenging to give a general overview of the healthcare system. However, these three levels of the healthcare are the foundation around which the healthcare system is structured. The research presented in this paper is mainly focused on a local level of the healthcare structure in Uppsala county. Therefore, many of the interviewees and stakeholders have ties to Uppsala.

4 Communication within the Healthcare System

It can be concluded from interview C with the director of a department at a healthcare center, the patient in interview D, the physicians in interview E, F and G and the head of the Patient Committee in interview J that communication plays a central role in the healthcare system. In interview C, the importance of good communication was emphasized. In the interview it was explained that information flow can be slow and that information loss increases proportionally to the number of people involved in a communication chain. Considering the effects, communication is critical and a vital tool in today's society, particularly within the healthcare system. Communication can have different meanings depending on the situation and the context where it is used. The following section refers to communication as the flow of information between different healthcare facilities, healthcare professionals and patients.

4.1 Communication between Healthcare Professionals and Patients

According to the *Agency for Healthcare Research and Quality* in the United States, one of the most important things for healthcare professionals to ensure is that patients fully understand information regarding their treatment and associated risks[11]. If a patient is not informed or if given information is misinterpreted, the patient can be at risk of being mistreated or not treated at all. Lack of communication between healthcare professionals, patients and departments exposes patients to unnecessary risk. Therefore, it is very important that communication within the healthcare system works well[11]. The patient from interview D experienced a scenario where communication between different departments failed to work properly, resulting in the patient being shuffled back and forth between departments.

Some of the most common reasons for lack of communication are[12]:

- Unclear work roles
- Lack of interaction between professionals and departments
- Reporting and handling of deviations
- Different documentation systems between different care providers

- Too many links in the healthcare communication chain

The Joint Commission for healthcare organizations in the United States performed studies showing that one of the most common causes for injuries caused by healthcare was a lack of communication[11]. Similar studies made by Socialstyrelsen in Sweden estimate that approximately 100 000 medical injuries occur annually in Swedish healthcare[12]. Of these medical injuries approximately 3000 lead to death and result in 630 000 extra care days. These medical injuries cost about 5.7 billion Swedish crowns yearly[13, pp. 38-39].

4.2 Communication between Healthcare Professionals and Departments

Communication problems between healthcare professionals escalated with the use of electronic medical records. In interview F a physician revealed that although much is written in the medical records, not nearly as much is read. The person sending information has a focus on recording a large amount of detail in order to appear competent. However, this lowers the consideration for the needs of the receiver. Often there is not enough time for the healthcare professionals to familiarize themselves with all of the information recorded in medical records. Furthermore, the medical records can often be interpreted differently between various healthcare personnel utilizing them. In extreme cases, this can lead to confusion and even incorrect treatments.

As derived from interview E, with a physician and director of a department, there are currently many problems with communication in the healthcare system. Problems can occur when healthcare centers use different systems to exchange information. Stated by a director of department in interview C, copies of medical records may be faxed and even, in worst case scenario, sent by letter. Due to the fact that all healthcare facilities do not use the same system, problems like the ones described above can occur.

4.3 Communication Improvements

According to the *Swedish nurse organization*, many of the communication problems can be avoided by working systematically and having routines for how to communicate[12]. A potential improvement to aid communication can be to utilize a communication model such as *SBAR*. The model was developed by the Joint Commission in the United States to improve communication between different departments. The model is also recommended by Socialstyrelsen in Sweden and is partly used at *Akademiska sjukhuset*[14]. The model is a four step process that intends to clarify how information should be structured, handled and delivered according to the following four steps[15]:

- Situation
- Background
- Assessment
- Recommendation

At Akademiska sjukhuset in Uppsala, standardized methods and checklists are used to support communication and make patient care as safe as possible. Within every surgical ward, special checklists provided by the *World Health Organization* are used. This, to be sure that nothing is missed and that everything seems correct. Akademiska sjukhuset trains their personnel continuously in communication to improve the safety of their patients[14].

According to Socialstyrelsen, online medical records provide smooth, quick and effective transfer of information. It is very important that the system is user-friendly and easy to understand, otherwise problems can occur[11]. From interviews C, E and F with healthcare professionals, it can be derived that more standardized medical records would be appreciated. This is explored in more depth in section 10.3 with suggestions for improvement. For example, check boxes and yes or no questions would speed up the process of filling out the medical records and make them easier to understand.

5 Current Situation in Uppsala

Today, patients can have many different healthcare providers. There are healthcare centers, emergency wards, private and public providers where different personnel such as physicians and nurses can work. If a patient is receiving treatment from more than one provider, this can result in many different medical records. Due to this, information gaps within a patient's medical history can occur. [16]

Uppsala County Council has different systems that are present to help with handling the online medical records from various healthcare providers. The systems are COSMIC, see section 5.1, Mina Vårdkontakter, see section 5.2 and Nationell Patientöversikt, see section 5.3. HSA Nationell Katalogtjänst and SITHS are explained in section 5.4 and an overview of the systems are given in section 5.5.

5.1 Cambio COSMIC

Cambial COSMIC, short *COSMIC*, is a system that provides an overview of a patient's medical history, ongoing treatments, medications, lab and radiology results. The system also provides warnings if the healthcare staff attempts to prescribe a medicine that the patient already received or if some medicines that are taken together produce unwanted side effects. [17]

The COSMIC system is used by almost every healthcare provider in Uppsala County[18]. When the healthcare staff make new entries into a patient's medical record, the information is stored in the system's database[16]. If healthcare providers belong to the Uppsala County Council, it is possible to access the medical records within COSMIC[17].

In COSMIC, healthcare personnel can send consultation referrals to other hospitals or hospital wards and communicate with other healthcare providers about a patient[16]. The information about a patient that is displayed in COSMIC depends on the user's professional role and ward, but if an active choice is made all information can be accessed in the system[17].

COSMIC is a complex system in which it is possible to add different modules to achieve different kinds of functionality[19]. Per Foyer, a security consultant within information technology employed at Uppsala County Council, said in an

interview that COSMIC is the base for keeping information regarding patients in Uppsala. The version used in Uppsala County Council has many functionalities and includes a lot of data regarding the county's patients. [20]

5.2 Mina Vårdkontakter, MVK

Mina Vårdkontakter, MVK, is the regional service for digital contact between patients and healthcare providers where it is possible for patients to view medical records online and to communicate with healthcare personnel[21]. MVK retrieves data in the medical records from the COSMIC system, described in section 5.1 and other similar systems used by healthcare providers in Uppsala County Council which are connected to MVK[20].

MVK is a framework to which new functionalities can be added. Today, patients can use the system to view medical records online, choose a healthcare center to be listed at or belong to, book an appointment at a healthcare center and request renewal of medicine prescriptions. [20]

The security is important in the system since all of the information that is sent within MVK is addressed as medical records. This means that the information must be protected according to the different laws regulating how electronic medical records are to be handled, these laws can be seen in section 8.4. To ensure that all data is secure the data is encrypted and stored in the system's databases. No data can be stored on a personal computer that is used when communicating with MVK. [22]

Since all data must be secure, it is not allowed to send information by email. When a patient signs in to MVK and requests a new appointment booking or prescription renewal, the requests are not sent to the physician it concerns directly by email. Instead, a nurse from the correct department has to log in to MVK and forward the patient's request to the physician fit to handle it, so that the requests remain within the system. [20]

In order to use the mentioned features in MVK, users must be identified. To log in to the system, the user needs to use an electronic id or a personal code. MVK will then use the patient's national identification number as the user's identification. This means that every time a user registers or logs in to MVK, the user identity will be checked against *the personal data registry* (in Swedish personuppgiftregistret). Healthcare professionals must exist in the county council's electronic catalog which contains information about all healthcare providers and their employees to be able to use MVK. [20]

5.3 Nationell Patientöversikt, NPÖ

Nationell Patientöversikt, NPÖ, is a part of the Swedish national IT strategy for health and social care[23]. NPÖ is used by a few county councils and municipalities in Sweden at this point[20].

If a patient consents to it, NPÖ makes it possible for qualified healthcare staff to look in medical records about the patient located at other county councils, municipalities or private healthcare providers[24]. The benefit of using NPÖ is improved quality of care, since the physicians can get an overview of the patient's medical status. It becomes less costly and time consuming because duplicate work can be avoided. NPÖ also provides better planning and coordination between healthcare providers. [24]

In NPÖ the user needs to confirm an established healthcare relation with the patient and has the patient's consent in order to view his or her medical records. In an emergency where the patient is not able to consent and the physician believes that information from medical records in NPÖ is necessary for the treatment, the physician can view the medical record without the patient's consent. [25]

The information that NPÖ provides is a list of all visits of a patient to healthcare centers and hospitals together with information about in which county council the visit took place, which physician is responsible for the visit and contact information of that physician and healthcare center. NPÖ also provides information about medicine prescriptions and medicines that have been collected at a pharmacy by the patient. [25]

5.4 HSA Nationell Katalogtjänst and SITHS

HSA Nationell Katalogtjänst is a quality assured organization catalog which contains information about people, units and functions within healthcare in Sweden. The main purpose of HSA is to provide an easy and efficient search of information regarding healthcare. The stored data in HSA are used to verify information, e.g. personal information, and to define eligibility for users of external systems. In the catalog it is possible to search efficiently among the information, and handling address information can be done within the local organization, regionally or nationally. [26]

One of the national services that uses HSA is *SITHS*. SITHS is a national security infrastructure which makes it possible to provide secure electronic identification[26]. SITHS and HSA is used by Uppsala County Council to identify users of COSMIC[20]. NPÖ and Mina Vårdkontakter also use SITHS and HSA for identification of healthcare personnel[26].

5.5 Overview of the Systems

COSMIC is connected to both MVK and NPÖ. COSMIC is the main system used by healthcare staff to register information in patients' medical records. This information is then stored in COSMIC's own databases. In other counties there are systems similar to COSMIC, or in some counties COSMIC but with a different configuration, with the same purpose. [20]

NPÖ gives an overview of all data about a patient that are stored in COSMIC and in other similar systems connected to NPÖ but it does not store any data itself. MVK works in a similar way; it displays information about a patient's medical record but the data is still stored in COSMIC. MVK is used by both healthcare staff and patients for communication with each other. Figure 2 displays an overview of how the systems are connected to each other.

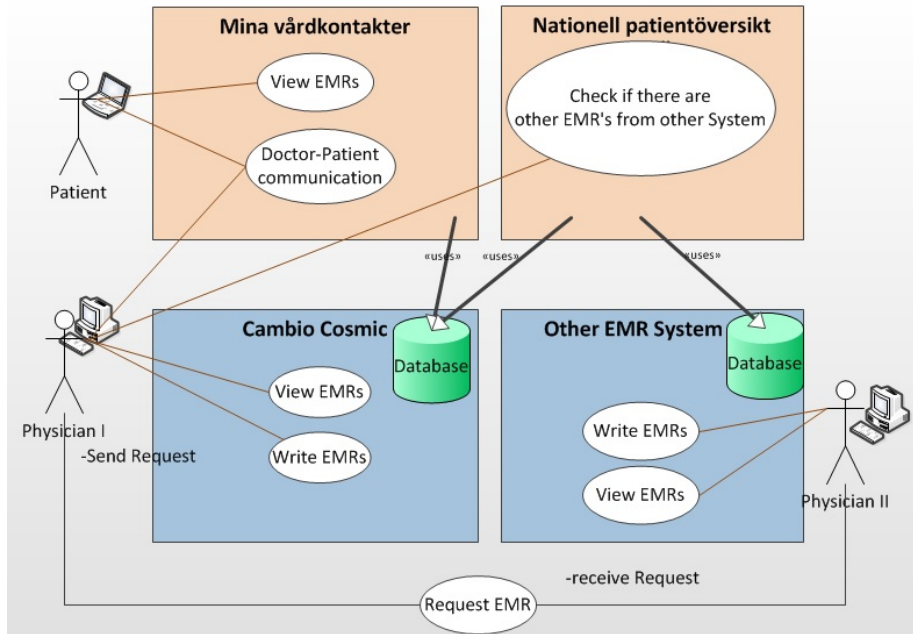


Figure 2: An overview of how the different systems are connected.

6 The Healthcare Guide Concept

Information synthesized from research revealed the opportunity for a *health-care guide* in order to overcome some of the previously discussed issues, such as inadequate communication and insufficient overview of a patients case. The healthcare guide could be one or a combination of healthcare personnel, information technology and other means of information sharing. A healthcare guide combines a number of qualities to provide a better standard of care for patients. These qualities include being knowledgeable, informative and communicative, while maintaining continuity, trustworthiness and empathy. The guide would also aid in improving the communication breakdown between departments, as well as developing transparency for patients. In the following section the qualities required for the healthcare guide are presented.

6.1 Qualities of a Healthcare Guide

The healthcare guide requires many different qualities for the concept to work, as deduced from interviews with patients and medical professionals. A description of how these interviews were conducted and synthesized can be found in section 2.1 and a table of every interview can be found in appendix A. The key qualities found are as follows:

- *Knowledgeable.* According to interviews C, D, E and F, being responsible for a patient's care would require both medical knowledge and an understanding of the medical profession. Performing the tasks required by the

healthcare guide concept requires looking over the patient's medical information. Therefore, the healthcare guide needs to have good insight to the inner workings of the healthcare system in order to help the patient effectively.

- *Informative.* Patients want to be well informed and know about their treatment and conditions, as seen from interviews D and K. The healthcare guide should support the patients' desire to be informed. Patients should be able to be prepared before and after hospital visits. This would help them take in all the necessary information and to know what to do when they return home. For patients with a longer treatment process, it can be good to receive a plan of what is to come, as mentioned in interview D. Being well prepared can be of great help, according to interview D and J, as patients can be often be in shock when receiving information. Interview J expressed that communicating with patients successfully can be aided through the use of written information to support any verbal communication. Interviewee E also expressed that to keep a patient well informed, it can be useful for the healthcare guide to look at the medical records together with the patient. The result would be well informed patients who, in turn, could facilitate the hospitals by ensuring treatments are handled effectively.
- *Communicative.* The healthcare guide needs to maintain good communication with both patients and healthcare personnel. For the healthcare guide to keep up good communication and share knowledge with other healthcare personnel, interview E expressed it can be useful to discuss treatments in a group. Interviews D, J and K mentioned that patients will continually have questions and concerns about their care. Therefore, there needs to be a means for the healthcare guide to be reachable and communicable with patients.
- *Continuous.* In the current healthcare system there can be a lack of continuity. This is backed up by interview A and D which state that patients are often treated by different personnel each time[27]. The concept of the healthcare guide will help the patient throughout the treatment process. One way to build up trust with the patient is avoid having the guide constantly changing throughout the treatment process. Maintaining continuity with the same healthcare guide all through the treatment will make it easier for both the guide and the patient to work together. It can also be beneficial if the healthcare guide follows up on a patient's case to keep up the continuity and relationship, as stated in interview J.
- *Trustworthy.* Interview J revealed that healthcare personnel and patients should be able to trust the healthcare guide. Having access to a patient's medical records gives the healthcare guide a very powerful position and makes it crucial that the healthcare guide does not misuse the information in any way. To ensure trust with both healthcare personnel and the patient, the healthcare guide should act as a neutral intermediary, without biased towards either party.
- *Empathic.* Currently patients may feel there is lack of empathy not only between patients and healthcare personnel, but in the healthcare system

as a whole. In interview D it was expressed that patients can feel less like humans and more like spare parts being fixed. This is supported by interviewee K, who thinks there can be a sense of being in a production line, being sent to different stations. The key is to value the patient and make them feel like people. The quality of continuity can help improve this problem as it can help build better relationships between patients and healthcare personnel. All of the above qualities are important for the healthcare guide concept. However, empathy is particularly crucial to ensure the healthcare guide can fulfill the important task of committing to and understanding the patient's situation.

6.2 Prospective Patients

The healthcare guide will increase the continuity and reliability of patient care, but much the same as other professionals their time will be both valuable and limited. Furthermore, not all patients will desire or require the assistance of a healthcare guide. In order to maintain the effectiveness and efficiency of medical treatment, a process for the assignment of healthcare guides must be established. To create the most fiscally responsible process while maintaining effectiveness when a healthcare guide should be utilized will be examined. The first factor to this is how often would a healthcare guide actually have had an effect on the patient's treatment. This can be identified by understanding the most common factors of medical malpractice. Medical malpractice will decide when a healthcare guide would be the most likely to prevent an act of medical malpractice.

The second major factor to be considered is the desires of both the patients and the physicians that a healthcare guide would be interacting with during the course of their duties. If a patient desires a healthcare guide even for a minor case, it is possible that this patient should be given access.

6.2.1 Medical Malpractice

Accidental medical malpractice is the incorrect treatment of a patient by a healthcare professional. Misdiagnosis, medication error, anesthesia error, and surgical preparation error are some of the more common examples of malpractice. [28] Besides malpractice there are also cases in which no error is made as part of the medical treatment but a miscommunication between physician and patient leads to undesired results. A healthcare guide could reduce the occurrence rate of both accidental malpractice and patient-physician miscommunication, as both areas must be understood to ensure a healthcare guide's effective implementation. Medical malpractice manifests in a multitude of forms. Implementing a system that is able to respond to each unique form, while maintaining cost effectiveness, is improbable. In order to make the system as effective as possible it is realistic to focus on using it to combat the most common causes of malpractice.

Examining malpractice cases and statistics identifies two main areas in a case that could determine the necessity of a healthcare guide: *the time a physician has with each patient* and *communication between physicians and patients* [29].

Time: A major factor in malpractice is time. How long the physician has available to spend with the patient directly correlates to the level of treatment a patient receives. [30] Insufficient time due to increased workload threatens the quality of care the physicians are able to give the patients. [31] Which in turn can lead to mistakes that are not in any way an accurate representation of said physician's skill. If a physician is unable to spend the minimum amount of time needed with each patient there is an increased possibility that smaller details will be missed. This can for example be what drugs the patient is currently taking and how exactly these might interact with one another, an area which would benefit from improvement since prescription error is one of the most common cases for a medical malpractice lawsuit. [32, 33]

Communication: Communication errors also result in problems for the treatment of patients. Communication errors between the patient and physician can cause misdiagnosis or mistreatment to occur. This can for example happen if a patient does not provide the physician with an adequate amount of information or if communication errors occur between medical staff. In any case of miscommunication, the patient is at risk of improper treatment.

One case of communication error, in which a healthcare guide could have been used, is mentioned in a study. In this particular case, an elderly patient is diagnosed with breast cancer. The patient discusses with a physician to determine that the best method of treatment would be to opt for surgery. The patient then undergoes a successful surgery to remove the cancer. However, after the surgery the patient learns more about various treatment methods from other cancer survivors and then decides that surgery was not the best option. Due to the success of other patients who chose to use hormone therapy instead of surgical removal, this patient feels that the decision was not the best one. The patient in this case then became depressed, and regretted the method of treatment chosen. [28]

While the treatment was successful, the communication errors resulted in a decline in the patient's mental health. Had the patient fully understood or been introduced to the other methods of treatment, then the mental health of the patient after the treatment would have been improved. If the patient had been fully informed about all of the treatment options available, avoiding the depression might have been possible. When a patient has a wide variety of treatment options available, as in this case, a healthcare guide could have been able to help the patient choose the best treatment for both physical and mental health.

In another case, problems again occur due to communication errors. In one particular case, a patient is properly diagnosed with breast cancer. The treatment determined by the physician and patient in this situation was chemotherapy. Due to a misinterpretation of the prescription given to the patient, the patient took four times the daily dose at one time, overdosing and dying as a result. If the patient had properly understood the prescription then the proper amount could have been taken and death could have been avoided. [34]

When errors occurs due to miscommunication, some of these errors could be avoided in the future through the use of a healthcare guide. In this case, if there would have been a healthcare guide, the patient could have been guided through the treatment process. By also including the patients opinions, the

misunderstanding could have been avoided. It can be seen from both cases that while a physician's opinion is important, the opinion of the patient is also important.

6.2.2 Healthcare Specialists' and Patients' Opinions

Healthcare specialists and patients are the direct beneficiaries of the healthcare guide. The specialists also possess direct and repeated experiences with cases in which the healthcare guide would be most effective.

Healthcare Specialists' Opinions: Healthcare specialists identified a number of areas where a healthcare guide would be beneficial. Based on a specialist's opinion in interview O, all complicated cases need more attention. The specialist then proceeded to identify a number of factors that would suggest a complicated case: multiple diseases, concurrent treatments, chronic illness, rare diseases, field of medicine regarding the treatment, illness that impedes communication, patient age and patient support structure.

Patients being treated for multiple diseases would greatly benefit from a healthcare guide. In interview Q a nurse suggested that the healthcare guide should be provided to patients with multiple illnesses because it would allow physicians and nurses to easily identify conflicts between treatments. The difficulty of managing multiple medications, and the aggravation of one condition due to symptoms or treatment of another, could be mitigated by a healthcare guide. In addition, multiple diseases also suggests that there will be multiple transfers from one specialist to another leading to gaps in communication. In interview T it was also stated that a healthcare guide could possibly alleviate communication issues in many of these cases.

A second factor that needs to be considered is chronic illness. Chronic diseases are the main concern of health care systems throughout the world[35]. Based on the opinion of one of the surgeons from interview N, patients that are in need of more attention are those with chronic diseases such as diabetes, cancer or schizophrenia. The necessity of improvement in the healthcare system based on chronic diseases is undisputed. Care models have been developed at the end of the 20th century to improve chronic care. One commonly used model is the Chronic Care Model, short *CCM*, which describes changes to the healthcare system and helps to improve outcomes among patients with chronic illnesses. [35] The results of the above model are promising, but improvements should be made using better tools[36].

The rarity of the disease is a factor designated by physicians. Primary care physicians might not have experience in appropriately managing the case, as the physicians do not see such conditions frequently. An appropriate specialist care is undoubtedly important as the case becomes less routine. [37]

Another aspect is the field of medicine. In interviews L, M, P and Q it was noticed that two fields of medicine, oncology and psychology, seem to need more attention than others based on the specialists' opinion. Several interviewees mentioned that cancer needs extra attention, compared to other diseases. This due to the fact that the diagnosis may be complicated and the localization of the specific part of the body that cause the problem might be difficult. Also, the complexity of the disease causes the physicians to be extremely careful with the patients in order to avoid misdiagnosis. In addition to oncology, the member

of the nurse association from interview Q mentioned that one of the cases that would benefit from the use a healthcare guide might be when someone has a psychiatric problem. In interview M, a physician within this field pointed out that “patients having psychiatric problems may not remember, feel confused or cannot help so as to give details about the patient’s health history.”

Cognitive deficiency could also add to the effectiveness of a healthcare guide. Cognitive deficiency, which is also called intellectual disability, refers to a cognitive impairment which limits people from learning and functioning[38]. The member from the nurse association in interview Q mentioned as an example a person who has *dementia*¹ and the effects of it. The interviewee emphasized the necessity of a healthcare guide aiding people in this situation. Impacts of dementia are that a person is not able to do different activities on their own and they need additional help. Dementia affects mostly elderly people and is caused by a variety of medical conditions. This adds to the complexity of the case and also introduces age as a factor to consider. [39]

Age also adds to the complexity of the case. If the patient is a child the medical history will be shorter than that of an elderly patient. The longer the medical history the more time is required to adequately review it, as mentioned in interview M. Elderly people are more likely to suffer from multiple health problems and may have larger and more complicated health histories.

A final factor is relations around the patient. This refers to family members or other relations that the patient may have. It is important for the patient to have someone to ask for help. The orthopedist in interview P mentioned that before a patient undergoes surgery, the patient is asked about family members or other relationships. If there are no relatives, then depending on the patient’s case, the patient will have to make some changes to their everyday life. Moreover, in interviews L and M it was mentioned that in cases where the patient has family members, it is still uncertain how the family will react to the patient’s situation and if they will support the patient or not. In the cases that the patient is alone, without family members or if patient’s family is not willing to support the patient, a healthcare guide can be a solution.

Patients’ Opinions: Input from patients show that there is a large spectrum covered by the patients’ beliefs regarding the utilization of the healthcare guide. Nevertheless, patients’ opinions seem to have one common factor. All of them focus on the need of a healthcare guide as a service which will improve the communication and the connections within the healthcare system.

Two of the patients believe that a healthcare guide could be a way for patients to communicate their problems to a higher level within the healthcare system. The patient’s opinion in interview S is that a healthcare guide is needed when “the patients are unable to speak for themselves in the face of healthcare.” The same opinion is shared with the patient in interview V who believes that a healthcare guide could give patients the chance to express their voice.

Another patient’s opinion in interview W is that a healthcare guide could act as a middleman between the patient and the physician. The healthcare guide

¹Dementia refers to an impairment that is related to a deterioration or a possible loss of reasoning, memory and various other abilities such as thinking, judging, language and behavior.

could be the first to be contacted before an appointment with the physician and may provide all the information needed for the examination of the patient.

The need of a healthcare guide which examines the different conditions of the patient's health and the patient's history is proposed in interview U. The patient went through multiple illnesses in the last few years. Under these circumstances, the patient felt the need for someone to examine in depth the symptoms and exclude the possibility of a more serious disease causing the others.

7 Related Work

In order to suggest possible improvements and to find solutions that can be helpful for a healthcare guide, systems that are used in other county councils and other countries have been studied to get ideas about possible solutions that already exist.

7.1 Other County Councils

Systems used in other county councils have been studied in order to get ideas about possible solutions. In this section a few systems will be explained.

7.1.1 Patientansvarig Läkare, PAL

One of the early attempts to solve the lack of medical continuity for patients in Sweden was the introduction of a *Patientansvarig Läkare*, short *PAL*, or patient responsible physician. The concept became statutory in 1991 during a reform of the Healthcare Act (Hälsa och sjukvårdslagen - HSL) which intended to overcome a perceived lack of responsibility for patients' overall care[40]. The act described the PAL as a physician assigned to each patient who would be ultimately responsible for a patient's diagnosis, treatment and care, while ensuring the patient was kept fully informed. The PAL should have aided a higher level of medical continuity and coordination, while also improving the patient's ability to understand and influence their own healthcare.

The PAL implementation did not have the intended effect and was largely unsuccessful. It seemed the PAL was generally not assigned as intended and in 2010 the requirement for a patient responsible physician was removed from legislation[41]. The source of this failure has been attributed to a number of factors[42]. One suggestion was that PAL was based on a concept of individual responsibility, while the Swedish culture promotes a workplace which encourages collective decision making. Furthermore the PAL legislation did not account for the variation in patient illness severity, where a patient with a minor illness may have no requirement, or even expectation, of having a PAL assigned to them. The law also ignored the diverse requirements of varying departments. For example, the emergency department is unlikely to support patient contingency, due to its short patient turnover. In comparison, other departments where a patient-physician relationship is more critical, patient contingency has far greater influence. These reasons may explain the root of unsuccessfulness of the PAL concept, but its removal continues to promote an absence of responsibility for a patient's overall care[41].

7.1.2 Contact Nurse

A more recent example of single contact being assigned to patients can be seen in the emergence of the *Contact Nurse*, Kontaktsjuksköterska, within Swedish cancer care. Due to the growing complexity of many cancer patients' cases, the Contact Nurse concept was established to focus on improving the continuity and safety of patients overall care[43]. It is also targeted to impact positively on a cancer patient's relatives, whose participation opportunities are greatly strengthened from the concept's focus on communication. The nurse's role has been defined to be a solid contact for a patient to provide them with information and support, while also mediating communication with other professionals within the healthcare system[44]. Together with the patient, the nurse is also responsible for investigating and creating a plan for their care. The introduction of the Contact Nurse concept provides a patient with a clearly named contact and a physical outline of their treatment plan, improving both support and involvement in a patient's own care.

The scheme has been received positively in the health centers where it has been implemented with one patient explaining her contact nurse "helped her survive"[45]. Despite this confident result, it is estimated only 60-70% of patients are currently offered a named Contact Nurse, well below the goal of one nurse for every patient[46]. This was also supported in interview D, with a cancer patient who also expressed that not many patients seemed to get a Contact Nurse and instead fall under the responsibility of a part-time oncologist position who handles about 350 patients each year.

This shortage of Contact Nurses is likely to improve as efforts grow towards advancing training and developing education options. Examples of this include the new higher education course offered by Linköping University, which provide nurses with the opportunity to learn the necessary skills for the Contact Nurse position[47]. Socialstyrelsen also continues to evaluate and improve the scheme, with on-going surveys likely to provide insights into patient experiences[48]. In reality, the scheme is still very much in its infancy and its progress will be able to be fully evaluated over the coming years.

7.1.3 Vårdlots

A *vårdlots*, care pilot, is someone who guides a patient in the right direction in order for the patient to get the best possible care. It can be a specially trained nurse or someone with medical training[49, 50]. A care pilot can, for example, answer a patient's questions or inform a patient about suitable healthcare professionals to contact[49]. Care pilots are now used in some county councils in Sweden. Stockholm, for example, has been using them since 2011[50].

Vårdlots in Uppsala County Council: According to a project manager in interview H, vårdlotsar were also implemented in Uppsala County Council in 2013. One of the goals was to reduce the costs for the patients and the total number of *patient days* at hospitals. Patient day is a unit that is used by healthcare facilities and healthcare planners to see how many patients visit hospital each day. Another goal was to increase the security for the patient by improving and coordination communication between the different county councils and their healthcare providers[51]. When vårdlotsar were introduced,

the main focus was placed on *patients who visit hospitals often* and *patients with heart failure problems*. In 2016, patients who have suffered from *COPD, stroke* and *atrial fibrillation* will also receive the services provided by vårdlotsar. [52]

There are three different aspects to take into consideration when discussing vårdlotsar. The first thing to do is to identify *patients that would benefit from having a vårdlots*. The patients that have been identified to need the service most are those who receive a lot of care from the healthcare sector, who visit or talk to a lot of different healthcare personnel and patients who have very complex medical situations. These three different types are identified by using statistical models that are based on calculated risk for a patient to end up in a hospital. The patients that are calculated to have a high and preventable risk are offered the services of a vårdlots. [51]

The second aspect considered is *intervention*. The patients who were chosen in the process described above receive temporary and personalized support from a vårdlots. From the vårdlots, these patients will receive a personal plan for their medical treatment. The people who are working as vårdlotsar are experienced nurses who have also received special training to perform the task. [52]

The last aspect to take into consideration is *monitoring*. This means that a vårdlots has to continuously monitor the patient's situation to ensure an efficient and correct treatment. [51]

The results so far has been that the total number of patient days has decreased, which was one of the goals[52]. Although, a problem that has occurred is that some of the patients have stopped using their vårdlots and a guessed reason is that some of the patients chosen to receive the service were actually not the correct ones[53]. In the beginning approximately 300-400 patients per year received the services offered by vårdlotsar, but with the increased number of medical groups that is planned to happen, the number is expected to become 1700 per year[52].

7.2 Other Countries

In order to suggest a solution that can work in Uppsala County Council existing solutions in other countries have been studied. How other countries are handling the same problem investigated in this project is very relevant in order to see how inspiration from these existing solutions can be applied in Sweden.

7.2.1 Study in Austria

A system similar to COSMIC was introduced in Austria in 2007 although its rollout was ultimately a failure. While physicians had many issues with the new system, four of the largest issues were[54]:

- Lack of complete information about the system
- Doubts about the security of the system
- Misgivings about increased workload
- A feeling that physicians were not consulted about the changes

The physicians interviewed did not know enough about the upcoming system. They were mistrustful of government information sources, preferring instead

information from their own professional networks and medical records. It is clear that any new system will need to consult these professional organizations and involve them as much as possible so that all information can be passed to their members. [54]

Physicians were also mistrustful of the system's security and ability to lock out unauthorized parties. There was little faith that the system would be well-made enough to adequately protect the crucial data. The physicians also found it difficult to believe that it would be able to keep unauthorized users out of a person's records. External security audits of the system could potentially be used to ease these fears, especially if high profile security experts were employed. [54]

Even ignoring the security, many physicians felt that the increased workload was not worth the marginal benefit. Some do not even believe the system is beneficial at all. This is a tough issue to crack, and can only truly be solved by increasing the efficiency of the system and increasing the overall understanding of its benefits. Finding ways to reduce the workload while maintaining high quality information is critical. Otherwise, some physicians may just ignore the system entirely. [54]

Many of the physicians interviewed felt that the above issues could have been somewhat alleviated if they had input into the system design. Instead, the physicians felt that the system was developed without their input and was being forced upon them by people who did not have any real experience in the medical field. It was previously suggested that those looking to roll out an electronic record system should involve physician organizations and this only re-enforces that claim. Physicians need to be involved well before the system is released so that they can have their voices heard and so that particularly bad issues can be resolved. [54]

Though the Austrian system only covered what COSMIC covers and not the other aspects of the proposed healthcare guide concept, the lessons learned still apply. Physicians need to be involved, and need to be informed by more than just government agencies. Nothing is quite as scary as the unknown, so eliminating as much confusion as possible will allow the introduce the healthcare guide with minimal friction.

7.2.2 United States Case Managers

A concept similar to the healthcare guide are *United States Case Managers*, which are very common in the US. Case managers are specially trained nurses that have been certified to manage the long-term care plans for patients. At a minimum, case managers must have an *Associate of Science in Nursing*, a two to three year degree which allows one to register as a nurse. [55] They are typically assigned by a patient's *Health Maintenance Organization*, short *HMO*, after they are diagnosed with multiple severe health conditions. Case managers work closely with healthcare providers to make sure the patient is not receiving overlapping care, and to ensure the appropriate course of treatment is being administered. Case managers also help patients navigate the rather complex American healthcare system by negotiating cost of treatments with hospitals, as well as locating and suggesting specialists that could help treat the patient. [56]

7.2.3 Healthcare Communication in Canada

In interview F, the physician explained that the solution to our project does not have to be a technical solution. Maybe the problem, of a lack of transparency for the patients and accountability for their doctors, can also be solved by improving the communication between different departments or practices. The main problem is that there is not always adequate communication between different specialists, particularly in complex treatments involving multiple physicians.

The physician from interview F has a lot of experience in a lot of different countries and believed there is a lot to be learned from the healthcare system in Canada. According to the physician, Canada has one of the best systems for communication between different departments and also between the physician and the patient.

For example, there is an organization in Canada, called *The Institute for Healthcare Communication - Canada, IHC-C*. The goal of this national organization is to improve communication skills in healthcare and thus improve the quality of the healthcare. The IHC-C provides different services like courses and workshops. These services are for different kinds of healthcare professionals, including physicians, nurses, and pharmacists. [57]

There is also another organization in Canada that is focused on the patients called *Canadian Patient Safety Institute, CPSI*. The CPSI takes care of the patients safety, and makes the Canadian health system as safe as possible. CPSI is also providing different kind of courses for healthcare professionals and leadership teams or boards of healthcare providers. Next to courses, this organization is also doing research and is providing different tools. [58]

Canada is also making use of Electronic Health Records, short *EHR*. There is a national organization, Canada Health Infoway, that is federally funded and has 14 clients, the 14 provinces of Canada. This organization invests in multiple EHR system projects. In Canada, they distinguish between EHR and Electronic Medical Records, short *EMR*. EMR is mostly referred to a healthcare system that keeps data in a particular hospital or practice. The information of the EMR's is then combined in wider EHR systems. The great thing about Infoway is that it is national, while the healthcare is regulated differently in each province. So the EHR systems are combining data from multiple provinces in Canada. [59]

Canada is renowned for its good healthcare system but is still facing a lot of challenges. If you look at the adoption of the healthcare information technologies, *HIT*, Canada is lagging behind of other countries. [60] The Canadian healthcare system is one of the most expensive ones, but healthcare organizations in Canada are only spending less than 2 percent of their budget on ICT per year. [61] Although it has been shown that HIT will improve the efficiency and effectiveness of the healthcare system, not all Canadians believe in the benefits of HIT. There is proof that good healthcare information technologies should improve the communication, the overall costs, patient safety and disease screening. [60]

7.3 Lessons to Learn

There is much that can be learned from looking at these different concepts in other counties and countries as well as looking at systems that have failed.

There has already been an attempt to give the responsibility of a patient to one physician in the failed PAL project. This project was shut down in 2010 because the culture in Sweden prefers collaboration between physicians above one person doing the decision making. Another cause for the failure of the project was that they did not think about who actually needs a PAL. With the idea of the Contact Nurse, the people behind the project did think about this. Different health centers feel very positive about the concept, so it would be good to educate more nurses to become a Contact Nurse. Additionally, one could even expand this concept by thinking about having a Contact Nurse not only for specific cancer patients, but also other patients who are undergoing long treatments. Similar to the Contact Nurses are the US case workers. They look at the treatments of the patients, suggest different specialists and are therefore a kind of guide for the patients.

The project they tried in Austria failed because the physicians had a lot of issues with the new system. The physicians felt they were excluded from the development of the system and they did not trust this new system. It is very important that physicians are involved in making a new system, because they have to work with it and also have to accept it. What Sweden can learn from Canada is focusing more on the communication skills in healthcare centers. It would be useful if Swedish hospitals and practices would give more attention to communication skills courses. For example, courses that teach the healthcare professionals how they should cope with complex treatments involving multiple doctors, and how those different specialists can communicate and work together in the most suitable way. Another example is to focus more on how the healthcare professionals should communicate with the patients. Sometimes the patients or family members could feel lost if they are seeing a lot of different physicians, and remain unsure of who the responsible physician for the patient is. To prevent this, there should be a physician, or someone else of the healthcare personnel, who should keep the patient updated about everything that is happening and can guide the patient through his or her treatment.

8 Problems and Limitations to Consider

When implementing a healthcare guide, it is important to know about problems and limitations that need to be considered. In this section some problems and limitations are listed.

8.1 General Problems to Consider

When considering possible enhancements for the healthcare system, there are some general limitations that must be taken into account if a healthcare guide is to be implemented.

Law: In order to be able to help the patient, the healthcare guide needs to take the laws into account, these laws can be found in section 8.4. According to the laws, a healthcare guide must have a healthcare relation with the patient and also obtain the patient's consent to be allowed to look in a medical record. This is a limitation that must be considered when suggesting solutions, because

the healthcare guide can not support the patient without having the permission to look in the medical record.

Blocking: A patient may choose to block the entire medical record, or only specific parts of it. If some parts of a medical record are blocked, the information will not be visible in COSMIC or in NPÖ even within the same county. The medical record will remain blocked until the patient chooses to unblock it. The purpose of this blocking is to make sure that information in a medical record is only viewed by healthcare personnel that the patient has approved. However, an emergency opening can be done if a patient for example is unconscious and can not consent to an opening of the blocked part at that moment. It is only possible to do an emergency opening if the physician is working at the same healthcare provider that the block was issued at. An emergency opening is only done if the information is believed to be vital for the treatment of the patient. [17]

In Uppsala County Council, it is common to partly or fully block information for an entire ward at a time. This could be a problem for a healthcare guide because then the blocked information cannot be viewed. [17] The result of this could be that the healthcare guide may not understand the patient's entire situation when some part or the whole medical record is blocked, which is a limitation. Because of this, it is necessary for a patient to give a healthcare guide permission to look at all the information within a medical record.

Economy and Politics: Economy and politics are things to consider when discussing possible solutions regarding a system for the healthcare guide. It is important to have these aspects in mind when suggesting improvements for the current system, because both politics and economy make it hard to develop and use new systems. The path to a decision is often long and slow when it comes to politics. There is a large amount of data and information in today's systems and therefore it is economically impossible to suggest a new system that suits the healthcare guide, even if this solution might be good in theory. A good solution could for example be to have a national system for electronic medical record handling in Sweden, but since each county council can decide what systems to use and have to pay for them as well this is in theory a good solution but not practically feasible.

8.2 Technical Problems in Uppsala County Council

There are a few existing problems in the systems used within Uppsala County Council that can affect the work of a healthcare guide. These problems need to be considered and understood to make sure a healthcare guide can do the best job possible, and to suggest development improvements needed to support the healthcare guide. Below are a few general problems that are detected in the systems used today. These problems are important to consider when suggesting how a healthcare guide can and will work, but are not the ones that solutions will be suggested for.

A healthcare guide will need a system that can provide all information needed about a patient in order to offer the best treatment. Today COSMIC is used by several county councils in Sweden, but each county council's version of the

system uses a separate database to store data. All of the healthcare providers in Uppsala County Council that use COSMIC can access information from each other directly in the system because the same database is used. If a healthcare provider belonging to another county council also uses COSMIC the information stored in Uppsala can not be accessed directly since the databases are separate. The problem with this is that it will never be possible to reach all information regarding a patient, if the patient has been treated in more than one county, by only using COSMIC even if the county councils use the same system. Because of this problem, the healthcare guide can not use COSMIC to get all the information that might be needed regarding a patient.

Another problem detected with COSMIC is the blocking functionality that is provided for patients, read more about this functionality in section 8. A problem that has followed from this is that patients sometimes block an entire medical record for a specific ward, often because the patient in question knows someone who works there and is scared this person will get access to the information otherwise. If a patient is blocking a lot of information within a medical record, it will be harder for the healthcare guide to make sure the right treatment is offered.

Some healthcare personnel have expressed that COSMIC's interface is not optimal to use. Vital functions that are used often are sometimes hidden and hard to find. [17] If this problem was fixed, it would make the use of the system easier and could also decrease errors caused by the human factor since less mistakes might be made.

Problems that will directly affect a healthcare guide have also been found in the systems. A few of these problems are functions that exist today but that do not work in an optimal way, other problems that can affect a healthcare guide are functionalities missing that would help a healthcare guide perform a better job. Below, the functionalities that exist but need to be improved are described.

General Overview in COSMIC: In order to have general information about a patient in one place that it is easily accessible, there is a function that allows physicians to add this information about a patient in COSMIC today. There are no fixed fields for what information should be included in this section so it is possible for physicians to add information that is believed to be general. This has resulted in physicians adding information that is general for a specific ward. The problem with this is that when many physicians at different wards do this, the general information includes a lot of data and the information that was intended to be easy to access and would provide an overview about the patient can not be used easily by everyone. [17]

Some healthcare providers and wards use this functionality now, but in many cases the general information section is not optimal to use. Therefore, physicians and nurses often have to rewrite the information (age, working place etc.) every time a meeting with a patient occurs. This means that this information is now present in several different entries within the medical record instead of only being available in the section with general information. Physicians also continue to rewrite this information during meetings since the data is not easily available.

Sorting by Keywords in COSMIC: A patient that has multiple diseases also has a lot of different entries in a medical record. These entries are arranged

by issue date and ward. If a physician wants to get all information regarding one disease or a specific diagnosis that a patient has, this will take a lot of time and effort since a lot of unrelated entries can be placed in between the relevant ones. In COSMIC there is a feature that helps physicians add certain tags to entries in order to classify them. The fact that it is possible to add new tags and that it is not necessary to use tags are problems that exist today. Due to this, a lot of different tags exist which make it hard to know which tags that are relevant when trying to find specific information within a medical record, and some information might not even be tagged. This means that the tags can not be used in a good way when searching for information. It also happens that physicians classify information differently which also increases the chance of missing information that might be relevant when searching for it. [17]

8.3 Technical Problems and Requested Features Nationally

NPÖ is a system that exists to increase the efficiency and simplicity when handling medical records nationally in Sweden. NPÖ could help a healthcare guide, but in order to be helpful the system would benefit from being further developed.

The interface in NPÖ today is not optimal for good usage, hints that are supposed to guide the user are not implemented in a good way. An example of this is when the mouse pointer changes to a hand, to indicate that the area that the user is hovering over is clickable. Normally this is supposed to happen in order to indicate to the user that this is where it is possible to click. In NPÖ the mouse pointer always has this look which results in it being very difficult to know which areas are clickable and which are not. [17]

Besides the interface problems present in NPÖ there are other features that are not optimal today. During a symposium for the DOME project held at Uppsala University 2014-10-17, different questions about NPÖ and requests that were sought for came up from personnel related to healthcare in Sweden. One thing that was pointed out was that functionality that is present in NPÖ today is not really used. Whether this depends on people being unaware of the functionality, if old ways of working are still present or if the functions are difficult to use is hard to say. A fact though is that it still happens that healthcare personnel requests medical records via fax or telephone instead of retrieving them directly from NPÖ.

8.4 Legal Aspects

When it comes to legal aspects related to medical record handling, a lot of different laws are applicable in different situations and depending on who the care giver is. Care givers at the county councils are obliged to follow many laws when handling personal information regarding patients and medical records[62]. These laws together are present to make sure that a patient's privacy is always protected. The laws are:

- The Healthcare Act (Hälsa- och sjukvårdslagen)
- The Patient Data Act (Patientdatalagen)
- The Privacy Act (Personuppgiftslagen)

- The Publicity and Confidentiality Act² (Offentlighets- och sekretesslagen)
- The Patient Safety Act³ (Patientsäkerhetslagen)
- The Freedom of Press Act and the Archives Act (Tryckfrihetsförordningen och Arkivlagen)
- The National Board of Health and Welfare’s regulations on information management and record keeping in healthcare (Socialstyrelsens föreskrifter om informationshantering och journalföring i hälso- och sjukvården)
- The National Board of Health and Welfare’s general guidelines on identity verification of patients in healthcare (Socialstyrelsens allmänna råd om identitetskontroll med mera av patienter i hälso- och sjukvården)
- The County Councils archives regulations on long-term storage of electronic health records (Landstingsarkivets föreskrifter om långtidslagring av elektroniska patientjournaler)

Three of these laws are described in a bit more detail below.

8.4.1 The Patient Data Act and the Privacy Act

The purpose of *the Privacy Act* is to make sure that the privacy for a patient is maintained, regulations for how personal information must be handled to achieve this is stated in the law[64]. These provisions are then incorporated along with more regulations in *the Patient Data Act* where it is also stated that all healthcare personnel are required to keep medical records and make journal notes for all patients treated so that no information is lost[65].

8.4.2 The Publicity and Confidentiality Act

The Publicity and Confidentiality Act is a general law in Sweden that states how governments and authorities are supposed to handle public documents. Documents are generally supposed to be made available to the public, but the law also states that there are exceptions where information must be kept secret[66]. Medical records and information exchanged between care givers and patients fall under these exceptions[67].

The main focus of this law is to protect a patient’s privacy, even between care givers. A care giver is not allowed to speak about the patient with other healthcare personnel unless the care giver spoken to is directly connected to the case. These restrictions are necessary to enforce that the privacy for each patient is protected.

8.5 Patient Perspective

From a patient’s point of view, interviews D, K & J revealed that a patient’s understanding of their own healthcare is an important factor in their treatment.

²This law deals mostly with confidentiality regulations that the public sector, municipalities and county councils must follow[63].

³This law deals mostly with confidentiality regulations that the private sector must follow[63].

The patient in interview D felt it was very hard to get an understanding of their own health from physicians, due to the jargon physicians tend to use. The patient further explained that this information aided a greater level of understanding and helped them feel included in the treatment process. During the treatment, the patient used the online medical record system MVK, see 5.2. In the system, the patient was able to follow the treatment and receive test results instantly. This saved time for both the physician and the patient, by allowing them not to have an appointment to receive the test results. This demonstrates the potential savings if the patient knows how to use and understand their own medical records. It also aids patients' desire to feel included and be better prepared to handle their care once back at home.

On the other hand, there is also a limit to the information which a patient should be able to receive, due to their lack of medical experience. For example from interview E, a physician revealed that many patients had been able to read their own medical test results from their personal online medical record before their physician had even authorized the results. In many cases, this had resulted in overreactions where the patient had misread the results and become unnecessarily scared. The physician believed that providing the patient support through sitting with them and explaining results with a medical professional was a crucial step.

Another important factor for a patient is the physician's ability to demonstrate empathy towards a patient's care. In many cases patients can end up being passed between multitudes of different physicians because the communication between departments is inadequate. An example of this was explained in interview D, where the patient had been treated for prostate cancer during 2010. During the treatment, the patient met with 17 physicians, almost a different physician every time. During this process the patient explained a feeling of not being treated like a person, but more a spare-part that needed to be fixed. Receiving the news of having cancer is sensitive information and in many cases physicians can struggle to convey this kind of information with the level of empathy necessary. This case demonstrates that some patients may need further external support to ensure a satisfactory experience within the healthcare system.

Receiving empathy from healthcare personnel is particularly important for the patients being treated for critical conditions. An example of such a patient is Åsa Nilsson, who struggled with the lack of empathy during initial treatment for breast cancer in 2013[45]. Under the treatment, Åsa felt offended many times. Physicians were arrogant and did not introduce themselves. Åsa was not taken seriously and treated as less knowledgeable. Physicians were replaced and test results got lost in the process. Many people are involved in the first stages of cancer treatment, and it should not be the patient's responsibility to keep track of everything. The result was that Åsa never felt safe and lacked full trust towards the healthcare personnel. The turning point came when Åsa received a contact nurse, the concept of which is described in section 7.1.2, who was able to support and act as a contact link between the hospital and patient. Åsa felt that the nurse acted as someone who was able to listen rather than treating a patient as an object. Without the contact nurse Åsa's treatment would have been much more difficult.

8.5.1 Not Sharing the Complete Medical History

In the current system, patients have the option to refuse to provide their medical history. Patients may choose that their history will not be accessible to the physicians. In some cases patients choose not to provide doctors with their medical history on purpose. Based on interviews L, M, N, and P with various physicians, it is identified that instances of patients not sharing medical history occurs throughout all fields of medicine, but is most common in psychiatric cases. Based on interviews L and M, there are cases where the patient may not remember, may feel confused, or might not have any relatives that can provide the patient's health history to the physicians. In psychiatric entries, not all the doctors have access to the patient's records. In some cases the patient may not be aware of their condition, or may believe that they are not ill at all. When this happens, the patient may not share any medical history with their doctor.

8.6 Cultural Issues: Impact on the Healthcare System

A physician pointed out in interview F that aspects of Swedish culture also influence the country's healthcare system. Almost forty years ago, Sweden became the first country in the world to introduce gender-parental-leave allowance[68]. The use of parental leave has been constantly increasing since its introduction. As a result, it is now deeply rooted in the Swedish culture and effects how the Swedish people organize their work environment. Other cultural issues such as vacation leave and sick leave also tend to be very important in the Swedish culture. As a consequence of this culture, patients may not be able to visit the same physician during multiple visits. This in turn can create a feeling of alienation between physicians and their patients. It can also generate inefficiencies and confusion in treatment plans as multiple physicians are with the same patient case. As discussed with the physician in interview F, while these cultural aspects can have a negative impact on patient care, the aspects are still deeply ingrained in Swedish society and improvements around such aspects could be challenging.

9 Acceptance

User acceptance is an essential goal of every healthcare system, because long-term success depends highly upon the adoption rate and perception by the those using it.

9.1 General Theories About Acceptance and Adoption

There are many theories available about the characteristics and key points of adoption of changes, one of which is a collection of ten critical dynamics of innovation diffusion[69]. Innovation diffusion theory talks about the effects of innovation on society and the market. One of its key questions is about the probability of a new idea being passed on from one individual to the next. The ten critical dynamics are:

- *Relative Advantage*: If the new system offers enough benefits compared to the old system

- *Trialability*: If there is a free trial of the system
- *Observability*: If the system is already in use in another organization where it can be observed
- *Communication Channels*: How the benefits of the system are communicated
- *Homophilous Groups*: Whether or not user group consist of like minded people
- *Pace of Innovation/Reinvention*: The stability of the system and how well it allows for customization
- *Norms, Roles and Social Networks*: If the environment contains barriers that block usage
- *Opinion Leaders*: If there are popular people ready to be so-called champions and can convince their coworkers or friends of the benefits of the system
- *Compatibility*: If the new system is compatible with older systems that it needs to be connected to
- *Infrastructure*: If the infrastructure supports an easy use of the system

These are all factors which influence the speed and thoroughness with which acceptance of a new system or idea spreads throughout potential user groups. This is most applicable to systems where people can decide for themselves how to use it or not. However, often this is not the case, because in most businesses the management makes decisions about a new system and the users are compelled to accept it. Nevertheless, most of the factors are still helpful when looking into adoption of healthcare systems. The dynamics of *Communication Channels*, *Norms, Roles and Social Networks* and *Opinion leaders* have a particularly large impact in mandatory use of systems because the influence on an employee's understanding of the change is very big. This in turn influences whether an employee is willing to cooperate with the changes instead of resenting them.

Another approach for organizational adoption of information technologies or change in information technologies is to structure the factors in three main categories [70]:

- *Organization*: A group of people with a common goal
- *Technology*: Technological systems that support the goal
- *Social*: The individuals making up the group of people and their interactions

These three categories provide causes or barriers for the success of adaptations. The barriers that the organization puts up are usually in the form of a rule, regulation or routine that would need to be changed in order to make the change possible. In the technical category, the main reasons for failure are mostly compatibility problems. The social category summarizes all the invisible barriers that are formed inside peoples minds. Its main message is that change is scary

if one is not convinced why a certain change is actually good. It was said in interview V that for accepting a system, it is important to take these three factors into account.

9.1.1 Mandatory Change

It is important to make a distinction between voluntary and mandatory use. If the use is *voluntary*, the acceptance and adoption will evolve naturally in such a way that most people will accept changes if they are popular or state of the art. In contrast, if the use is *mandatory* all the users are forced to be early adopters, which is not natural. This is a reason why communication is so important. This is the only attempt that seems to be accepted to help the users understand the benefit of the change and therefore feel comfortable in their role.

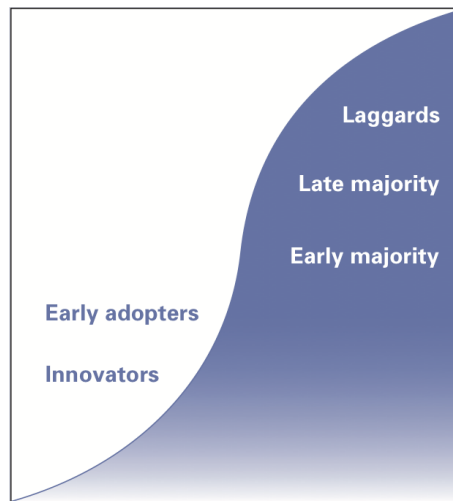


Figure 3: The Diffusion S-Curve

In figure 3 the diffusion of an innovation over time is shown. This curve shows that a change is first adopted by only a few people, the early adopters. After this, it goes very quickly. More people will accept the change. When most people who were willing to accept the change, accepted the change, the diffusion will move more slowly again. [69]

To visualize the stages of an adoption process, one can look at the technology adoption curve in figure 4. This figure displays a model for any change in any organizational structure. However, it displays the cycle of an isolated change and in reality there are usually many changes happening simultaneously and influencing each other. Nevertheless, there are some important things to learn from that curve. [71]

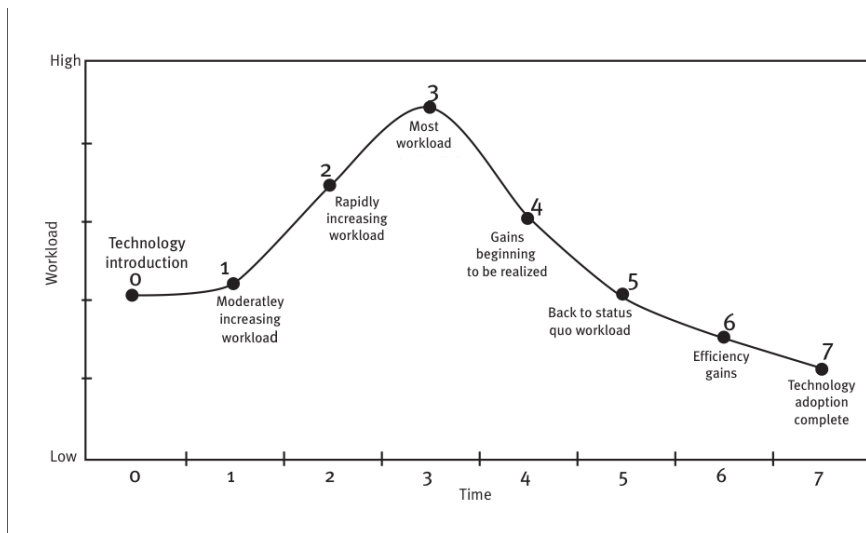


Figure 4: Technology Adoption Curve

First of all, the extent of the accretion of workload in the beginning is a lot more serious than many managers think. If one is aware of this, it already makes the adoption easier because the mutual understanding is better and expectations can therefore be adapted.

Secondly, it is important to note the fundamental importance of point seven requiring less work than point zero because otherwise the change was not beneficial. However, it is important that point seven represents the average. While for some users the benefit can be negative, for the majority it should be positive. The latter is a consequence of a common characteristic of change which is the shift of workload from one group to another. This is usually scary for both groups since the group with the decreasing workload is scared to lose the job, while the group with the increasing workload is scared that the group will be overloaded with work. But if the people from these two groups are all informed about the details of the change on time, rumors do not have the opportunity to develop and these people should not have to be so afraid of the change. In practice, however, it can be hard to reach everybody with significant information. The people who show up to information meetings are usually the ones who are willing to accept the change or would have made an effort to learn more about it anyways. Because of this, many of the people who really should be reached and informed about the implementation of a change are mostly not there and unaware.

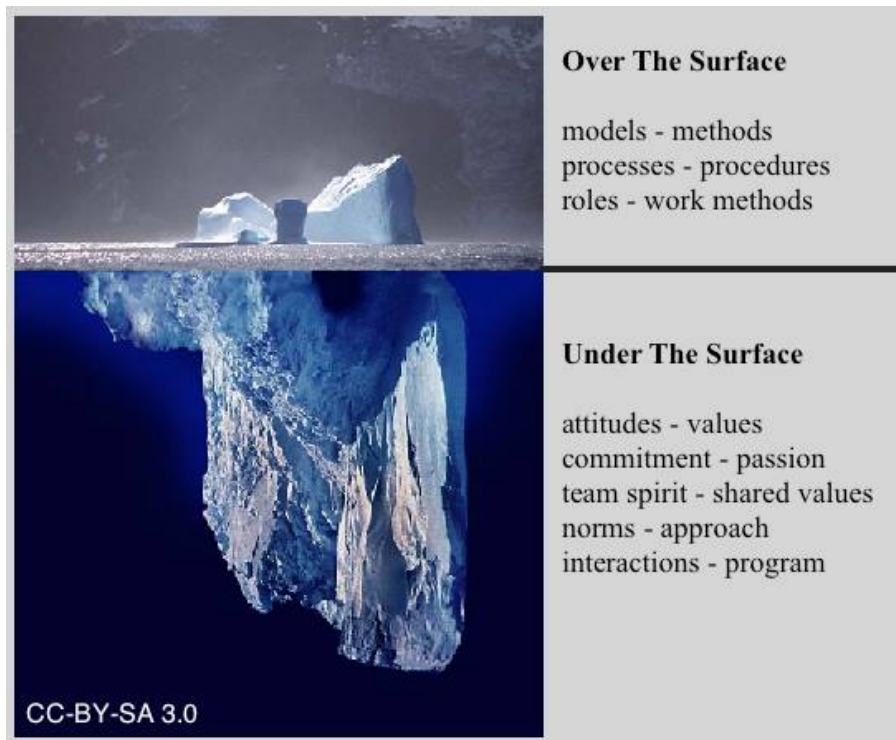


Figure 5: Iceberg Metaphor

Figure 5 illustrates the Iceberg metaphor [72]. The idea of this metaphor is that a person can only see what is on the surface, not below. The figure demonstrates that it is necessary to take the factors below the surface into account when implementing a system. Above the surface, there are the factors like *models, methods, processes, procedures, roles* and *work methods*. The more psychological factors that can not be seen are *attitudes, values, commitment, passion, team spirit, shared values, norms, approach, interactions* and *program*. These psychological factors are hard to reckon with if a new system is to be implemented. Some managers are only taking the factors above the surface into account, which will delay the implementation process. In reality, the factors below the surface are significant because the managers determine if the users will accept the new system or not. It is very important that the people in charge of the implementation are thinking about the attitude and experience of the individuals and organizations who have to work with the systems.

9.1.2 Adoption of New Systems in Healthcare

When trying to implement and promote a new system, only those interested in it will listen to the arguments for the system since many believe that change is scary. A physician might not happily listen to an engineer or a manager who has no medical knowledge. Healthcare is a long standing profession and many physicians can be very conservative when it comes to their work methods. However, if a physician that really trusts and believes in the new system can be found, it is easier to convince the other physicians. Furthermore, healthcare

professionals prefer scientific facts and this is why the implementers of the system should provide good proof and clear results to show that the system works effectively. Unfortunately, this is not always the case. If all the benefits of a new system can be stated clearly, it is possible that users are more willing to accept it and use of it.

Interview V revealed that in Uppsala it can be really hard to convince physicians to accept new systems or features. This could be in part due to poorly thought out previous attempts that have since soured the impression of physicians. As a result of this, it gets progressively harder to convince physicians to accept new systems.

Another factor that influences the change in healthcare in Uppsala considerably is the nature of the COSMIC system. It is a really large system and so it takes a long time before a new change in the system is actually released, the release cycle is 18 months, a point discussed in interview V. This release cycle is not that long because of the coding, but because all of the different municipalities that have to agree on the change in the system. The municipalities have to discuss the priority of this change and how it is going to be funded. This long release cycle can be a problem because when something has to be changed, the wait to see these changes is 18 months. By this point the change may no longer be necessary or an even better option may now be available.

9.2 Implementing the Electronic Medical Records in Sweden

In the middle of the 2000s, Sweden started to implement *Electronic Medical Records*. The idea from the county councils was to have the same system in the whole country. The reaction from physicians about electronic medical records varied[73]. At Karolinska University Hospital, the physicians were able to accept the electronic medical records, but only if it was well established, user-friendly and did not require a lot training to understand[74].

The first electronic medical record system in Uppsala was COSMIC and it was introduced by the county council in 2005[75]. In 2007-2008, a survey was made to get to know more about experiences in information exchange by primary healthcare physicians and physicians at the hospital. The advantage of the system was that it was easy, time saving and the physicians did not have to put focus on trying to understand other physicians writing style. However, the disadvantage of the system was that it was hard for the physicians to get a good overview of the medical record. Another thing that did not go well when the new electronic system was implemented was that different physicians wrote different pieces of information in the medical record. For example, some of the physicians still wrote the medication prescription of a patient on paper, while others put it in the electronic medical record. This caused a problem because handwritten prescriptions do not appear within the electronic system. [73]

When electronic medical records were implemented in different counties, it was introduced in different ways. Some of the counties introduced it incrementally, while some counties introduced it all at once. The best response from physicians was when several or all of the parts in the system were introduced at the same time, such as the common drug list and e-prescriptions that can be found in the medical record for any who have access to see it. The electronic medical records were also received well when it was a centralized organization

that implemented and introduced it. Some of the hospitals introduced first a group of physicians and nurses to it, and then let this group teach the rest of the relevant staff about the system. This was because the hospitals wanted to do the introduction their own way because different hospitals have different standards. [73]

One big problem, when introducing COSMIC, was finding time for the physicians and nurses to understand and begin utilizing the system. Many people thought that if all the hospital staff had to learn about the new system, it would distract them from their regular tasks during the day. [73]

Another problem with the new system was that it was introduced to several hospitals before all the critical features were implemented. The medication part was one of those features, and its absence confused staff. [73]

Yet another issue with introducing electronic medical records was that the developers lacked good contact with the end-users, namely the physicians and the nurses[74, 76]. If they would have had their input during the development of the system, it may have been easier to use. Some county councils also think that it would have been good to invest more time and money to get to know the system before starting to use it[73].

9.3 The Nurses' Acceptance

Nurses represent the profession who documented the most in the electronic medical records. As such, they provide an important perspective when discussing e-health systems. [77]

Some nurses argued that electronic nursing documentation was a time-consuming process and they experienced concern that they would have less time for the patients[78, 79]. The sign-in process, technical problems and slow computers contributed to the nurses negative attitude towards electronic documentation. The nurses also described electronic nursing documentation as something that interrupts nursing. These nurses felt that the electronic medical record did not provide information about the patients overall healthcare which was clear and relevant enough to warrant the additional effort required to use it. [80]

Even so, there were not only negative comments. Some other nurses thought the electronic nursing documentation was flexible, since it was possible that the computer was being used in close proximity to the patient for documentation during the conversation. They also found it to be a really convenient way to communicate valuable information to physicians. As it seems, the different properties of the nurses affect the acceptance of the electronic nurse documentation. Those who seemed to accept the solution tended to be flexible, organized and creative. [79]

A study conducted by Törnvall and Wilhelmsson found that about half of the participating physicians always read the nursing notes, a third read the notes sometimes, and less than a tenth rarely or never read the nursing care documentation. [81]

9.4 Guidelines for Successful Implementation of New e-Health Systems

Change in e-health systems can dramatically impact patients, physicians, and organizations. It is important that the change is actively controlled and lead in

the right direction. Furthermore, the effort it takes to lead change is generally immensely underestimated. In a report which summarizes the findings from 37 different studies which evaluate the practical implementation and integration of e-health systems, researchers from Great Britain list the most frequently mentioned barriers and facilitators for implementation and adaption of new e-health systems, see these below[82].

9.4.1 Coherence

Coherence is the term for the processes that should help the users understand the reasoning behind the new system. As a first step, they should understand the purpose and possible benefits for the implementation, as well as the consequences it has on their everyday work. The analysis of the reviews found that this first step has been rarely mentioned in the studies. However, it is regarded as a critical step and a good start to get an initial willingness of the users to work with the system. [82]

9.4.2 Cognitive Participation

Cognitive participation stands for the section where users and especially health-care professionals are actively involved in the e-health service. It is central to every implementation because it helps the users relate to the system and make them feel like they have a say and therefore, are more constructive in their criticism. In the best case, these activities do not only include general recommendations but also specific design and delivery considerations. [82]

Also, in this field is the question of how to motivate the professionals to participate in the implementation. One possibility is to recruit local opinion leaders, also called *champions*, which should have the ability to convince the colleagues of the merit of the e-health service and the implementation activities. The choice of these opinion leaders should be a careful one since they can also jeopardize the commitment of the colleagues if they project a negative attitude. [82]

9.4.3 Collective Action

Collective action discusses how individuals, groups or organizations get engaged in the operationalization of the new technology in practice. This is the work that is mentioned most frequently in the combination of the analyzed reviews. On the one hand, it is work that puts emphasis on organizational issues including management of resources such as money. On the other hand, it also includes the more modern approach of the socio-technical issues, which discuss the effect that the new technology has on the everyday work of individuals and physician-patient interaction. [82]

Things to be discussed, especially in this section, are the effects on healthcare tasks, confidence and accountability, as well as roles responsibilities and training. The users should be adequately trained and provided with support. [82]

9.4.4 Reflexive Monitoring

This last section concerns managers estimation of whether the e-health update is worthwhile or not. Mostly, it covers the collection of insights gained for future

implementations of new technologies but also it is an important tool to find out if further amendments are needed or if the remaining concerns are minor and can be neglected. [82]

9.5 Barriers that Prevent Acceptance of e-Health Systems

When a new electronic medical records system is being implemented, it is important for the physicians to accept the new system since they will be the main front-end user group. How to handle the system and how to work with it affects all the other user-groups. Albert Boonstra has conducted research showing that there are eight barriers that can make the physicians unwilling or unable to work with new electronic medical record systems. The barriers found are: *financial, technical, time, physiological, social, legal, organizational* and *change process*. [83] Analysis of these barriers is useful as many are likely to be applicable when considering the acceptance of the healthcare guide.

9.5.1 Financial

When implementing a new electronic medical record system, one of the most important things to look into is the financial aspects. It is imperative that the financial benefits received from the system exceeds the costs in the long term. There are several components that need to be evaluated: start-up costs, ongoing costs, return on the investments (ROI) and the lack of the financial resources. Sometimes the start-up cost can be large because of resources, such as computers, telephones, etc, that has to be bought in the beginning of the project. That may prevent a project from starting because the initial costs are too high. [84]

9.5.2 Technical

Another potential barrier when implementing a new electronic medical record system is the technical barrier. If the system is not developed correctly, if it is hard to understand or if it includes a lot of different functionalities it can be hard for the physicians to use the system. It can also be hard for people who are not used to using a computer. It is then necessary to first figure out how to use the computer and then also the system, which can be hard if it is a complex system.

Furthermore, there were more than 264 different types of electronic medical record systems in the world in 2010, which causes a problem when physicians moves around to different hospitals in different countries [85]. It may also be difficult, and sometimes even impossible, to share data between different systems. If a physician is not familiar with using a computer it will take a long time to type. These physicians would prefer writing the documentation by hand. Two-thirds of the physicians consider the technical aspects to be a big barrier[84, 86].

According to Randeree, many physicians also think that there is no system that would meet their special needs because no system will have all the features the physicians want. Even if there was a system that did include all the functionalities, the physicians might have a difficult time using it. Many physicians are also worried about the reliability of electronic medical records and are afraid

of losing information during times when computers crash, power goes out and when security is compromised. [87]

9.5.3 Time

Physicians are busy people, often having more work to do than there is time for. Forcing the physicians to learn how to use a new electronic medical record system will take a lot of time out of their day. Even beyond the initial learning curve, it may take more time to use the new system than it took to use the old. Every minute a physician spends doing paperwork is a minute less spent with patients. As systems grow more complex, the potential time taken away from patients increases. [88]

9.5.4 Psychological

By introducing a new electronic medical record system, the physicians' working styles will have to change. It is likely to stop some of their normal routines and start new ones. Physicians also like to have control over their work, to know what to do, how to do it and when to do it. Some things are often just targeted at themselves. By changing the system, the physicians may be worried about how to do the things that always been done and how to make sure that no one is reading or changing the things that have been written. [89]

9.5.5 Social

Physicians must learn to work together and to cooperate without talking to each other all the time. However, when most of their work is in front of a computer there is less opportunity for communication and the feeling of being lonely and isolated can appear. A smaller degree of communication and collaboration between physicians can negatively impact their overall effectiveness. [84]

According to Shachak, research shows that 92% of the physicians think that electronic medical records are disturbing the social connection between the physician and the patient. When the physician and the patients are talking about the patient's condition, having to turn to the computer may disrupt the discussion. [90]

9.5.6 Legal

Many physicians are afraid of that electronic medical records not are secure enough to maintain the safety for the patients. If there is a flaw in the system, a person with malicious intent may be able to access files they normally would not be allowed to see. If that would happend, the integrity for the patients is destroyed.

9.5.7 Organizational

According to Miller, the acceptance of new systems is a more significant issue at larger practices. That is because the rollout is more often conducted successfully by utilizing their ability to obtain a greater level of support than at a smaller practice. The small practices may also struggle to finance the rollout because their budget for IT-services is likely to be smaller. However, within a larger

practice it may take more time to rollout the new electronic medical record system because there are more physicians to be trained and more data. [91]

9.5.8 Change Process

To get the new electronic medical record system to work correctly, it is important that the physicians are motivated to use it. If the physicians are not motivated to use it, the point with the new system will fail because it will not be implemented and used as intended. [84] To get the implementation to work it is important that strong project leaders are present who believe in the project and are willing to take the risk and the cost to make the implementation successful. [84]

10 Recommendations

In this section, recommendations will be presented as a potential way to overcome the issues that can be derived from the research. The recommendations will not necessarily solve all of the issues but can be seen as guidelines to help improve the current situation. Many different aspects need to be taken into consideration and thus a variety of different recommendations will be presented to help overcome the issues described in section 1 and 1.1. If recommendations discussed in this chapter are implemented into the already existing organizations, it is unlikely to radically change the architectural structure of the healthcare system. As mentioned in chapter 3 the Swedish healthcare system is complex and constantly changing, thus it is hard to make radical changes that are beneficial for society as a whole. Despite this, incremental improvements can be implemented to enhance the healthcare system. The recommendations could be relevant for any organisation in the world that are contemplating to implement a healthcare guide. The healthcare guide could eventually end up changing the fundamental structure of the healthcare system.

10.1 Healthcare Guide

The healthcare guide builds upon a number of required qualities and can be a combination of healthcare personnel, information technology, or other means for information sharing. The broad range of qualities required shows that the complexity of the healthcare guide is not given by one single solution. Depending on where the healthcare guide is applied, different qualities may be more relevant than others. A single recommendation may not solve all issues but a combination of the different qualities can together cover a wider area. There have been many different approaches to help overcome the issues that the healthcare guide aims to solve. Some mentionable professions that have been studied closer in order to define the healthcare guide include the PAL, contact nurses and American case managers, which were discussed in section 7.1. These concepts have been shown to have positive impact when having been implemented as intended. However, there are a number of factors which prevented full success in Sweden, particularly those discussed concerning the PAL implementation in section 7.1.1. The implementation of the healthcare guide concept should take these factors into account, for example, by supporting Sweden's unique preference for collective decision making over the American prepossession for individual responsibility. Overcoming these issues with the healthcare guide will aid

a successful implementation, unobstructed by the failures of similar, previous solutions.

Research shows it is important the healthcare guide has some insight in the healthcare system. The healthcare guide should not simply be a family member or a third party, due to the lack of insight of the healthcare system. For a family member, the burden will most likely be too heavy and emotional engagement may affect the judgment. Empathy should be provided from a professional point of view, together with other qualities described in section 6.1.

The healthcare guide is not necessarily a person. It could be material that supports the patient such as informative papers, books, and other tools. However, it cannot be excluded that a person or a group of people can take the role of the healthcare guide.

As technology is constantly evolving, it is important to understand and see when it is a useful resource. The healthcare guide can partly be information technology as it can contribute to the qualities of communication and information. However, a healthcare guide based solely on information technology lacks sufficient empathy. Technical suggestions that can aid a healthcare guide can be read in section 10.3.

Communication is one of the fundamental causes of the issues in healthcare today, showed by the research above. The healthcare guide can be combined with standardized models and methods such as SBAR to further improve communication. More about already existing models and methods can be read in section 4.3.

The outcomes of making radical changes to the healthcare organization are hard to predict, which is why it is a risky approach. The concept of the healthcare guide aims to work as a guideline when incrementally making decisions about different solutions. By following the healthcare guide, small changes may one by one change the healthcare system.

10.2 Prospective Patients

One of the goals for the healthcare guide is to increase the effectiveness of physicians and lessen the number of errors made by said physicians. Considering the healthcare guide as a costly and limited resource, it stands that a process must be implemented that will efficiently utilize the guide. The factors behind the assignment of the healthcare guide should be the complexity of the case, read more about this in section 6.2.

A complex case is defined by a rare disease, multiple present diseases and treatments, poor patient condition and support system, or physicians working in tandem. Rare diseases will require increased amounts of time for the physician to reach a conclusive diagnosis. When multiple conditions or treatments are present, the physician has to cross-reference these in order to avoid complications between treatments. The patient's condition often directly limits their ability to communicate, which then requires the physician to do research their records in order to obtain an accurate picture of the medical condition. The support system affects how much time is required for the physician to complete said research. The number of physicians working together on a project increases the odds that miscommunication will occur between one or more, possibly leading to improper treatment of the patient. The complexity of the case directly relates

to how much time is required, the likelihood of miscommunication, and the need for a tool to assist in preventing accidental malpractice.

The healthcare guide should be assigned to patients who possess a complex case. Complex cases are where more time is needed or there is a challenge in communication, which increases the likelihood of undesired outcomes for both the patient and physician. In these cases, the greatest benefit of assigning a healthcare guide will be received.

10.3 Technical Suggestions

If a healthcare guide is implemented in Uppsala County Council, this role should have access to the same systems that a physician or nurse can use today. See these systems described in section 5. The main system that a healthcare guide will use is likely COSMIC. In COSMIC today, the start view for a physician is the last entries made about the patient at the current ward. The physician can then relocate within the system to look at entries made at other wards, or at a higher level other healthcare centers. A healthcare guide would benefit from having a start view in the system at this higher level, seeing where in Uppsala the patient has medical records, and then having the option to go deeper into specifics that are present at each healthcare center.

A requirement for the healthcare guide concept to work is that the healthcare guide gets access to all information about the patient that exists in the systems. This requires the patient to give consent to share the information stored in the healthcare records.

10.3.1 General Overview

As described in section 8.2 the general overview that exists in COSMIC today does not work optimally. Therefore, it would be useful to improve this section and to have a general information section which can be updated only when necessary. This section should have specified fields or areas that the county council can decide are relevant for all wards to avoid the problems that exists today and in order for the information to be useful. This section should contain at least the following information about the patient:

- Name
- Age
- Address
- Phone number
- Job
- Allergies
- Chronic diseases
- Genetic disorders

Some of this information, for example name, age and address, could be retrieved from Skatteverket to guarantee that the information is always up to date and correct. The other fields should be possible to modify by the physicians to make sure that each field can be updated when needed. A history of older entries should be saved together with the valid period's information.

This section will help a healthcare guide since it will provide the general information about the patient and will guarantee that the healthcare guide can access this information in an easy way. Contact information to the patient is also present in case the healthcare guide needs this information.

10.3.2 Sorting Medical Records by Keyword

The keyword function that exists in COSMIC today is not used in a good way, see section 8.2. It would be good to make this function better and easier to use. A helpful tool would be to give medical records the option to search for entries based on keywords. When a physician enters information into a medical record an option to add a keyword associated with the entry should be present, at least one keyword should always be used. It should then be possible to search for entries that healthcare personnel have associated with certain keywords. This will reduce the amount of time that is required to find relevant information in a medical record significantly.

These keywords should be possible to add manually by the user, but it could be a good idea to add some keywords automatically as well. An example of this could be to add a keyword to the entry based on the physician's role or position. At this moment, COSMIC has information about where the user is working and what the user's role is [17]. If the physician is working at the oncology ward for example, an automatic keyword *oncology* could be added to the entry. The physician should be able to remove these automatic keywords in case others are more appropriate. In order for this to work optimally the county council should decide on certain keywords that healthcare personnel should use and the option to add new ones by physicians must be removed. If this should be developed further and implemented together with NPÖ, specific keywords that every county council in Sweden should use could be added to create a good standard.

Automatically tagging entries when words that are written in the entry corresponds to existing tags is another option that might be good. For example, if a tag *cancer* exists and a physician writes the word cancer in an entry, the entry should automatically be tagged with this. If the physician feels that the automatic tag is not relevant, it should be possible to remove it before saving the entry.

Another option could be to add a function in COSMIC that allows a physician to start a *case* for a patient. At this moment, a physician signing in to COSMIC will see the last entries made for the current patient at the specific ward. This means that within the ward, it is possible to see entries others have made for the patient as long as these are not blocked. It is then the user's responsibility to only look at relevant entries. If a functionality to start cases is added at the different wards, it would be possible for a physician to start a case when a patient is diagnosed. For example if a patient is diagnosed with lung cancer a case *lung cancer* can be created in the patient's medical record, if other physicians at the same ward are treating the patient for the same condi-

tion it should be possible to add the entries to this case. This will also increase the patient's privacy since the chance of healthcare personnel seeing irrelevant entries when signing in is removed, a case folder will instead be displayed.

A possible healthcare guide could save time and energy if an option to sort by keywords existed in COSMIC. Avoiding the problem of all entries within a medical record being sorted by issue date and ward would really decrease the amount of time and energy that must be used to find relevant information today. Also, today it is very easy to miss relevant information because of this as well. If keywords in general were used it would be possible for a healthcare guide to search for information more efficiently. If the case functionality described above was added, a healthcare guide could look at all entries regarding a diagnosis made at the relevant department very easily.

10.3.3 Chat Client

As described in section 4, communication plays a central role within healthcare. It is also stated in this part, based on information gained in interview C, that information loss is directly affected by the number of people that exist in a communication chain. Two areas where communication would benefit from improvement are between different healthcare professionals and between healthcare professionals and patients. In section 4.1 it is stated that communication problems within these areas exposes patients to unnecessary risks. Also stated in section 6.2.1 is that miscommunication between healthcare professionals and patients can lead to undesired results, such as accidental medical malpractice. Miscommunication is believed to decrease between healthcare professionals and patients if a healthcare guide is implemented. In section ??, a quality that is established to be important for a healthcare guide is to be *communicative*. Besides oral communication between the healthcare guide and patient, technical solutions can also aid with improving communication. An easy communication channel that can be provided between the healthcare guide and patients is a chat.

MVK, see section 5.2, is a system for digital contact between patients and healthcare providers[21]. In the system, the patient can book an appointment or ask the healthcare provider to contact the patient. This system provides a good and easy way for healthcare providers and patients to communicate.

In order for patients to have good communication with a possible healthcare guide a solution is to implement the features that are now present in MVK, between a patient and healthcare providers, between a patient and the healthcare guide as well. To simplify the communication even further, a chat client could be implemented in MVK. A chat in MVK would make it possible for the patient to contact and ask questions directly to the healthcare guide instead of having to send a request that the patient wants to be contacted. This is also a good feature for the healthcare guide since a chat makes it possible to keep the patient up to date more efficiently. If a functionality like this is implemented, it can help a healthcare guide to accomplish the communicative quality described in section 6.1 more easily.

A chat in MVK is not only efficient for the healthcare guide and the patient, it is also secure. Since MVK already is a system used by Uppsala County Council for communication, the security of the system is believed to guarantee that the patient's privacy is maintained. MVK is also accepted and used by the

healthcare personnel already, which will make it easier to get a healthcare guide to use it.

In section 6.2.1 communication errors between medical professionals is also concluded to be a reason for possible errors in a patient's treatment. A healthcare guide, together with standardized communication models, is believed to help decrease these errors, read more about this in section 10.1. One way for the healthcare guide to help with decreasing the mentioned errors is to provide a chat as an easy communication path between the healthcare guide and other medical professionals, similar to the chat suggested for the healthcare guide and patients.

A chat client between medical professionals and the healthcare guide could be added in COSMIC. The purpose of this chat would be to simplify the communication between the healthcare guide and specialists at different wards. A healthcare guide can not be a specialist in every area and will therefore need to have contact with different physicians with different specialties. A chat will make the communication a lot faster and easier if it is implemented in COSMIC, since the physicians already use COSMIC and are familiar with it.

10.3.4 Possible Solutions Nationally

NPÖ, see section 5.3, is a tool that could help a healthcare guide from a national perspective. If a patient has medical records in more locations than within Uppsala County Council, using a tool like NPÖ could provide the healthcare guide with a better overview of the patient's medical history in a fast and efficient way. In order for NPÖ to actually be a valuable tool though the system needs to be developed further and the difficulties described in section 8.3 should be addressed. A problem with this is that since NPÖ is a national system, questions regarding payment and responsibility for the development might be hard to decide[20]. Therefore, in order for NPÖ to be a valuable tool to use all county councils must work together to develop the system. By doing this NPÖ can be used more successfully in Sweden and if the healthcare guide concept is adopted in Uppsala and maybe even other counties, all of these will benefit from a better working system.

As mentioned in section 8.3 problems in the NPÖ interface exist. Another problem that is mentioned there is that functionality is not used as intended in NPÖ. Since a possible reason for this is that the interface is poorly designed and hard to use, improving the interface might at least help with this problem to some extent.

Features that could be implemented in NPÖ to help other healthcare professionals than the healthcare guide are for example options to send referrals to other wards or hospitals, or communicate with other healthcare providers directly in NPÖ. This is something that was suggested from the audience during a symposium for the DOME-project held at Uppsala University 2014-10-17 as a possible tool to make healthcare on a national level more efficient.

If NPÖ was further developed a possible upside would also be that a standard for what information NPÖ should include could be set. Right now, each county council can choose what information to share with NPÖ which can result in problems when interpreting information. If a county council is sharing little information, this might be a problem for a healthcare guide who will not know if there is some information that is not shared and if so, what this information

is. [17]

10.4 Acceptance of the Healthcare Guide

A single way to introduce a new role into an organization successfully does not exist today. In the case that a healthcare guide is to be introduced, each hospital or healthcare center will have its own culture and personnel with personalities that must be dealt with. In some aspects the introduction process could learn from when electronic medical records were introduced, read more about this in section 9.2, but there are other elements that will need to be considered when a healthcare guide is introduced.

An important aspect that helped increase the acceptance of electronic medical records during its introduction was to make sure that the users of the system understood the overall picture and the importance of the new system. Understanding how a new system fits in to an already existing environment and what benefits it can bring is an important factor to increase acceptance of a new system. One of the critical points that caused the project's failure was not understanding the importance of this aspect and failing to provide this for the users during the rollout of the electronic medical record system in Austria, as seen in section 7.2.1. Physicians in Austria that took part of this rollout expressed that if information would have been received from the government and professional organizations, instead of just the government which was the case, the acceptance might have been better from their perspective[54]. It follows from this that when introducing the healthcare guide, care should be taken to prioritize disseminating information fully to physicians and their professional organizations to increase acceptance of the new role into an existing environment.

Cognitive participation, mentioned in section 9.4.2, and collective action are no less important. It is critical that physicians take part, not only in filling out the electronic medical records, but also in interacting with the healthcare guide. As before, having a *champion*, described in section 9.4.2, promoting acceptance and cooperation could be a strong motivator. Though the physicians' professional organizations should also be sources of support and motivation, the champion should be from the local organization if possible. When dealing with a hospital, for instance, the champion should be a physician at that hospital. If a champion does not appear qualified, convincing physicians to trust the healthcare guide will not be possible. A standardized education program or certification will help with easing physicians' fears about the competence of a healthcare guide, thus increasing their cognitive participation.

Finally, reflexive monitoring, see section 9.4.4, should always be used when introducing any sort of change. There will almost certainly be unexpected issues, so an open line of communication needs to be maintained with the physicians and the healthcare guides.

11 Summary

As the physicians' level of specialization increases in Swedish healthcare today, issues that are becoming more important are lacking communication and accountability. The overall area that a physician is responsible for decreases in

the same pace as specialization increases. To overcome these issues, solutions have been suggested in this report in the form of a possible healthcare guide. The healthcare guide concept aims at combining a number of communication and information delivery techniques in order to address and hopefully overcome these mentioned issues. The concept healthcare guide builds upon a number of qualities that can be a combination of healthcare personnel, information technology or other means for information sharing.

To find a solution to these problems, a lot of research has been done. Finding out how Swedish healthcare works today, what systems are being used and solutions that are similar to the healthcare guide concept are areas that have been researched in order to find the best solutions possible. Investigating these areas has been done in several different ways, interviews have been conducted, demonstrations have been attended, surveys have been sent out, and a lot of research has been performed. In order to find the best possible solution, the healthcare guide concept was divided into four different parts regarded as the most necessary areas to find solutions for. These four parts were *what or who is most appropriate to take on the role of the healthcare guide, which patients are in need of a healthcare guide, what technical solutions can aid a healthcare guide and how will the solution be accepted in Swedish healthcare*. These four parts have then been combined to one final concept that is presented in this report.

The project has resulted in a few different recommendations suggested to the county council that together are believed to offer a good solution, in the form of a healthcare guide. The recommendations are based upon the four different parts described above. One solution is that the appropriate role to take on the responsibilities of a healthcare guide has been established to be someone who is medically trained and has knowledge about how the Swedish healthcare system works. Another possible solution is that the healthcare guide does not have to be a single person, it can be material that supports a patient, such as books or informative papers or a group of people. The qualities that have been established to be required from a healthcare guide are being *knowledgeable, informative, communicative, continuous, trustworthy* and *empathic*. The patients that have been concluded to need a healthcare guide most are patients with complex cases. A complex case is defined as a rare disease, multiple present diseases and treatments, poor patient condition and support system, or physicians working in tandem. These cases will require an increased amount of time from physicians and it is believed that a healthcare guide will help in these situations.

If the healthcare guide is a person or a group of people, technical tools and solutions have been suggested in order for the healthcare guide to do a better job. These technical tools are functionalities that can be added to the already existing systems in Uppsala. The suggestions expected to help a healthcare guide are improving the general overview about the patient's information in the system used for handling electronic medical record, improving the function to sort entries in a patient's medical record by keywords and adding a functionality for the healthcare guide where it will be possible to chat with both the patient and specialists at different wards. All of these tools are supposed to help the healthcare guide fulfill the qualities mentioned above. In order for healthcare personnel to accept this solution it will be important to educate these people about what the healthcare guide concept actually is and why it is needed. Informing healthcare professionals will be crucial for this to work, as well as making sure that their input is considered during the concept's development.

The belief is that if the recommendations suggested in this report are adopted by Uppsala County Council, the problems mentioned above will decrease. Communication, accountability as well as the patients' overall treatments and experiences will be better if a healthcare guide is implemented. A financial gain is also believed to be an outcome as a result of a reduced number of cases with accidental malpractice caused by miscommunication and lack of overview of the patient's medical situation.

12 Discussion

The research confirms that problems exist with communication within the healthcare system and that there are many underlying factors causing these problems. The project was conceptualized from the principal concern that there was no one within the Swedish healthcare system to take full responsibility for a patient's care.

If a healthcare guide is introduced into the current healthcare system, a few problems could be solved. Firstly, the overall care in more complicated cases can be greatly improved if a healthcare guide is present. This is one of the areas where a healthcare guide have been established as appropriate to use, see paragraph *Healthcare Specialists' Opinions* in section 6.2.2. Also, the well-being of the patient can increase. The treatment of the patient will be more pleasant since the healthcare guide will be a person that the patient can talk to and receive support from. In interview H it was said that approximately one percent of patients today are responsible for 25% of the total costs in healthcare. This number is likely to be reduced if a healthcare guide is implemented.

A healthcare guide can also help with reducing the number of unnecessary physician visits that occur today. A healthcare guide can help with answering a patient's questions about information in the medical record. In cases where the questions can not be answered, the healthcare guide can be responsible for booking an appointment or talking with the physician that is responsible, relieving the patient from this burden. If appointments can be booked in this way, the number of visits a patient makes to physicians that are not responsible for their case will also decrease. If this is avoided, coordinating visits and prioritizing requests from patients will be easier since a *Single Point Of Contact*, the healthcare guide, will be used for these tasks[92].

Since it has been established in this project that a person will be most appropriate to have this role, see section 10.1, this person can benefit from getting technical solutions to work with. These technical solutions will have to provide all the necessary information that a healthcare guide needs. A completely new system is not provided, due to economic and practical reasons, but improving the current systems used and adding functionality to these might be a good idea, see section 10.3. If these suggestions are implemented, the belief is that the work a healthcare guide will be doing will be a lot easier to perform and more focus can be placed on the patients rather than on how to use technical systems. Which in turn will make the patients' overall treatment better and their experience of the healthcare system will be hopefully be improved.

There are inherent trade-offs between a variety of the different imperatives within healthcare caused by a limited amount of time. A physician must balance spending time with patients, communicating about patients' medical records

and status, as well as insuring that their actions are well accounted for. Adding additional representatives within the communication system is only cost effective if it reduces the overall time that is spent on communication from both the physicians and healthcare guides combined. Many physicians believe that the primary issues within the system that lead to the problem discussed result not from a poor accountability system or negligence in any way, but simply a lack of time. This is where such a new mechanism could provide value: reducing the overall overhead of communication in the healthcare system.

12.1 The Responsibilities of a Healthcare Guide

Optimally, a healthcare guide should be responsible for a patient's medical situation which includes final decisions about diagnosing a patient as well as treatment for said patient. A healthcare guide could in this scenario be the one person who will have complete control over a patient's medical situation and can be responsible for the overall care and decisions made with the patient in mind. This is the scenario that is likely to be the best solution from the patients' point of view, since one person will have all the knowledge about their entire medical situation and can make sure that all decisions are in line with their medical history. The problem is that for this to work, the healthcare guide would have to be the person who would make all the decisions. Even if this in theory is the optimal scenario, it would not be feasible to implement a solution like this. The healthcare guide can not legally be responsible for decisions made by other physician since this would relieve physicians from the responsibilities associated with treating a patient. If a healthcare guide would be making all decisions, this would require a healthcare guide to have a lot of specialized knowledge, time and a lot of healthcare guides would be needed in society, which is not a likely scenario.

The more realistic case would be for specialized physicians to make decisions regarding treatments within their area of expertise, while communicating and discussing with a healthcare guide about how this affects the patient's medical situation. Since a healthcare guide can not be ultimately responsible for a decision made by another physician, the healthcare guide can unfortunately not be responsible for all decisions regarding the patient. Therefore, the best solution that is also possible to implement is for a healthcare guide to be responsible for guiding a patient within the medical system and helping the patient when needed. Also, the healthcare guide will be responsible for making sure that when larger decisions about a patient's care or treatment are made by physicians, information that might affect the decision must be conveyed to the right people so that the best care is provided. In this scenario, the care the patient receives will be better since a healthcare guide will be involved in the process even if the decision is made by a specialized physician. The healthcare guide will also guide and communicate information to the patient, two aspects that today are not working optimally but that hopefully will help the patient. By implementing a healthcare guide in this way, the problems described in section 1 and 1.1 can hopefully be avoided.

12.2 Healthcare Guide and Communication

Our research has revealed that one of the underlying causes was ineffective communication. The complexity of the healthcare system makes viewing communication as a singular problem virtually impossible. By investigating different parts of the healthcare domain it can be concluded that there are advantages of breaking down the problems into smaller ones. This approach paves the way to solving the problems as a whole. Doing radical changes to a structure as complex as the healthcare sector can be very inefficient, this is because it is hard to predict outcomes and it can be resource demanding. Instead a goal would be to aim for smaller incremental improvements. Using a flexible method like the healthcare guide would be both more effective and efficient in the long term. We think that this conclusion is reasonable because of the previously mentioned complexity.

12.3 Finance and Resources

When implementing the healthcare guide a few things needs to be taken into consideration. Swedish citizens pay high taxes and therefore expect healthcare costs to be covered. At the same time, the county councils' resources are limited and gaining appropriate funding can be challenging. Introducing the healthcare guide will clearly come at a cost. However, resources are always limited and are likely to make funding hard to come by. Our research suggests that there are a number of improvements to the communication within healthcare which could result in significant efficiency gains if improved. This would include reduction of errors which could lead to direct financial improvements. From this we believe that some of the healthcare guide concept could be at least partially self-funded from the reduction of a number of the costly problems explored throughout this report.

The healthcare currently offers a restricted amount of professional personnel for patients who are in need of them. As previously mentioned, the county council has limited resources. This was one restriction that impacted our approach to overcome the issues within the healthcare system. It is unlikely that a radical change of the structure of the healthcare system will be successful, therefore the healthcare guide was designed to be a flexible solution. The qualities which form the base of the healthcare guide can be implemented individually. Ultimately however, a combination of all the qualities would be required to ensure optimal healthcare. For parts of healthcare some qualities may already be upheld but the concepts forming the healthcare guide can be easily broken down to improve only what is needed. The qualities of the healthcare guide are also easy to adopt anywhere within healthcare, making it flexible for any situation.

12.4 Changes over Time

Another thing that needs to be taken in consideration is that changes take time. To implement the healthcare guide and make it work as intended may take a long time and the benefits may not show immediately. The healthcare system is large and complex. Thus, the system demands time to adjust and be reshaped at a pace that does not affect the quality of the care itself. In particular, the quality of *trustworthiness*, see section 6.1, is not something which can be built

overnight and so it is likely to take time for people to accept and adjust to the system of the healthcare guide.

Lastly, one must realize that drastic changes could adversely affect healthcare as a whole. With small changes it is easier to detect if something goes wrong or does not work as intended. Furthermore, small, individual changes may not be as costly as changing the overall architecture of healthcare at once. Implementing the healthcare guide will be a challenging process where all changes should be closely monitored in order to improve something as critical as healthcare.

12.5 Technical Solutions vs Acceptance

When suggesting new technical solutions that can aid a healthcare guide, see section 10.3, an important aspect to think about is that implementing the solutions will not be enough. A necessity is to also educate the people who will use the new solutions, in this case the healthcare guide and personnel who will be connected to and communicate with the healthcare guide. Education sessions when the systems are introduced and regular training sessions after the implementation is done will be two steps that can help users understand the system better and use it with more success. As mentioned in section 10.4, this can help with increasing the physicians' and healthcare guide's acceptance of new solutions.

Feedback forms or a functionality in the new systems where it is possible to send feedback directly could be one way to let personnel feel more involved in the development process and might also let educators know what to focus on if many feel confused about certain parts.

12.6 Long-term Expectations

The main goal when change is introduced is to achieve a long-term benefit from it. This means that as soon as the implementation cost and the transition effects have worn off, the new solution should be cheaper or more beneficial than the old system. For the a new system should to be regarded as successful, this means that the county's resources should be used in a better way, for example communication within the health sector will improved. Also, the costs associated with healthcare will be reduced since more appropriate and efficient work can be done by the correct people. A healthcare guide can focus on the overall care of a patient and make sure that the patient will be updated and informed, while also communicating with the physicians that are connected to the patient. The hard part of introducing change in this way is to make sure that the new system is accepted and used and to improve old routines. If the suggestions made in this report are followed, our belief is that the concept of a healthcare guide will improve Swedish healthcare and improve the patients' experiences.

12.7 Limiting Factors

The interviews conducted throughout our research provided an otherwise unobtainable insight into healthcare systems, however, gaining these insights was not possible in all cases. Examples of this include the Vårdlots system briefly discussed in section 7.1.3, as well as an another in Canada known as HEC. In

both cases attempts to contact individuals from both projects were made. However, the information that was gathered was limited due to an unwillingness of those involved to share their research findings. We believe that improving the transparency of research results would allow more people to be involved in the research process and conclusions to be drawn more efficiently. Had this information been more attainable within our project in particular, it seems likely that it could have contributed to our research and improved the depth of our findings.

13 Future work

Our study provides a set of flexible and adjustable guidelines that can be used in different situations and contexts. The results can lead to many different outcomes, which is a factor that affects future work. A broad range of healthcare institutions could benefit from utilizing and continuing this research. The healthcare guide can improve different aspects of the healthcare system, and healthcare personnel and patients can both benefit from these improvements. Redundant work for healthcare personnel can be avoided and thus improve the efficiency of their work. Another notable outcome is that patients can get a better understanding of their medical situation and may be subjected to less malpractice.

To continue the research, the next step could be an in-depth look into how the different qualities of the healthcare guide can be implemented. Another useful step for future work is to investigate a method that can be used for evaluating when and what parts of the healthcare guide are needed.

From the research, also some new questions were raised. An interesting topic that may be worth looking closer into is the possibility of coordinating people and other tools to work optimally together. Some of the most notable results from the research are the importance of using all available tools favorably and doing small incremental improvements to not impact the healthcare system dramatically and bring it out of balance. To use available tools and keeping up with technological advancements is crucial for improving the healthcare system. However, this must be done properly to not miss important aspects that tools cannot provide, such as empathy.

14 Conclusion

Medical practice requires precise communication in order to provide appropriate treatment. Communication within the healthcare system is often impeded by a lack of time among healthcare professionals. Due to the complexity of the healthcare system it is unlikely that a single solution could be reached. Many of the problems stem from miscommunication but manifest in unique ways. By establishing a set of guidelines for system implementation, unique solutions could be effectively generated to fit scenarios as they arise. What these guidelines represent is referred to as a healthcare guide. The concept of the healthcare guide draws together a number of improvements to facilitate better communication within the healthcare system and provide an empathetic and informative method of keeping patients involved.

The healthcare guide should be able to act as an intermediary between the patient and the physician, increasing information flow. A variety of entities could act as a healthcare guide, from an automated system that provides information to the patient, to simply a simplification of a patient's medical history.

It is our hope that our research, findings and recommendations will aid improvements and inspire future work within this area. As healthcare is such a complex issue, our recommendations are tailored to be implemented incrementally to make it as flexible as possible. Each suggestion aims to overcome the original issues of communication, patient involvement, and lack of responsibility. It is our wish that our research will aid and inspire future work in this area. Ultimately, we hope our findings and the healthcare guide concept can contribute positively by providing potential improvements within the healthcare information network.

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Glossary

Agency for Healthcare Research and Quality An agency within the United States Department of Health and Human Services with the mission to produce evidence to make healthcare safer, higher quality, more accessible, equitable, and affordable.

Akademiska sjukhuset Swedish name for Uppsala University hospital.

Associate of Science in Nursing A 2-3 year degree which allows one to register as a nurse in the United States.

Chronic Diseases Chronic disease is a long-lasting condition that can be controlled but not cured.

Contact Nurse A nurse with expertise in cancer care and psychosocial support.

COSMIC A medical record system used in Uppsala County Council that provides an overview of a patient's medical history, ongoing treatments, medicine list, lab and radiology results.

Electronic Health Record, EHR A complete system to store journal of a persons' healthcare.

Electronic Medical Record, EMR Is referred to a healthcare system that keeps data in a particular hospital or practice. The information of the EMR's is combined in wide EHR systems.

Health Maintenance Organization The most common form of health insurance organization in the United States.

Healthcare guide A number of qualities that can be combined to help solve issues within the healthcare. The qualities can be a set of healthcare personnel, information technology or other means of information sharing.

HSA Nationell Katalogtjänst A quality assured organisation catalogue which contains information about persons, units and functions within healthcare in Sweden. The stored information in HSA is used to verify information, e.g. personal information, define eligibility for users of external systems and efficient search and handling of adress information within the local organisation, regionally or nationally.

Journal entry/note A note made by a care giver during or after a meeting between a care giver and a patient.

Medical record A record with multiple journal notes. Usually there is one medical record at each healthcare center, but one medical record can be kept between different care giving units if *Sammanhållen journalföring* is used between the units.

Mina Vårdkontakter, MVK Regional service for digital contact between patients and healthcare providers where it is possible for patients to view their medical records online and to communicate with the healthcare personnel.

Nationell Patientöversikt, NPÖ A part of the Swedish national IT strategy for health and social care. NPÖ makes it possible for qualified healthcare staff to take part of medical record information about the patient located at other county councils, municipalities or private healthcare providers.

Patientansvarig Läkare, PAL Licensed physicians who have the responsibility for a patient.

Personal data registry A national registry containing information about Swedish citizens.

Qualitative data analysis Procedure for analyzing qualitative data to understand and interpret the people and situations investigated.

Qualitative research A research method dependent on smaller but focused samples of material aimed to understand human behaviour.

Rare diseases The European Commission on Public Health defines rare diseases as life-threatening or chronically debilitating diseases which are of such low prevalence that special combined efforts are needed to address them. The term low prevalence is later defined as generally meaning fewer than 1 in 2000 people..

SBAR A shortening for Situation, Background, Assessment, Recommendation. It is a technique used for direct and appropriate communication in healthcare organizations.

Semi-structured interviews Interviews with open frameworks consisting of some predetermined topics.

SITHS A national security infrastructure which make it possible to provide secure electronic identification. SITHS and HSA is used by Uppsala County Council to identify users of COSMIC, NPÖ and Mina Vårdkontakter also use SITHS and HSA for identification.

Socialdepartementet A ministry under the Swedish government that handles the social care, healthcare and public health questions.

Socialstyrelsen The Swedish National Board of Health and Welfare is the administrative authority for activities related to healthcare and other medical services. For example dental care, health protection, disease prevention, social services, support and service related to certain disabilities and questions about abuse of alcohol and drugs.

Swedish Nurse Organization Is the nurse's professional organization, representing the profession's area of expertise with a view to promoting research, development, education and quality improvement in healthcare.

The Joint Commission An independent, non-for-profit organization. Accredits and certifies more than 20 500 healthcare organizations and programs in the United States.

US case workers Specially trained nurses in the United States healthcare system. They manage the long-term care plans on behalf of patients diagnosed with multiple severe health conditions.

Vårdlots A professional who supports patients with contacting physicians, understanding medical records, creating cross-references between different physicians and who improves communication between all parties.

World Health Organization World Health Organization is the directing and coordinating authority for health within the United Nations system.

A Interview Table

Interview	Profession	Date
A	Director of Department at Health Center	2014-10-02
B	Nurse	2014-09-27
C	Director of Department at Health Center	2014-10-02
D	Patient	2014-10-06
E	Physician and Director of Department at Private Clinic	2014-10-06
F	Physician	2014-10-07
G	Physician and Nurse	2014-10-10
H	Vårdlots - Project manager	2014-12-02
I	Nurse	2014-09-21
J	Head of Patient Committee	2014-10-10
K	Relative to Patient	2014-10-30
L	Oncologists	2014-09-25
M	Psychologist	2014-09-25
N	Surgeons	2014-09-25
O	Internal medicine physician	2014-10-16
P	Orthopedist	2014-11-21
Q	Nurse	2014-11-15
R	Patient	2014-10-28
S	Patient	2014-10-28
T	Researcher	2014-11-20
U	Patient	2014-11-25
V	PhD Student, Department of Information Technology, Uppsala University	2014-12-02
W	Patient	2014-12-02