



## ALOHA: ACHIEVING LARGE-SCALE ONLINE HEALTH ACCOUNTS

UPPSALA UNIVERSITY, UPPSALA, SWEDEN  
ROSE-HULMAN INSTITUTE OF TECHNOLOGY, INDIANA, USA  
FALL 2009

## **Abstract**

The health care sector is constantly looking for better ways to perform tasks, ways that are more cost effective not only monetary but in terms of time and required effort as well. Currently it requires a lot of effort and many procedures to obtain one's own medical record; even when this can be obtained, these records may easily be missing much information crucial to one's health. In the upcoming technological age, society will demand that this process is improved. One way in which this industry can be improved in terms of maintaining and locating Health Care Records (HCR) for patients throughout a country is to make them accessible online.

This report proposes ways to introduce online health care and Online Health Accounts (OHA) for patients on a large-scale, national level. The white paper [White paper, EPOATTHR, 2009], produced last year, references this term. This OHA provides the patient with possibility to not only view their HCR online but also introduces new functionality that improves health care quality for the patients and offers improved efficiency for the health care providers.

# Contents

1	Introduction . . . . .	4
2	Users of Online Health Accounts . . . . .	5
	2.1 Importance of user identification . . . . .	5
	2.2 Identify users . . . . .	5
	2.3 Personas . . . . .	7
3	Health Care Record . . . . .	8
	3.1 Description . . . . .	8
	3.2 Views and Aspects . . . . .	8
	3.3 Legal Issues . . . . .	10
4	Accessing Online Health Accounts . . . . .	11
	4.1 Description . . . . .	11
	4.2 Users Analysis . . . . .	11
	4.3 Authentication . . . . .	11
	4.4 Authorization . . . . .	12
5	Online Health Accounts . . . . .	13
	5.1 Description . . . . .	13
	5.2 Health Care Record . . . . .	13
	5.3 Contacts . . . . .	14
	5.4 Emergency information . . . . .	14
	5.5 Appointments . . . . .	14
	5.6 Prescriptions . . . . .	15
	5.7 Test results . . . . .	16
	5.8 Interaction . . . . .	17
6	Related Work . . . . .	22
	6.1 Online Health Care in Sweden . . . . .	22
	6.2 Online Health Care in Denmark . . . . .	22
	6.3 Smart Open Services for European Patients . . . . .	24
7	Future Work . . . . .	25
	7.1 Prototype evaluation . . . . .	25
	7.2 Handling prescriptions and test results . . . . .	25
	7.3 Broken healthcare chains . . . . .	26
	7.4 Handle medical readings from distance . . . . .	26
	7.5 Investigate system architecture . . . . .	26
	7.6 Broader Cultural Research . . . . .	26
8	Conclusion . . . . .	27
	<b>Acknowledgements</b>	<b>29</b>
	<b>Glossary</b>	<b>32</b>
	<b>Appendices</b>	<b>32</b>
	<b>A Interview Per Edblad, Censoring Unit, CESÅ</b>	<b>33</b>

<b>B</b>	<b>Interviews with politicians</b>	<b>35</b>
1	Interview Arne Sandemo, Politician, Uppsala County Council . . . . .	35
2	Interview Johan Edstav, Politician, Uppsala County Council . . . . .	36
3	Interview Anna Karin Klomp, Politician, Uppsala County Council . . . . .	37
<b>C</b>	<b>Interview Ture Ålander, Medical Doctor, Uppsala</b>	<b>39</b>
<b>D</b>	<b>Personas</b>	<b>41</b>
<b>E</b>	<b>Survey</b>	<b>45</b>
<b>F</b>	<b>User Interface Requirements</b>	<b>50</b>
1	General Design Guidelines . . . . .	50
2	Health Care Record Guidelines . . . . .	50
2.1	Health Care Record Login Functions . . . . .	50
2.2	View Health Care Record . . . . .	51
3	Health Care Record Access Privileges . . . . .	51
3.1	Access Privilege Management . . . . .	51
4	Administrative Information . . . . .	52
4.1	Appointment Management . . . . .	52
4.2	Billing Management . . . . .	52
4.3	Contact Information . . . . .	52
4.4	Messaging . . . . .	53
5	Health Care Functions . . . . .	53
5.1	Prescription Management . . . . .	53
5.2	Test Results . . . . .	54
5.3	Referrals . . . . .	54
<b>G</b>	<b>Pidoco Prototype</b>	<b>55</b>
1	About the Prototype Software . . . . .	55
2	The Design of the Prototype . . . . .	55
3	Limitations of the Software . . . . .	55
4	Screenshots . . . . .	55
4.1	Common Components for all pages . . . . .	56
4.2	Pages within the Prototype . . . . .	56
<b>H</b>	<b>OHA System Communication Standard</b>	<b>60</b>
1	Web Service . . . . .	60
1.1	Web Service Definition Language (WSDL) . . . . .	60
1.2	Simple Object Access Protocol (SOAP) . . . . .	61
1.3	Universal Description, Discovery and Integration (UDDI) . . . . .	61
2	CORBA . . . . .	61
3	Comparison and Discussion . . . . .	62
<b>I</b>	<b>International perspective</b>	<b>63</b>
1	Sweden . . . . .	63
2	Norway . . . . .	64
3	Finland . . . . .	65
4	Greece . . . . .	66
5	Spain . . . . .	67
6	United Kingdom . . . . .	69
7	United States of America . . . . .	70
8	Germany . . . . .	71
9	Italy . . . . .	72



# 1 Introduction

The purpose of the ALOHA project was to create guidelines on how to realize a large-scale online system for maintaining and viewing patients' Health Care Record (HCR). ALOHA is a continuation on the work presented in a white paper created last year [White paper, EPOATTHR, 2009]. The focus was on the usability, architecture, cultural, international, ethical, and economical aspects of such a system. These aspects, combined with the work concluded last year, should serve to give a better overall picture of the feasibility of an online health account system which could interact with existing health care systems and how patients could benefit from such a system. The project took place from September 2009 to December 2009 and involved 29 total project members (8 from Rose-Hulman Institute of Technology in Indiana, USA and 21 from Uppsala University, Sweden).

In recent years, researchers in Uppsala, Sweden, together with the local County Council, have been testing a new system for maintaining HCR in an online, internet based environment. Then, in the Autumn of 2008, a project was conducted jointly with members from Uppsala University, Rose-Hulman Institute of Technology and the Uppsala County Council in which this idea was explored more extensively. The outcome of that project was a white paper [White paper, EPOATTHR, 2009] detailing the exploration and the conclusions found. That white paper has since had a large impact and has led to the desire to do another project which would better cover some areas which the previous project left unfinished. The goal of ALOHA was to cover some of these areas.

The major reason behind last year's project was a change in the Swedish Patient Data Law [Datainspektionen Web 1, 2009] in the summer of 2008, which made it possible for Swedish patients to view their HCR electronically and also provided the patient with some power over who gets access to their HCR. The project last year set out to do a broad spectrum analysis of the feasibility for creating an Online Health Account (OHA) system and produced the white paper mentioned earlier that strongly suggests that the public is ready to use and benefit from such a system. Their work laid ground for the work made in ALOHA where the goal was to put more depth to the subject.

The ALOHA project looked more extensively into some subjects which were only touched last year to produce a more in-depth coverage of the subjects mentioned. This report is directed to multiple countries; it is intended to help them determine if such a system of online HCRs can be achieved in their own country and if it is feasible to implement. The report also provide a baseline for implementing such a system.

In order to best cover all desired areas, ALOHA's participants were divided into five groups and each of these groups was then assigned a different aspect of the project to investigate. Those areas are as listed above – that is, the usability, architecture, international and cultural, ethical, and economical aspects of the project. More detailed information on each of these facets and how they connect a whole follows in later sections.

# 2 Users of Online Health Accounts

## 2.1 Importance of user identification

For a new system or product to be successful it has to be generally adopted. In order for this to happen it has to be easy to use, or *user friendly*. Regardless of how useful a system might be, if it is too hard to use only advanced users will use it, which is a very limited subset of the potential users.

To help make a system successful users have to be identified. For an Online Health Account (OHA) everyone that is or has been a patient of the health care system is a potential user, but not all users stand on the same ground for using the system. Some of the potential users have a lot of experience using computers while others have none at all, and some users have perfect eye sight while others have limited eye sight or color blindness. All this effect the way a system will be used by each individual. [Benyon,D.,Turner,P.,Turner,S., 2005]

Identifying users is primarily about grouping users with similar needs or requirements for the system together. Users can be grouped in multiple ways. For example, users that seek the same functionality can be grouped together (making the system *useful*), or users can be grouped together regarding their ability to use the system (making the system *user friendly*).

For an OHA it is expected that most users will want to perform many similar tasks. A patient should also be able to view their whole health care record which limits the flexibility to choose what functionality to implement when building an online health record system. This flexibility leads to the use of an approach where users are grouped according to their ability to use the system. These groupings then provide developers with a reference point when designing and implementing the system.

Listed below are a few examples of what have to be taken into consideration when developing user interfaces for systems that might be used by all types of people.

- Handicaps, such as:
  - Poor eyesight
  - Rheumatism
  - Shaky hands
  - Poor hearing
- Age
- Computer experience
- Nationality/Culture

All of these items are factors that influence the way users use computers and other systems. For a system with a wide audience, it is really important to identify the users and their needs to make the system user friendly for everyone.

## 2.2 Identify users

When designing a graphical user interface (GUI) it is important to consider how different kinds of users use the same system, as mentioned in the previous section. One way to accomplish this is to interview

the potential users, or to make a survey where potential users have to answer questions regarding their age, education, profession and computer experience. The ALOHA project developed a survey based on this information and used the results to group similar users together.

### 2.2.1 User grouping

Users can be grouped in many different ways and on many different levels. On a high level users can be divided into *patients* and *health care personnel*. In this report user refers only to patients if nothing else is mentioned.

#### Patients

In the survey users had to fill in the age range they belong to, their education and profession. They were then asked about their general computer experience as well as experience with secure login technologies, to see if there were some links between for example age/education/profession and computer experience.

Patients were then grouped together primarily by age, and secondarily by computer experience. These groups then acted as the basis for creating personas (explained in [section 2.3]) to use in the development of the prototypes. In order to cover all user needs, some characteristics that were considered common for different age groups were added to the personas. This included bad eye-sight, color blindness, bad memory, family conditions and so on.

#### Health Care Personnel

Doctors, nurses and administrative personnel are all important user groups as well, but due to limited time this project does not cover their point of view in the research. The idea is that this system will function as a read-only system, that reads from existing systems databases and does not write anything to them. Doctors and administrative personnel will then mostly continue to use the systems they normally use at the hospital.

### 2.2.2 User Survey

In order to evaluate the basic needs and experience of users of the OHA system, an online survey was created to gather data. A total of 119 people participated in the survey. Participants were asked questions pertaining to online access of health care records such as who should have access to the data and the types of information that should be available for access. A full list of the questions that were presented in the survey is available in [Appendix E]. Many conclusions were drawn from the results of the survey. For example, 46% of the people who were not interested in an OHA system cited security concerns as one of the reasons behind this disinterest. Data was also collected to get an idea of the technical background of potential users. Data such as the number of people with access to internet via a cell phone has been important in assessing how to make the system usable and more accessible to the greatest number of users possible. A table detailing many of the results gained from the survey may be found in [Appendix E].

#### Survey distribution

To distribute the survey e-mail were used. A link to the survey were sent to acquaintances of the developers together with an introduction to the project and the reason for the survey. This way a high level of participation could be ensured because of the relationship between developers and participants. However, this also meant some limitations regarding reaching all age groups desired.

When using this distribution method participants are limited to the kind of people that the developers know, and got an e-mail address to. To start off the survey participants were asked to select their age group (<18, 18 - 30, 31 - 50, 51 - 70, 70<). Unsurprisingly most of the participants were in the ages of 31 - 50 years of age, and the number of participants in the groups on both sides of this are approximately the same. See [Appendix E] for exact numbers. Distribution through e-mail also ensured that all participants had internet access, which unfortunately meant no input on what users without internet



access think about an OHA. The oldest age group were a minority among the survey participants, and is a result of the biggest limitation with this survey, the distribution technique.

## 2.3 Personas

Personas are a method that are used when developing systems and user interfaces and that can be used as a complement to user interviews [Benyon,D.,Turner,P.,Turner,S., 2005]. When designing a new system it is important to consider all potential users and what can be done to make it user friendly for all of them, this can be achieved by using personas. In an article Christine Perfetti states that if developers get a clear understanding of their personas they can design a system that fits these perfectly, and after some iteration they will end up designing a system that delights a lot more users than originally thought of [Christine, P., Personas: MDUG, 2001].

A persona is a fictional person that is created by the project team. After dividing users into groups, it is possible to identify specific characteristics that apply to each group, and then a persona is created with these characteristics. Personas usually include the following information according to [Usability.gov Web 1, 2009]:

- Name and picture
- Demographics (age, family status)
- Education, profession and major responsibilities
- Goals and tasks in relation to the system
- Environment (physical, social, technological)
- A quote that sums up what matters most to the persona with relevance for your site

Personas can then be used when designing the system to make it more user friendly. When researching and designing different pieces of functionality, developers can ask themselves whether this will actually help the personas using the system or not. If the piece of functionality will not help then the function may not be a good use of space in the interface. When designing the general look and feel of a system, personas with handicaps, like bad eyesight, have to be considered so that they will be able to use the system as well.

Personas can also be useful when evaluating the finished prototypes before presenting them to users. In the evaluation process, developers takes on the role of a persona and try to complete different tasks. This process is used to try and identify flaws in the design that might make it hard for that user group to use the system.

To view the personas used in this project, please go to [Appendix D].

# 3 Health Care Record

## 3.1 Description

A Health Care Record (HCR) consists of information stored about a patient. This information may be defined as all information that is needed to give the best possible health care. Usually, this includes information such as the patient's anamnesis (defined in the next paragraph), personal number, social and lifestyle information, diseases, medication, status, and more.

Anamnesis is the story about the patient, usually the doctor asks questions that the patient will answer. The patients can decide not to answer a question if they feel the information is too sensitive. Status is when the doctor medically examines a patient. The information in the HCR can be entered in free text but it is also possible to use search words. In ALOHA, a majority of the data in the HCR will be parsed into a table format. This will allow for increased search efficiency and make it easy for nontechnical users find what they want. Search words can be terms in the user's anamnesis, diagnosis, and many more. The health care record should be written so a patient can understand it. Reports are often geared toward medical professionals, but an online health care system needs to contain information that is easily understood by people not in the medical profession. In Uppsala, a computerized system called Cosmic is used and this data is accessible for both the hospital and the care centre [Appendix A].

## 3.2 Views and Aspects

The view of online health care accounts in Sweden seems to be generally positive [Appendix E]. Most of them tend to see opportunities with added features instead of focusing on negative aspects and risks. The main risks generated by this system are risks that is present even with health care records today. Considering the research about "Vårdkontot", when The Swedish Data Inspection Board denied the use of the system because it was not safe enough, they were referring to the risks that could come up when someone tries to physically force another individual to give them information pertaining to their health care record from the internet. However, this risk exists with any system that is in place already as well as any system that could be put in place. Both doctors and politicians have agreed that the possibilities and benefits that will come from a well implemented and widely used online health care record system will outweigh the potential risks [Appendix 1].

Politicians tend to want the health care record to be owned by the county council. This will make it easier for the patients not to worry about additional responsibility with their online account. There are always risks involved when people receive more responsibility, but this should not prevent them from the potential to receive better health care through a system like ALOHA. The ones that should be able to view Online Health Accounts are only the patients themselves, their doctors and family members who have been given consent from the patient. A possibility to get medical records for medical research is important, this will enable medicine to have better quality.

All the information of a patients health care record should be available to the patient in the Online Health Account. Politicians, doctors, and patients agree on this issue. Some doctors are having second thoughts about however, saying some of the information is useless to patients since patients don't understand all the parts of their record. This increased confusion could lead to more questions and

dissatisfaction from the patient. However, the records can contain summaries and modify their language to fit the average patient. The benefits gained are that patients will be more aware of what is written and are able to ask questions about things not understood. Patients will also be able to be a part of the treatment instead of just standing on the sidelines all the time. There are times when some information should not be seen by certain individuals who might have a mental illness, so there should be special cases where certain information should not be shown. This is also the view agreed by the politicians and doctors.

**Possible benefits of ALOHA versus current system:**

- Safety

A patient's HCR would be protected by conventional and accepted authentication and authorization methods. A log of activity will be kept to see who accesses the record and what they do to it. Even though it is highly unlikely that an intruder would be successful he will leave tracks in the system and will not pass unnoticed.

- Awareness

Patients will be more aware of their own health, they will be able to contribute and be part of the treatment. Patients will be able to connect specific instances in their life with aspects in their health issues to increase the effectiveness of health care and prescription drugs.

- Research

Through the system the medical research industry would be able to gather information about prescription drug uses and what types of treatment work in certain situations. This would make the research more effective and the possibility to evolve medicine would increase. Currently it is extremely inefficient to request records to go through from several different health care providers to see which treatments were successful and which were not.

- Structure

Instead of there being many different systems the patient needs to request their HCR from, they would get all the information available in one place. The quality would then increase and the documentation would get better. This would also allow for a patient to go to a doctor in an area that they are not from and have the doctor know everything necessary about their medical history. This can be extremely useful in an emergency situation when one is on travel.

- Medicine management

This will become easier and patients will get more information about medicine received and other alternative medicine. Notifications about when to take medicines will also increase effectiveness of the prescriptions being taken because the patient will not miss any doses.

- Test result tracking

Through the system it will become possible to see test results gathered from several health care providers and to look at the test result history without need to request the information from different locations. This will greatly improve the patients knowledge and ability to help the health care personnel in their work regarding his/her health.

**Possible risks with the ALOHA system:**

- Mentally ill patients

Mentally ill patients could be seen as a group of patients where censoring of a HCR should be performed, so that they do not view information that could harm them. However since the patient is very much aware of the treatment he/she is receiving and the health care provider always is determined to not write things that could harm the patient this should not be a problem. The possibility of something harmful to the patient being present in the HCR should instead be con-

sidered a malpractice.

- Domestic violence

One risk could be that the information in the Online Health Account (OHA) is used to oppress family members. This is a very difficult matter to assess and even if it is a very important problem in society something that unfortunately can not be solved by an OHA system like the one described in this report.

### 3.3 Legal Issues

In each country, there are many legal regulations imposed upon the healthcare industry. However, because a system like ALOHA has not previously existed, most countries do not have laws that directly address the possibility of an online health care system. Some countries do have laws that very specifically describe the process which must be followed in order for a patient to view their own health care record, which by default would make an online health care system illegal. Every investigated country had at least some laws regarding the security and privacy of medical information, which would need to be followed by any online healthcare system. As long as ALOHA follows the proper security and privacy regulations, it would be legally possible in the following countries:

- Sweden
- Norway
- Finland
- Denmark
- Germany
- Italy
- Spain
- United States of America

# 4 Accessing Online Health Accounts

## 4.1 Description

Providing users with a sense of safety and trust is of the utmost importance. Making the common user feel safe will be a prerequisite for the user to make any use of the Online Health Account (OHA) system. This will be achieved by making use of available, well known, security measures and design principles.

The OHA system will provide different login authentication based on what technique is widely used in a specific country. E.g. [BankID Web 1, 2009] provides a safe and trusted way of authentication to various internet based services in Sweden. Since this option may not be available in all the countries in consideration, options such as authentication via mobile phones could be considered as an alternative to ensure a friendly and widely used OHA system. By using standard and platform independent ways of publishing the interface to the system such as web services or CORBA [Appendix H], it will be easy to connect the system to different external systems.

## 4.2 Users Analysis

A user of the OHA may choose to share their HCR with another user, giving them the opportunity to access the information when needed, e.g. for a consultation or an emergency. Parents, for example, could be set as such guardians for their children. Patients with severe disabilities will also need this kind of help from other people in order to use the OHA. It is important that the right person is chosen as a guardian as they will have access to all information about the patient. Family and relatives who the disabled patient can trust could be chosen as a guardian. The idea is for a user to share chosen parts of his HCR rather than his whole account.

## 4.3 Authentication

A user will log into a database that is provided by each country and the workload could be spread across multiple servers if needed. The database will hold the login information for the users within its area, as well as a database of what services and actions a specific user is allowed to take.

A reliable way of accomplishing distribution of login information is by posting it to the users at their registered home address. Physically meeting your doctor or authorized authorities with appropriate identification and receiving login information is of course a viable option and may provide more initial security.

A user's session contains regulations such as an expiration date to increase security measures. Providing the users with the option of choosing their desired means of authenticating themselves provides additional comfort to them when logging in from different locations and devices. When passwords are used as authentication measures, ensuring secure password strength is one way of helping users keep their private information intact.

To facilitate the login process for every type of user, login via fingerprint can be used. Modern laptops enable users to easily authenticate themselves without keeping track of long and difficult passwords, this enables users with limited memory to easily access their OHA.

When a password is forgotten, a new one can be requested and sent by email (if settings allow), to an address registered at authorities or picked up at a suitable department.

#### 4.4 Authorization

As several entities will have access to a patient's HCR, different types of authorization will be required to enable guardians and consultants to view the record without accessing information beyond their bounds. From an ethical point of view, it is important that it is stated who has access to a patient's HCR such and what kind of medical personnel that can access it. The patient should be aware of who these people are in order to make them feel more comfortable with the system. Keeping a record of everyone who has accessed a HCR in particular will be effective as it gives the user comfort in knowing exactly who has retrieved or changed information in their HCR. Keeping an access log will also ensure judicial evidence if foul play is suspected.

According to [Datainspektionen Web 1, 2009] (Swedish law), a patient may at any time choose to block information within their HCR to a health care provider who then must comply at a moment's notice and make that information unavailable to other caregivers unless an emergency occurs. A patient can block certain health care providers and also choose to revoke such a decision, upon which information is again shared with every health care provider. For example, a patient may want to block sensitive information from a doctor or nurse which he is related to in some way. Changes to default access rights are stored by the OHA system in a database alongside user-shared access permissions.

Letting the user have access to and change their own personal contact information will ease the work for medical personnel whom today manually manage the data. It should be possible to change any kind of personal information for the user, the social security or national identification number being the only unvarying attribute.

A system similar to ALOHA exists today in Uppsala and is called Vårdkontot [SUSTAINS Web 1, 2009]. This system uses social security number for login name and a personal PIN-code for password. These usernames and passwords are dispatched by responsible personnel at the local practice and these are also the only ones who can change it. This system is still under project development and tested on a small number users with specially trained personnel assigned for administration but have overall received good judgement and has been proven to be a working method for login.

# 5 Online Health Accounts

## 5.1 Description

An Online Health Account (OHA) is an online account containing a summary of the health and medical history of an individual. This account should initially only be accessed by permitted medical personnel and the specific user. Medical personnel that access the Health Care Record (HCR) should always have a valid reason to do so, e.g. in case of emergency or doctors treating this particular patient. The initial user can grant other people access to the account. The information accessible from the account should be all information stored in a HCR.

## 5.2 Health Care Record

### 5.2.1 Content

A HCR is a collection of data relating to a specific patient's health. As the OHA system will be communicating with several sub-systems, there will be many variations of what a HCR looks like. The OHA system will not introduce yet another interpretation, rather it will follow the design of sub-systems. All data in a HCR will normally be presented from a sub-system to the user. Examples of information that an HCR can include are medical history, medical encounters, progress notes and test results.

### 5.2.2 Storage

The OHA system is more concerned with gathering information from sub-systems containing relevant information rather than storing HCR's. Since a record needs to be reloaded every time it is accessed, in case updates have been made, there is no need to store the HCR in a separate database. When retrieving a HCR, the option to exclude images and large attachments should be available to relieve server load. The attachment option can be set to select pictures automatically as well, but for most users, a file attachment is not critical, the text and diagnosis are the most important items.

### 5.2.3 Log

Part of the security of the OHA is the log. It shows who has accessed the HCR and at what time. It also shows all changes that have been made to the HCR. Administrative personnel can see which internet protocol (IP) address the HCR was accessed from. The log is important since it helps the user feel confident and secure about their HCR and aware of the actions performed on it.

Since the OHA is going to be accessible from multiple places and by multiple persons, it is obvious that there is going to be a log showing who has read the HCR and what changes that has been made to it. But who should be able to read the log? If the full log is available to all patients as it is to doctors and nurses, could there be sensitive information that might be harmful to the patient? Many patients would probably want to have access to the full log in order to see who has accessed it and who has changed it, mainly because someone who should not have access to the HCR has read it or made changes to it. On the other hand, some patients may not be in the condition to see all this information as it could be harmful to them in some way. But giving just some patients access to their full log might not be the best and easiest solution either. Who decides if a patient should have access to the full log?

Is it politically correct to give just some patients access to their full log? Questions of this sort needs to be taken into account.

### **5.3 Contacts**

The OHA enables the patient to keep useful information readily available. Contact information for health care personnel and for close friends and family will be stored, both for the patient's ease of use and as a way for health care personnel to have a quick way of contacting close relatives in case of an emergency. Whenever a patient has an encounter with a hospital and is treated by a doctor, it is convenient to remember the name of the doctor if the patient has follow-up questions or additional information to provide. The OHA will feature a list of the recent doctors a patient has had appointments with and make it easy to contact them. This feature will function like an address book and will not only include your doctors but also your next of kin and other contact persons. A patient can interact with the persons in their address book by sending messages, booking appointments and selecting a new family doctor. Health care personnel are added automatically to the address book when they access a patient's HCR. Family members are automatically added as well. This list of contacts can be edited as desired. A contact can be manually added and a user may have as many or few as the user desires.

### **5.4 Emergency information**

Access restrictions in the HCR may be disregarded if health care personnel see the situation as an emergency. Providing these personnel with the full picture of a patient's situation may be the difference between good and bad health care when treating a patient in an emergency. It is important to keep an access log to let patients argue whether medical personnel had the right or not to access their uncensored HCR. In case someone accesses the HCR without a valid reason, action will be taken. Ignoring restrictions should always be an active choice, and not something that routinely occurs.

### **5.5 Appointments**

Today when a patient want to book an appointment with a doctor, he or she must either visit the actual doctor at the hospital or call the hospital. If the patient cannot attend a meeting it must be rebooked, which is accomplished either by visiting or calling the hospital. All these kinds of administrative tasks take up both time and resources for hospital assistants and doctors. For instance, tasks such as rebooking a cancelled appointment or reminding a patient about an upcoming appointment take up several minutes...and the patient might not even answer! Online Health Accounts (OHA) will enable patients to manage their appointments in a much more easy and efficient manner.

Through this system patients will be able to see their currently booked appointments online, along with a history of previously booked appointments. Managing appointments will also be possible so that they can easily be rebooked, deleted, or booked when the doctor is available. Allowing patients to rebook or cancel their appointments through online health accounts may lead to holes in the schedule of the hospitals if they are canceled or rebooked on short notice. To fill these vacant spots, a solution may be to announce them as drop-in times instead of having the times ending up unused. The appointment part of the system would definitely change the work load for the assistants and doctors in a hospital. As of today much of their time is spent handling the patients bookings. With the online health account these tasks are managed completely by the patients online, freeing up time for the assistants to handle other things.

With patients booking appointments themselves, thus being more active in their booking, it would most likely improve the rate at which patients show up at their appointments. Missed appointments is a cost for the hospitals which preferably should be avoided. Connected to the appointments functionality is also a reminder function. The reminder function can remind patients either by email or a phone text message about that their booked appointment is approaching. Having notifications sent out to confirm booked times via email or text message is a simple way to make patients feel that the system is robust.



### 5.5.1 Referrals

The referrals a patient receives from their doctor will be displayed as appointments. This will ensure that the patient is aware of any upcoming appointments with a doctor that they have been referred to. The patient will also be able to find past referrals by searching through their past appointments. To ensure that referrals are distinct from other appointments an indication should be placed on the entry.

### 5.5.2 Payment

Having a payment system connected to the online health account system may also lower the administrative costs to hospitals. The workload of the assistants also consists of handling money and payments, in addition to scheduling appointments. Invoices are a cost for the hospitals as well; for example managing them, sending them out, sending out reminders and keeping track if people have paid their invoice.

An online payment system could save both time for the assistants and money for the hospitals by removing the need for them to handle money and invoices. The total time taken for a hospital visit may also be shortened, because this system allows patients to pay for the visit in advance or when they have returned home.

One feature of the payment functionality will be to store your credit card number for payments. This will make it possible to have your bills paid automatically as soon as they appear in the system, saving time for both the patient and the hospital.

## 5.6 Prescriptions

The online health account should have support for these main functions:

- Prevent over consumption of drugs  
Since all prescribed drugs are stored at one place it is easy to see if drugs are over-used. Alerts can also be implemented for when people receive too many drugs or even add block for patients that misuse drugs.
- Renew prescription  
Patients have options to send requests for renewal of prescriptions to doctors. So now doctors only need to approve or deny the request received through the system without having new appointments.
- Home delivery service for drugs  
From the OHA it should be possible for patients that have need for that to order drugs to the home address.
- Prescription Printing  
Some people prefer having their prescriptions printed to have a physical evidence of their ordination and therefore a print function should be available.

### 5.6.1 Benefits

A prescription system that is connected to pharmacies and the online health accounts may have several positive effects on the economics of the pharmacy's operation. The pharmacy can obtain more direct information on the types of medicine that are often prescribed to patients. This information can be used within research, but more than that it can be used to streamline orders and alert for overuse of medications. With this statistical information it will be possible to streamline purchases from the manufacturers which may lead to reduced costs, and this will reduce the risk of purchased medicines being left unused and thrown away. The system will give pharmacists an improved understanding of what orders are coming so that patients will not have to wait as long once they arrive. On a larger scale the manufacturers could have use of the connection between the doctors and the pharmacists in the same way as they do market surveys. It will be easier to let the market rule the production this way.

If the same type of medication is used too frequently by patients, it is a risk that they will become

more immune to that medication. This type of problem will only result in more people being hospitalized with requirements of more expensive medications.

Medical management systems already exist in the form of e-prescriptions, and today the system “vårdkontot” is already using these e-prescriptions. This has worked out well as those who used the “vårdkontot” have given lots of positive feedback. Yes it could still be more effective in some areas. Patients could have more overview on what medicines they are using and why they should take that kind of medicine. Today, many patients have got more medicine than they sometimes might need. The patients do this because they think that it might be good to have in case it becomes necessary, but in reality they never use it.

## 5.7 Test results

One of the main features that OHA will include is the ability for the patient to view his test results. This can include several different types of tests and will allow the patient to have access to all the information relating to the test. While this will be extremely beneficial, it also presents some risks to potential users as well.

One issue with publishing test results is that some material could be harmful for the patient, a patient may not understand the test results and could become needlessly scared. At the same time, the content of the HCR should not be censored, because that would put constraints on the HCR which could damage the relationship between a patient and their health care provider. Balancing these measures and the ability to guarantee the patient’s safety is a major aspect that needs to be considered in the ALOHA project.

A common view of the interviewees [Appendix C] is that all the information should be available for the patient, including their personal test results. Test results are often not that sensitive for the patient. However, users should be able to choose how they want to be notified for each type of test. E.g. for a patient that is undergoing a cancer test, it may be more beneficial for them to have a call explaining the test result to them prior to seeing the information in the OHA. Some test results may also be better suited to be mailed to a patient, which is something that is not currently done in Sweden. A patient should at least have the option of choosing how he wants to receive the news. If a patient wants to receive the news with the patient’s family in the privacy of his own home, then the patient should have that right.

According to interviews performed in the ALOHA project, few people believed that patients could potentially harm themselves when receiving bad news. A possible worst case scenario could be a psychiatric diagnosis. e.g. if the patient is not aware of his mental condition and reacts badly because of the news he receives. These kinds of situation are extreme and should be dealt with in a way proper to the situation.

Having patients reading test results by themselves could lead to a lot of misinterpretations and patients drawing their own conclusions about matters that they do not really understand. That is why there is a clear danger in writing a HCR in a way directed primarily to medical professionals. The risk of misinterpretations is always a possibility, even if a patient talks to a doctor. To better assist the patients, the results should also be summarized and targeted toward a audience that is not proficient in the medical field.

These scenarios show that the system needs to be flexible enough so that the patient’s needs are met. When interviewed, some of the medical staff [Appendix C] involved in part of the Sustains Project [SUSTAINS Web 1, 2009], agreed that the patient should be allowed to see the whole HCR. However, they did say that sensitive material was rarely an issue in their clinic and that there might be reason for some censoring if it was used by Uppsala University Hospital.

An online system that presents these test results together in an understandable manner will be an

enormous time saver. A lot of administrative work within this area could be reduced by having automatic messages and notifications via the online system.

Work efficiency will be improved in the way that patients will be treated faster and more accurately. This is also dependent on how results are presented. If results that are considered more important for the patient are highlighted this will be a gain both in terms of efficiency and patient safety.

## 5.8 Interaction

This section describes how the different parts in the Online Health Account interact and what the user experience is intended to be like. The overall layout is presented at first, and then specific functions are presented in more depth.

### 5.8.1 Overall Layout

The first thing the user sees in the system is the login screen. If the language selected by default is not at satisfactory, the user may change this by clicking the desired country flag corresponding to the language desired, displayed directly above the login box. The user then needs to provide some kind of authentication. This authentication could be user name and password, an authentication code via SMS or via a standalone device or a bankID. If the user has forgotten his password it is possible to get help with this by clicking the *Forgot your password?* button. Similarly in the case of any other login-problem, the user will always be able to get help regarding the issue.

Once the user has clicked the *log in* button, an introduction page appears where the user will be presented with some introductory text which explains where support about the system can be found. The user is also informed that it is possible to change the layout. Lastly on the introduction page, the user is asked to choose from two different standard layouts, one with a simpler, more direct design, and one where more information is displayed. There are also screenshots of these different layouts to help the user choose the one with which he or she feels most comfortable.

Once in the system, the user has one header bar at the top of the page, which displays the name of the user, the ability to quickly change language of the page, and the size of the font. There is also a search bar in which the user can search for anything within the online health account. For example, if the user wants to know what happened on a meeting with a doctor five years ago, all the user has to do is to enter the year or month the meeting took place, and the user will be presented with all the meetings that year or month. The more accurate the user specifies the search, the better the results will be. To the right of the search bar is a *log out* button, for when the user wants to leave the system.

The left side of the screen contains a menu bar in which all the functions of the system are listed for quick and easy access. The list of functions is divided into three sections: *Main*, *Medical Functions* and *Additional Functions*. These sections will be collapsed except for the section currently marked, which will be expanded, to make it easier to separate the different sections and functions and to enable the user to more easily focus on what is interesting at the moment.

In the beginning the *Home* button in the left menu bar will be marked or “shadowed” to indicate that this is where the user is located at the moment. On some buttons, for example the *Messages* button, there is an indication of how many new messages there are, so the user doesn’t have to actually click the button to check if there is any new messages available. This is indicated by a number to the left of the button title, for example “Messages (2)” meaning that there are two new messages to be read.

On the body of the page, below the top header bar and the left menu bar, is where the actual information is shown. In the beginning this shows the main page. The main page is a page with the six most commonly used functions, easily accessible for the user not so experienced with computers. When the user clicks one of the six buttons or one of the buttons on the left menu bar, the body will be updated

to view the page desired.

### 5.8.2 Messages

On the left menu bar, the user sees the opened section *Main* with the sub-function *Messages* together with a small number in brackets. This number shows the user how many unread messages he has in his mail inbox. The user gets displayed his inbox as a default. Further functions in this sub-section are to display the sent messages (by the user) and to send new messages.

### 5.8.3 Support

The support function of the Online Health Account system currently provides two sections: *FAQs* (Frequently Asked Questions) and a *Tutorial*. The FAQ page shows the most asked questions as clickable links, structured by subject specific headlines. Statistics needed to determine the questions that appear here could be provided by the support instance. If the user clicks on one of these links, it will be opened and the answer displayed. Other open question-answer combination will be closed automatically in that case.

Furthermore, the user has the option to ask questions in a text box at the bottom of the FAQ list. These questions are processed by the system support center. Replies will be sent to the message inbox of the user in the Online Health Account system. In the Online Health Account System, more possibilities to contact the system support may exist, such as a hotline function when email is not an appropriate tool or for disabled persons. For the final system it is also worth considering implementation of a medical hotline which can help with any kind of medical question, such as interpretation of lab results, drug descriptions, and health record entries.

The tutorial subsection will provide an introduction to the Online Health Account system:

- First steps (including the most important functions and settings)
- Links to a corresponding online help

The name of the tutorial subsection will be adapted to a native language expression in order to show inexperienced user what to expect from this section. For the “final” Online Health Account System it is worth considering that the tutorial subsection is displayed as a default when the support function is activated for the first time. It is also foreseeable that the manual of this system could be found in the *support* section.

### 5.8.4 Health Care Record

The subsection *Health Care Record* represents your online patient record including your profile data, such contact information, as well as access to further records from others such family members and others who have allowed access.

Per default, your medical facts are displayed on top of the page as a summary. They become editable if the user clicks on the *edit* button at the top right corner.

Below medical summary, the entries in the user’s health care record are displayed in a list giving the most important information on the corresponding entry. The user is able to click on each line, which will also be highlighted by a mouse over. When the user clicks, the line will be expanded and additional information will be displayed. This description will include a link to a detail page which contains every available data connected to this entry. This functionality is currently not possible in the prototype but should be implemented in a later version of the system. The list can be searched and filtered by the option shown below the list. Every filter, such as predefined entries, change instantly influences the list of shown entries. The entering of a calendar date or a search term requires that the user presses the *search* button to update the list.

Under *My Profile* the user can access and change his contact information. If the user clicks on the name of his current family doctor, the user is brought to the contacts page, highlighting the information about his family doctor. There he can also change this relationship.

Below the contact information, the user can change the restrictions of access to his health care record. The *edit* button here will lead the user to the corresponding settings page.

### 5.8.5 Test Results

In this view, all of the test results get listed in order to give the user an overview of all of the results from tests taken in the past. For example, if an X-ray examination has been taken recently, the result from that examination is presented on the top of the list. The most recent test result is always placed at the top of the list. In the list there are four fields: *Doctor*, *Date*, *Type* and *Description*. If the user wants to sort the list by doctors' names, it is done by clicking the *Doctor* headline. This will list all the test results in alphabetical order. This option is available for all four fields. Clicking on an item from the list will bring up a more extended view of that item, showing the result as a whole.

Furthermore, it is possible to search for a specific test result by entering the required information in the search box below. For example a user can enter the phrase "X-ray" to list all the X-ray results received in the past.

### 5.8.6 Prescriptions

The prescription page shows all of the user's prescriptions. This page is divided into two tabs: *Current prescriptions* and *History*. The *Current prescriptions* tab lists prescriptions the user is currently supposed to be taking. This list has five fields: *Name*, *Issue date*, *Expiration date*, *Doctor*, and *Dosage*. This list works in the same way the Test Results list works, enabling the user to sort the list in the way desired. Clicking an item in the list expands the item giving a more detailed view of that item. The extended view also offers a way of contacting the doctor responsible or making a request of renewing the prescription.

The *History* tab is very similar to the previous tab with the only difference that the list is showing prescriptions taken in the past. In both the *Current prescriptions* tab and the *History* tab it is possible to search for specific prescriptions in case it is difficult finding the prescription item in question.

### 5.8.7 Appointments

Clicking the *appointments* tab in the left menu bar will bring the user to a calendar view, showing appointments, reminders, the doctor's available times and more. This section uses a standard calendar that should be easy to navigate for most users. The user can add an appointment or a reminder by clicking *New event*. Below this, on the left side, a box containing all the dates is placed to make it possible to quickly pick a date to see what is happening that day or if a new event is to be created on this date. Going further down, the user has the ability to customize what calendars that should be shown. These calendars are divided into two sections: *My calendars*, and *Other calendars*. *My calendars* contains the user's own appointments and reminders while *Other calendars* shows calendars imported from other places. This could include public calendars such as the local hospital's visiting hours, or perhaps a schedule for a group therapy session or a specific doctor's available times. These calendars all have different colors to make it easier to distinguish what type of event an event is. For example a reminder could be green while an appointment might be red.

In the body of the page the list of all the events are listed. In the standard view, only three days are presented at a time; however, this can be customized if the user wants to see only one day at a time or if the user wants to see a whole month at a time. Clicking an event will bring up a more extended view of that event in case the user wants more information about the event or if an edit of the event is desired.

Below the calendar view is a search box, enabling the user to search for events using different pre-defined search filters. For example, it is possible to search for all the available times of a specific doctor within a desired time span, and after clicking the Search button the result from that search will be presented to the user shortly after.

Under the referrals tab the user can view all the referrals made by doctors in order to easily be able to make appointments accordingly.

### 5.8.8 Emergency Information

The emergency information page is a page for quickly getting the most vital information about a patient. Under the *Critical* tab the medical concerns, current medications and other necessary information are shown. In case of an emergency, this enables anyone with the proper authentication or rights to fetch vital information about the patient in question. The information presented on this tab is edited by the doctor only.

The *Overview* tab shows a bit more detailed information about the patient. Of course, this could be read in the health care record, but it is listed here for quick access. This page is also editable by the user, in order to add other information.

The next tab is the *Notify* tab. Here all the people to notify in case of an accident or an emergency are listed in a quick and easily accessible way. Lastly, under the *Shared emergency info* tab it is possible to customize who will have access rights to view the emergency information of the patient in question.

### 5.8.9 Contacts

The Contacts tab contains two tabs: Medical contacts and Family contacts. Under the Medical contacts tab all contacts that are related to the user's health care are listed. One item is one contact. At the top of the list is the most important medical contact, namely the family doctor. Below the family doctor the remaining doctors are listed. In an item there is information such as name, department, type of doctor, contact information and what visiting hours the contact has. The user has the possibility to edit the contact or add a personal description about the contact. It is also possible to send a message to a contact by pressing the *Send message* button, or send a request for a meeting via the *Book appointment* button.

Most of the time, a medical contact will be added to the list of contacts automatically when the user first gets in touch with that person, but if the user wants to add a custom medical contact this is possible via the *Add contact* button below the list of contacts. If the user is not satisfied with the current choice of family doctor, it is easy to make a request for a change of family doctor by pressing the *Change family doctor* button. This request will be evaluated by medical staff to prevent a too frequent change of family doctor.

In the *Family contacts* tab, all the contacts currently enlisted as family members of the user are listed. Usually this is where a spouse or children are listed. This list can be edited in the same way the medical contacts can. More contacts can be added, even though this is added automatically in the standard case. A contact can also be deleted but this can be restored if an error was made.

In case of an emergency or if an accident has occurred it might be required to contact a family member to get further information about the user. In the bottom of every family contact there is a checkbox that can be checked to make that family contact become a contact person in case of emergency. This is closely connected to the Critical info page, where the notify tab lists the contacts to be notified in case of an accident.

### 5.8.10 Settings

This system addresses a broad variety of possible user types. Therefore it is supposed to be highly customizable, yet user friendly. Under the sub-group *Settings* the user finds two sections: *Main Settings* and *Advanced Settings*. It is thought that the main settings should include all adjustable features of the system which the user probably wants to set at least once in the system usage life cycle. Currently this includes the possibility to choose between a function oriented main page or an information oriented start page. In addition to that, one can currently set privacy related system properties.

Each possible setting is connected to an additional help link placed next to the setting (e.g. “what does that mean?”). By clicking on this link a kind of pop-up windows shows up, explaining the corresponding function or setting while the background of the not covered page fades to grey. The user can close this pop-up by clicking on the “close” button on the top right corner of the pop-up.

The advanced setting currently provides settings regarding the viewable info boxes and function button on the main page. By selecting or deselecting the checkboxes the user can choose which are to be displayed. It is planned that this section includes all settings which advanced or frequent users would like to have to adjust or customize the system appearance to their needs and habits. This might include a customizable side bar menu, changing colors, setting default font size, content of information boxes, etc. Besides the customize settings in this section, it should be possible to change the appearance of the main page directly as well – for example the size of the info boxes or the layout.

The user must always press the *Save my settings* button in order to save changed settings. If the user has changed any possible option a message is display and highlighted like *Settings have been changed. Please press the “Save my Settings” button to save your changes.*

### 5.8.11 Log

The log can be accessed either by the function *Log* in the left side bar menu or through various sub-functions in the other system parts, probably filtered accordingly. In general, the log displays a list of actions in the health care record and the Online Health Account system itself. Not only the patient’s actions are monitored but also the actions of any other user which has access to the health care account, such as medical staff or family members. When the user clicks on one entry line, it is expanded and more information is shown. It is possible to include a link into this additional description which can lead to a corresponding details page.

Below the log entries list is a box with possible filter options and a full text search. The predefined filters influence the list instantly, while the calendar and the free text search function require that the user presses the *Search button*.

## 6 Related Work

Research of eleven European countries has shown differences of how far online health care has been developed. The countries researched were Belgium, Denmark, Estonia, Finland, Germany, Great Britain, Greece, Italy, Norway, Spain, and Sweden. A clear geographical distinction can be made, where the Nordic countries have come furthest when it comes to research and development of online health care. The countries of continental Europe have, according to their specific health departments, no operational systems of online health care. Sweden has several projects in development, including this project and a pilot project has successfully been carried out in Uppsala called Vårdkontot [SUSTAINS Web 1, 2009], where almost 500 patients received access to their health care record online. Furthermore, Finland has shown great interest in the concept of online health care and research of a system called Feelgood is well under way. The Feelgood project is currently in a phase where an outline of how to realize the system has been presented.

### 6.1 Online Health Care in Sweden

A previous attempt at making a system like the ALOHA system has been carried out in Sweden, with a system called Vårdkontot, where patients mainly had access to their medical records together with some additional functions, for example booking appointments and sending questions to your doctor. Vårdkontot (also known as Sustains) [SUSTAINS Web 1, 2009] started out as online access to some basic health care functions from the Uppsala University Hospital, and then after a evaluation by the users had been done it developed in to a system where patients could read their own health care record together with sending messages to their local clinic and it was well met by the patients who got to test it. Vårdkontot did however need to be shut down because the Swedish law did not approve anyone else than the health care personnel to be responsible for handling the health care records. The project has since then been picked up by Ture Ålander as a research project for his private medical practice and has been running since with good results and satisfied users.

### 6.2 Online Health Care in Denmark

One of the most interesting countries when it comes to Online Health Account (OHA) system is Denmark. This is due to their e-health portal, [www.sundhed.dk](http://www.sundhed.dk) [Sundhed Web 1, 2009], which is a working, nationwide online health care system. The Danish public health sector realized early on that there is need for a system that focuses on patient interaction as well as sharing of sensitive information. A relatively small amount of money was invested, considering the scale of the projetct, and the cooperation between Danish health authorities led to the launch of Sundhed in 2003, after only nine months of development. The first goal of the portal was to expand the existing online services and the second goal was to improve health care.

Sundhed was implemented in three phases between 2003 - 2004 and new functionalities are being added regularly. Before the portal health care information was stored in separate databases, using different standards, scattered all over the country. The process of bridging the databases in order to create a nationwide system provided for the complex structure that is the foundation of Sundhed. However, the user interface level has been kept as simple as possible.



Authentication is always important when dealing with high-security information online. Sundhed uses a form of electronic signature that every citizen can apply for.

The portal gives Denmark's 150,000 health care professionals access to a variety of data about their patients. Easy access to different kinds of patient information such as test results, electronic health record and current prescriptions provides a platform for efficient care. There are also several benefits to the patient when using the system. They have the ability to take part in their own treatment through easy access to their health care information as well as a variety of other features. The following is a complete list of features as presented on [www.sundhed.dk](http://www.sundhed.dk):

Online services available to the general public:

- Directory of names and addresses
  - Contact information
  - E-services (booking, prescription renewal, consultation)
  - Health appointment calendar
  - Comparison of prices, quality and accessibility
  - E-commerce (pharmacies)
- Information about prevention, treatment and coping
  - Contact information
  - Medical information (eg. information about treatments)
  - Waiting list information from hospitals
  - Preventive medicine
  - Health laws and regulations
  - Patient to patient dialogue in online patient networks
  - Test yourself
- Access to own health data
  - Cross-sectorial personal electronic medicine profile
  - Patients medical history (since 1977)
  - Online Donor Registration and access to own data
  - Online Living Will
  - Online Electronic Health Record from hospitals (not yet available in all parts of Denmark)

Online services available to healthcare professionals:

- Information for general practitioners
  - Patient appointment calendar
  - Web access to laboratory data
  - ICPC search of diagnoses from general practitioners electronic healthcare program (Linkportal)
- Other data
  - Patient records (medicine records, medical records etc.)
  - Waiting list information from hospitals
  - Secure e-mail communication
  - Encyclopedias (Cochrane etc.)
- Regional information
  - Contact information (authorities, departments, health personnel)
  - Visitation information from hospitals/regions
  - Preventive medicine

- Health laws and regulations
- Laboratories and consultants
- Regional health reports

In January 2009 the site had 304,000 unique, registered visitors out of the 5.4 million Danish inhabitants. Economically the site has proven to have a very high maintenance cost, but many of the features provided by the site have cut costs in other areas. One example is the implementation of a server that handles prescriptions, generating an estimated annual saving of 12 million Euros due to automatization. Medication errors also decreased which has led to savings as well.

### **6.3 Smart Open Services for European Patients**

Another project relating to ALOHA is an EU initiative called [Smart Open Services for European Patients Web 1, 2009] (epSOS). epSOS is organized by a coalition of twelve EU countries and enterprises to promote interoperability between the large set HCR systems currently on the market. The project will achieve this by realizing a collection of goals, including

- Defining what data a patient summary consists of.
- Defining requirements and dataset needed to work out an international ePrescription service.
- Define requirements to access the information above.

Whilst a timeline has yet to be composed for epSOS, a work plan has been finalized. It states that each country is to contribute with different work packages, taking advantage of local competences

# 7 Future Work

This is the second year that the university has collaborated with the county council and on the topic realizing Online Health Accounts(OHA). The overall feeling is that much of the research needed to make a valid decision on whether to apply OHA or not was covered, without getting too detailed on the technical issues. This paper gives a good overview on what the possibilities are. More research is to be done on actually how and when it is to be implemented.

There should have been some more interviews with patients who have experiences with similar systems. It would have been interesting to find out what the users of the Sustains system [SUSTAINS Web 1, 2009] think about the system and what opinion they might have. Their contribution could have helped in developing a prototype.

Future work could include research in additional systems and additional countries. For this project the research has been focused on how some of the health care systems that are used in Sweden and in the United States work. To get an online system that can be used in several countries, a more thorough research of health care systems in several other countries should be performed.

In this project, the focus is on the patient's view of the system, as the main user. Future projects will have to investigate the functionality and usability aspects that need to be provided for other users like medical staff or administrators. Effects are still to be tested and evaluated, e.g. if doctors will take time from doing medical investigations to write nicer looking medical records, if patients will be able to understand these notes, if this will lead to improved health care and healthier patients and if this will save time and costs and if so, for who?

## 7.1 Prototype evaluation

Even though the prototype fulfills most of the interface requirements (see also appendix E) mentioned by the participants in our survey and provided by previous projects and courses, there are still other aspects that could have been accomplished. Future work considering the development of a prototype could evaluate the prototype with the given personas and include a workshop with test subjects solving tasks and browsing information that covers the different functionalities of an OHA system. Similar tests have been done with paper sketches which the prototype is based on. These usability tests will help to make sure that our system is designed to best suit the potential users. Following these tests, there will probably be design changes to the interface and workflows based on the feedback from the test subjects.

Sadly, a majority of the test subjects for the prototype and the survey takers have been young or middle aged as well as very experienced in computer/internet technology. In the future, usability related research with a focus on elderly and/or people with poor or no computer experience would be desired.

## 7.2 Handling prescriptions and test results

Handling prescriptions and test results are things that needs further research. This area could easily be one of the most critical parts of the system if it will be realizable. There are technical and safety aspects, as it handles critical information that should not be accessible to anyone except the persons

concerned. But it also involves the ethical questions. Broader ethical research is needed in order to establish a conclusion on how much critical information this system could cover i.e. what test results can be sent here and what should be discussed in person with a doctor.

### **7.3 Broken healthcare chains**

The majority of returning patients in the health care sector are the elderly and many of them are being sent to hospitals on regular visits. If the same work can be done at the geriatric care, it would save a lot of time and resources for the hospitals. For this to work, the employees at the geriatric care should be enabled to review the patients journals and edit them. This is not possible today and is often referred to as a broken health care chain. Interaction and communication between different health care providers is often expressed as something that could be improved. Duplicate work such as writing health care records and administration would be reduced this way. Standard treatment that could be done at a geriatric care for example would cut costs and save resources for the health care. Future work could be to investigate whether the OHA can improve the cooperation between hospitals and care centers.

### **7.4 Handle medical readings from distance**

Remote tasks such as to get blood glucose readings from a distance would be a beneficial function of the OHA system. With proper tools, a patient's readings can be uploaded directly to the journal system. Doing this from home or from a geriatric care for example will save time and resources for the medical personnel. This data will be available for the responsible doctor of a patient through the online health account. Future work could investigate more on the risks and benefits of an OHA system on this.

### **7.5 Investigate system architecture**

Considerations should be made about the system architecture that should be used. It is a good idea to look at already existing systems, such as the Danish eHealth portal [Sundhed Web 1, 2009] or the Swedish health care information system COSMIC [Cambio COSMIC Web 1, 2009]. As many systems as possible should be evaluated, concerning aspects like the expected size of the system, the required response time and the desired reliability. Then, the best practices that were used to design those system should be used.

Another thing that should be looked upon is what users, may it be health care personnel or patient, feel is good and bad about the different systems. These findings should then be used when deciding on the design of the system architecture. For example, one of the main success factors of the Danish system [Understanding Sundhed.dk Web 1, 2009] is that it is build around the patient, giving him security and confidence towards the system, therefore encouraging him to use it.

### **7.6 Broader Cultural Research**

Though some research has been done regarding the health care systems in the different countries, there is still quite some more that can be done. This project was limited to Europe and the USA. There could be research on a wider range of countries, that is countries from Asia, Africa or South America for example. The cultural differences would be big and it would be possible to get another perspective on the project.

The research of countries could benefit from focusing more on the cultural aspects. That means how people of different cultures live and act in groups. This should also cover the ethical differences between cultures since this may limit the usage of the system.

Furthermore there were some questions that didn't get answers in the area. Hopefully a continuation of this project can help find these answers.

## 8 Conclusion

Internet-based services have expanded throughout the world today. A lot of services such as banking, a service that have historically been done by administrative personnel, has now become prevalent on the web. Many of these services allow for greater interaction with the end-user, and often offload some of the workload onto the users themselves. These small tasks that are completed by the customers result in such benefits as error-free checking, improved interaction between the customer and the service provider, and a feeling of empowerment over the customer's own information. The ease of use for customers motivates them to use Internet-based systems, and Internet today creates endless possibilities for these systems.

Today's health care records have been digitized to a large extent, but the relationship between the patient and the health care provider has not changed. With respect to the current Internet age there is opportunity to further develop the health care sector and move a lot of the administrative work to the patient. The ALOHA project researches this important aspect and provides guidelines concerning how to achieve a large-scale online health account system.

Regarding usability, the research has been focused on the patients as the biggest user group, which was addressed by the online survey. Based on the survey results, subgroups in the patient group were identified and refined into personas. These personas laid the groundwork for a prototype designed to not only conform to usability aspects but also to the demands, concerns, and limitations of the participants of the survey.

Based on these results, as well as the product of extensive research, many decisions and recommendations regarding the overall architecture of the system have been made. The Online Health Account (OHA) system should be able to connect to different types of health care system's. To make it easy for other systems to implement support for the OHA system, the communication should be implemented using standard communication technologies such as web services and CORBA. Using these technologies will ease the implementation process since a large number of tools are already available to aid when implementing these technologies.

Creating a safe environment for the user and giving him or her different options of authentication makes the user feel comfortable with the OHA system. Some users are not able to use a computer to view their Health Care Record (HCR). It is therefore convenient to give relatives access and in this way making sure everyone can make use of the benefits of the OHA.

People interviewed in this project have agreed that there should not be any form of censorship for the OHA. The patient will have full access to their HCR and have the responsibility on handling this information. If a patient were able to censor information, it could prove harmful for themselves because they might be censoring vital information of which the doctor needs to be aware. Shifting this responsibility from the health care providers to the patient gives the patient more freedom but much more responsibility.

Test results should be treated with care. Ultimately, it should be the patient who decides how he or she receives important results. There are risks for misinterpretation, but the doctors have to change the way they write the HCR. In the sustains project they did not have these problems. Tracking of the

test results leads to free error-checking, the patient knows a test have been done and traces it until the test results are published.

The security issue was not a threat as the same issues exist today in the Banking systems and there have not been a lot of problems there. In the event that someone would try to read the HCR, it would be much easier to trace the intrusion than if it was in a purely paper-form. If anyone abuses the information in someone else's HCR, it would be a crime but it is not a reason to avoid realizing OHA. The patient should decide which people get access to his HCR.

The OHA presents functions that will reduce administrative work for the health care personnel. The workload can be reduced if more responsibility is moved from the doctor to the patient. Tasks that could be completed online by the patient with the ALOHA system will liberate more resources within the health care sector and allow them to be allocated towards other services. As the average age of the population gets older, the health care industry will have less money to spend, while having to treat more patients. That is why this project is so important.

From an international perspective, it is clear that there is an overall positive attitude towards the implementation of an OHA. Whether or not it is possible by law to implement a system that includes an electronic health care record feature remains to be fully addressed. While a majority of the countries researched do allow this, it is a complicated matter that is not perfectly clear in all countries.

The privacy of medical information is highly valued by potential end-users. Most of these users will only use this system if the security is of an exceptionally high level. However, the success of other high-security systems such as online banking has led to an increased level of trust for technology.

# Acknowledgements

Special thanks to everyone who have contributed and taken their time to help us. Your contributions have been greatly appreciated and influential.

Benny Eklund (Uppsala County Council)  
Maria Pettersson (Uppsala County Council)  
Charlotta Gullbrandsson (Uppsala County Council)  
Fredrik Borg (Uppsala County Council)  
Anne Björk (Information Doctor)  
Arne Sandemo (Politician Uppsala County Council)  
Börje Wennberg (Politician Uppsala County Council)  
Johan Edstav (Politician Uppsala County Council)  
Anna-Karin Klomp (Politician Uppsala County Council)  
Per Edlund (CESÅ, Uppsala University Hospital)  
Cary Laxer (Rose-Hulman Institute of Technology)  
Mats Daniels (Uppsala University)  
Åsa Cajander (Uppsala University)  
Ture Ålander (Ture Ålander Family Doctor)  
Torbjörn Söderström (Uppsala University Hospital)  
Brian Caruso (Epic Systems)  
Usability Group Survey Participants  
Leif Lytkens (The Skandion Clinic)  
Per Olof Egnell (Lule University of Technology)  
Jaakko Lhteenmki (VTT Technical Research Center of Finland)  
Niilo Saranummi (VTT Technical Research Center of Finland)  
Steinar Pedersen (Department of Telemedicine at the University Hospital of Troms)  
Silvia Mancin (Arsenà.IT, the Telemedicine Consortium of Italy)  
Niels Rossing (MedCom Organization of Denmark)

# Bibliography

- [White paper, EPOATTHR, 2009] White Paper, 2008, Enabling Patients Online Access To Their Health Records, 2009-03-23
- [Datainspektionen Web 1, 2009] Datainspektionen, Patient data law, 2009, <http://www.datainspektionen.se/lagar-och-regler/patientdatalagen/>, 2009-10-02
- [Usability.gov Web 1, 2009] <http://www.usability.gov/analyze/personas.html>, 2009-12-01
- [Christine, P., Personas: MDUG, 2001] Christine Perfetti, Personas: Matching a Design to the Users' Goals <http://www.uie.com/articles/personas/> 2001-08-01
- [Benyon,D.,Turner,P.,Turner,S., 2005] David Benyon, Phil Turner and Susan Turner, Designing Interactive Systems: People, Activities, Contexts, Technologies, Pearson Education Limited
- [W3C Web 1, 2009] <http://www.w3.org>, 2009-12-10
- [W3C Web 2, 2009] <http://www.w3.org/2002/ws/>, 2009-12-10
- [WS-I Web 1, 2009] <http://www.ws-i.org/about/Default.aspx>, 2009-12-10
- [CORBA Web 1, 2009] <http://www.corba.org/>, 2009-12-09
- [Wikipedia CORBA Web 1, 2009] [http://en.wikipedia.org/wiki/Common\\_Object\\_Request\\_Broker\\_Architecture](http://en.wikipedia.org/wiki/Common_Object_Request_Broker_Architecture), 2009-12-09
- [BankID Web 1, 2009] <http://www.bankid.com/>, 2009-12-09
- [Greek Internet Usage Web 1, 2009] <http://www.internetworldstats.com/europa.htm>
- [Greece Guide Web 1, 2009] Greece Guide: The National Health Service, Health care in Greece: The quality of health care <http://www.justlanded.com/english/Greece/Greece-Guide/Health/The-National-Health-Service>, 2009-11-30
- [Iason Athanasiadia Web 1, 2009] Iason Athanasiadia Al-Ahram Weekly. <http://www.iason.ws/greece/articles.aspx?id=9>, 2009-11-30
- [Health Care in Italy Web 1, 2009] Health care in Italy, 2009 International Living Publishing Ltd., Elysium House, Waterford, Ireland. <http://www.internationalliving.com/Countries/Italy/Health-Care>, 2009-12-09
- [National Health Service Web 1, 2009] National Health Service (England) - Wikipedia, the free encyclopedia, The Wikimedia Foundation, Inc. 2009-11-16 [http://en.wikipedia.org/wiki/National\\_Health\\_Service\\_\(England\)](http://en.wikipedia.org/wiki/National_Health_Service_(England)), 2009-11-29
- [NHS Careers Web 1, 2009] Pay for doctors, NHS Careers. <http://www.nhscareers.nhs.uk/details/Default.aspx?Id=553>, 2009-11-30
- [World salaries Web 1, 2009] UK Average Salary Income - Job Comparison, 2008 Worldsalarries.org. <http://www.worldsalaries.org/uk.shtml>, 2009-11-29



- [Tech Crunchies Web 1, 2009] UK Internet Users Statistics - Tech Crunchies - Internet Statistics and Numbers. Anand. <http://techcrunchies.com/uk-internet-users-statistics/>, 2009-11-29
- [SUSTAINS Web 1, 2009] The home page of the SUSTAINS project (Swedish). <http://vardkonto.lul.se/>, 2009-12-10
- [Swedish Health Care Web 1, 2009] <http://www.sweden.se/eng/Home/Work-live/Society-welfare/Health-care/Facts/Swedish-health-care/>, 2009-12-10
- [World Internet Institute Web 1, 2009] <http://www.wii.se/publicerat/faktabanken/301-internet-och-bredband-i-svenska-hushall-2009.html>, 2009-12-10
- [Uppsala Nya Tidning Web 1, 2009] [http://www2.unt.se/avd/1,1826,MC=1-AV\\_ID=502908,00.html?from=read\\_more](http://www2.unt.se/avd/1,1826,MC=1-AV_ID=502908,00.html?from=read_more), 2009-12-10
- [Norwegian Board of Health Supervision Web 1, 2009] [http://www.helsetilsynet.no/templates/ArticleWithLinks\\_\\_\\_\\_5520.aspx](http://www.helsetilsynet.no/templates/ArticleWithLinks____5520.aspx), 2009-12-10
- [Norwegian Institute of Public Health Web 1,2009] [http://www.fhi.no/eway/default.aspx?pid=238&trg=MainLeft\\_5895&MainArea\\_5811=5895:0:15,2846:1:0:0:::0:0&MainLeft\\_5895=5825:72303::1:5896:1:::0:0](http://www.fhi.no/eway/default.aspx?pid=238&trg=MainLeft_5895&MainArea_5811=5895:0:15,2846:1:0:0:::0:0&MainLeft_5895=5825:72303::1:5896:1:::0:0), 2009-12-10
- [Health Systems in Transition Web 1, 2009] <http://www.euro.who.int/Document/E88821.pdf>, 2009-12-10
- [Finnish Health care system Web 1, 2009] [http://www.isc.hbs.edu/pdf/Finnish\\_Health\\_Care\\_System\\_SITRA2009.pdf](http://www.isc.hbs.edu/pdf/Finnish_Health_Care_System_SITRA2009.pdf), 2009-12-10
- [Kela Web 1, 2009] <http://www.kela.fi/in/internet/english.nsf/NET/080808144303HS>, 2009-12-10
- [Feelgood Web 1, 2009] [http://feelgood.vtt.fi/FeelGood\\_finalreport.pdf](http://feelgood.vtt.fi/FeelGood_finalreport.pdf), 2009-12-10
- [Smart Open Services for European Patients Web 1, 2009] <http://www.epsos.eu/about-epsos/purpose-of-epsos.html>, 2009-12-10
- [Danish eHealth portal case study Web 1, 2009] Case study - Danish eHealth portal - Sundhed.dk 2009 Morten Godiksen, <http://www.epractice.eu/en/cases/sdk>, 2009-12-09
- [Understanding Sundhed.dk Web 1, 2009] Understanding Danish eHealth portal Sundhed.dk 2009 Morten Godiksen, [http://www.hitug.org/CA/article\\_read.asp?item=34](http://www.hitug.org/CA/article_read.asp?item=34), 2009-12-10
- [Sundhed Web 1, 2009] Danish eHealth portal, 2009, <https://www.sundhed.dk/>, 2009-12-10
- [Cambio COSMIC Web 1, 2009] Cambio COSMIC Healthcare System, 2009, <http://www.cambio.se/zino.aspx?articleID=14946>, 2009-12-10

# Glossary

<b>Anamnesis</b>	Story about the patient (Part of HCR).
<b>Authentication</b>	The process of identifying a user.
<b>Authorization</b>	Identifying what actions a user is a take.
<b>bankID</b>	A digital identification for online use. BankIDs are certificates distributed mainly by banks in Sweden and can be used as a means of identification on many governmental and business websites.
<b>Cosmic</b>	A System for Digital health care records. It is used in Uppsala hospital and all of the care centers.
<b>HCR</b>	Health Care Record, contains all information about the patient.
<b>HCP</b>	Health Care Provider.
<b>IP Address</b>	Internet Protocol Address, the addressing system used to connect computers over the internet.
<b>Kovis</b>	A system for storing photocopies of paper health care records.
<b>OHA</b>	Online Health Account, patient account for accessing HCR and medical functions online.
<b>OHC</b>	Online Health Care.
<b>Password strength</b>	A measure on how good a password is. A strong password is one that is unlikely to be guessed or cracked quickly.
<b>Sundhed</b>	A Danish e-health portal which supports online access to a patient's medical record. The word sundhed is Danish for health.
<b>User session</b>	The time-span between logging in and logging out in the system.

## Appendix A

# Interview Per Edblad, Censoring Unit, CESÅ

Interview with Per Edblad, CESÅ, Uppsala, 2009-09-03. This interview was done via telephone and was translated from Swedish to English. Ceså is the council organ that handles Health Care Records (HCR) and takes care of requests from patients that want to view their own HCR. Ceså also evaluates the content of the HCR before sending it to the patient.

**We have heard that HCRs are sometimes censored before they are sent to the patient, so the patient will not always see all information. What information is censored when sending a HCR to the patient? Does the patient get notified if the HCR has been censored?**

No censoring is done in the HCR that is sent to the patient. If there is information in the HCR that the patient should not read the patient is denied receiving the HCR. The patient can then go to court to get a trial on if the patient shall receive this HCR.

**How long have the HCRs looked like they are doing today?**

Cosmic was introduced in 2004, but it was done department for department. The introduction was finished in 2006. General practitioners have used computerized HCRs since the beginning of the 1990's, with a system called Profdoc. Before this all the HCRs were in paper form. The paper form has been digitalized into a system named Kovich by using scans. Kovich is much bigger than Cosmic and contains more data. The Kovich system is badly structured and every department has its own rules about how to add information and sort it. They also get to name their own department. This makes it hard to search for information in Kovich.

The HCR is also copied onto microfilm. Earlier, when a patient had not been to the hospital for 5 years, they copied the HCR to microfilm and the paper version was thrown away. A new HCR was opened if the patient came back. This leads to the fact that a patient can have more than one HCR on microfilm, usually one for every department the patient has visited. These microfilms are being moved into Kovich, but it takes time and a lot of money.

**Do all hospitals have the same look on HCRs? Do you know any differences from other countries? Can you write in free text into the HCR or are there pre-defined subjects to fill in? Does the HCR contain a summary of important information?**

The HCRs are written mostly with free text, but the doctor can click in search words and fill these with information. Search words can be anamnesis, current health problem, diagnosis etc. These are

on the left column in the paper HCR. It is possible to search for these words in Cosmic. There is no summary in the HCR, but a search word like “diagnosis” can be filled in and all the diagnoses are shown. You can not search this if the diagnosis is in free text.

**Does a HCR look the same in Cosmic as it did on paper? If not, what is the difference? Do you want to change anything in the HCR?**

The HCR looks exactly the same on the screen in Cosmic as on paper, except for page breaks. I would like to see an improvement in Cosmic on how many pages a HCR has when it is printed on paper. Today you can not see the page count before it is printed. You can show the HCR with different views and search words as diagnosis, clinic, doctor etc.

Cosmic uses a couple of different modules, e.g. one for x-rays and one for test results. But there is also a medicine module where all the drugs for the patient are written down. I am not sure if they are entered automatically when doing e-recipes or if the doctor has to enter them manually, but this section should contain valid and updated data.

**Who have rights to modify a HCR? Can you change old entries in the HCR?**

Everyone that has a login to Cosmic can make changes in a HCR, but everything is logged. It is not possible to view what has been changed, only by whom and when. But no data is lost, everything is backed up in every version. If a doctor made a change that seems wrong, earlier versions can be collected via the it-support department.

**Who writes the HCR? How long does it take to fill in an entry? Is the information filled directly into the HCR or later that day? Any usage of dictaphones or other accessories?**

I can not say how long it takes to fill in the HCR, but it can be done in several ways. One way is that the doctor writes in the HCR directly, another that the doctor uses a program to dictate and a nurse enters the data. The doctor then has to sign the information. There is no time limit on when a HCR should be updated, a doctor can wait two weeks before a entry is made and then put the date of the visit in the HCR.

# Appendix B

## Interviews with politicians

### 1 Interview Arne Sandemo, Politician, Uppsala County Council

Interview Arne Sandemo, politician, County Council in Uppsala, 2009-11. This interview was done live and was written by hand. It has been translated from Swedish to English.

**What do you think about the health care system today?**

Today's system is not only one system, it actually is several different systems, which I find very alarming. The problem with this can be that a lot of useful time is wasted on trying to gather information from other places to be able to give proper treatment. Time is also wasted on filling these journals as they are today.

**Do you see any problems with the system that we have suggested today?**

No, not that I can see just now. But the patients' expectations should be fulfilled in the development of this system, these expectations are not considered carefully enough if you look at how the system is today. Wrong medications could be given out and there is a risk of maltreatment today. These kinds of things could be tackled by the new system.

**Have you ever seen your own journal?**

Haven't seen my own journal but a lot of people might have a lot of use with it. It would extend the knowledge of the patient about the matter at hand.

**Do you think that all the information should be available to the patient?**

The general perspective of this is that all the information should be available. This might be for the doctor treating the patient to decide, since there are cases patients might be suicidal or something alike. So there are risks and there are reasons for why some information should not be there.

**Say that an insurance company changed their policy for how they handle their insurances and started demanding to see the journals of the patients, now that it is so easy to get a hang of online. What do you think about this?**

There must be specific guidelines on how the system should be used and who exactly will have access to a patient's journal. Many people might accept the insurance companies' policies just to make them satisfied. There is a higher risk of a malicious person getting the information today in paper form without anyone ever knowing about this. This issue can be solved by an online system, since you

will always know that someone has tried to get information as things like that are registered in computers.

It is all about balancing the risks. Banks today take the risk of paying the money back themselves if someone steals money from someone else's bank account.

**If relatives to the patient would like to take a look at a patients journal, what is your standpoint in this?**

It is up to the patients themselves to decide.

## **2 Interview Johan Edstav, Politician, Uppsala County Council**

Interview Johan Edstav, politician, County Council in Uppsala, 2009-11. This interview was done live and was written by hand. It has been translated from Swedish to English.

**What do you think about the current health care records system?**

It is not good enough. There had been progress in making a similar system that you have suggested but the Swedish Data Inspection Board turned it down because of the risks in the security aspects. There is a need for a system like this since the quality of the HCR would become better with the system you have suggested.

**How would the prospects look like with our new system?**

The quality of the HCR would increase, the documentation would work in a better way and the usability would get better.

**Have you ever seen your own HCR?**

I have read parts of it.

**Do you think that all the information should be available to you in the HCR?**

Yes, all the information should be available, except for special cases for people who might have a tendency of hurting themselves. But it should be a special case if anything is to be withheld.

**Would it make any difference if the doctors were not able to censor sensitive information to patients?**

There are always risks involved when patients get access but it is about balancing the risks with the possible benefits.

**Do you believe that with this new system, new risks could arise? e.g. insurance companies changing policy and asking to see HCR of new costumers before giving away insurance.**

There is always a risk that insurance companies demanding to see HCRs, they are able to do so already. I don't see them demanding HCRs before signing new insurances but the risk does exist.

**If a close relative would want to see your HCR since you are unavailable. What would you think about that?**

Family members should not have access to the HCR unless they have been given consent from the patient themselves.

**There is a risk with the new system that responsibility might change from the hospital to the patient. What do you think about this?**

I do not see any risks with the responsibility.

**Who should be responsible for the HCR?**

The county council should own the HCR.

**Are there any similar systems active today?**

Tax declaration online is a similar system.

**Who is considered to own the HCR today?**

The healthcare giver. I would like the County Council to own the HCR, not the patients or the individuals. Society should be responsible.

**Do you think patients should be able to hide information in the HCR from doctors?**

Patients should not be able to remove or hide any information from the doctors. Denied access for some people should certainly be there. e.g. extra log in to get access. This process is active in the COSMIC system active today, several log in access levels and such. If you have reached a level too far you actually have to explain why you were in there.

### **3 Interview Anna Karin Klomp, Politician, Uppsala County Council**

Interview Anna Karin Klomp, politician, County Council in Uppsala, 2009-11. This interview was done live and was recorded. It has been translated from Swedish to English.

**What do you think about the current health care records system?**

Today you can get your HCR written on paper. But you only do that if you have any questions about the HCR. Very few people do it, it is only done when they suspect something is wrong. It is not something that is done just of curiosity, you can not see if a referral has arrived, for example. You can not use the HCR that way, you can just read it in paper form.

**How will the increased availability of the HCR affect the patients?**

If you can read the referrals and test results you can become more active. You could be able to fill in forms in advance. This way you can prepare and follow up an appointment in a easier way.

**Do you think that all the information should be available to you in the HCR?**

There has been a discussion about psychiatric patient, if they do not have disease awareness. But it is very difficult. It is possible that there are some special cases. But generally yes.

**What are the negative implications of having people reading their HCR?**

Obviously people can always misinterpret the things that are written there. The HCR should maybe be written differently. As it is today, the HCR is written for other medical professionals, but a change

would just be positive. It may take a while to develop. The patient could get worried by something that is in the HCR but he could get worried by something the doctor tells him to.

**Do you think patients should be able to hide information in the HCR from doctors?**

It could be difficult because there could be vital information in the HCR that the doctor needs. In that case the doctor should at least know that there is a HCR, and not be allowed to view the content of it. In that case you have to look at what problems may arise. I understand the need of privacy, but it could be that the patient does not understand the importance of the information. And then the doctor thinks that there is no information even if there is. But on the other hand, that is how it has always been with HCR in paper form. Patients can have many HCR, and a doctor can only view his own. So it will not be worse than before. It will never be worse than before no matter how much information is censored.

But it is also difficult for the patient to know how important the content of the HCR can be for the doctor. If a patient has broken his leg it can still be important for the doctor to know if he has diabetes or not, even if the patient does not think so.

**Do you believe that with this new system, new risks could arise? e.g. insurance companies changing policy and asking to see HCR of new costumers before giving away insurance.**

It may be easier for unauthorized people to read the HCR. But on the other hand, it can be traced in a electronic system. And there is a risk that patients misinterpret what is on the HCR but the patient can misinterpret what is said to.

**If a close relative would want to see your HCR since you are unavailable. What would you think about that?**

That is up to me as a patient. I should decide who gets to read it, and the content.

Relatives do not need to read it for medical reasons.

**There is a risk with the new system that responsibility might change from the hospital to the patient. What do you think about this?**

That can never be the case. You can not demand that patients read their HCR online. You should still have the possibility of having things sent by mail. The responsibilities should not be forced on the patients.

**Should test results be published as soon as they are done? Should all types of test results be published?**

Yes, I think so. If you get the result of a diagnosis, you should have discussed how you want to receive the news. And then you should book a personal visit with the doctor. It is like posting test results. Cancer result are usually received from the doctor, nobody receives cancer results in the mail. But when you have received a positive cancer result you will start to treat it and you will find out if the treatment is working or not. So it is not just about one test result but maybe ten different results on different occasions, each of them being potentially very dramatic. So if there are patients that want to receive the results directly online the doctor should talk to the patient and tell them that they maybe do not have a good overview of the situation. But if the patient wants to receive the results at home so that he can read it with his close ones and call the doctor afterwards that should be possible to. It is up to the patient. But it should not be done as a routine to just send out e-mails with the test results.



## Appendix C

# Interview Ture Ålander, Medical Doctor, Uppsala

Excerpts from the interview with Ture Ålander, doctor, Ture Ålander medical practice in Uppsala, 2009-11-19. Vårdkontot is a system used in the clinic owned by Ture Ålander. Many of the functions this project covers are used in this system. Patients can review their health care records online, book appointments and more. The system has worked well on the clinic and Ture Ålander is pleased with it. The system works on a small scale and has had at most around 400 users. Patients are satisfied with the system, especially the elderly patients. There are no calculations of how much costs have been cut since the system was installed, but Ture has the feeling that this system has saved resources for the clinic.

This interview was done live and was written by hand. It has been translated from Swedish to English.

### **What are the benefits of using a system like vårdkontot?**

The system has saved time for patients because they can see their lab replies online. Patients are booking fewer meetings because they can see the HCR online and the hospital staff does not have to answer questions on the phone as they had to before we used vårdkontot.

### **How have the patients reacted to the system?**

To read their records online has only been positive and the patients have become more involved in the documentation, which only means more quality for patients.

### **Do you miss any features in the system?**

A payment method for vaccination, reservations, etc. would be nice to have implemented in the system.

Today each clinic has its own journal, there should be a system implemented in a way so that patient can see all the records from all hospitals if the patient has been in several places.

### **Do you think security is a risk for these kind of system?**

Safety for vårdkontot is said to be more secure than some internet banks. But for the safety of patients, there should be a log file that says who has been inside and checked a record.

### **Do you think that you should be able to enter test results in the OHR system?**

It would be nice to be able to upload tests as blood pressure, etc. It could also be useful if the patient was able to keep a diary/logbook in the system.

**Do you think that all information in the health record should be available to you?**

You should be able to read everything in a record as long as it is not something that can harm a third person.

# Appendix D

## Personas

The ALOHA project personas were developed based on the data gathered from the user survey. They were used while developing the user interface prototype to provide a basis for design decisions and to ensure the team thought about all possible user cases.

### *Heiko*

---

**Age:** Adult

**Marital/Family Status:** Single

**Profession:** Non-medical

**Technology/Internet Experience**

1. Uses a cell phone regularly
2. Almost no computer or other technology experience.
3. Only browses the web and uses email

**Additional Considerations**

1. Heiko sees his psychologist every second week because he has a problem with patience.
2. He is concerned that his family doctor may see his psychiatrist's notes.

### *Alice*

---

**Age:** Adult

**Marital/Family Status:** Married, 2 children

**Profession:** Non-medical

**Technology/Internet Experience**

1. Uses a cell phone regularly
2. Almost no computer or other technology experience.
3. Only browses the web and uses email

**Additional Considerations**

1. Her son is chronically ill and receives many different kinds of drugs. One of her concerns is that he might suffer (additionally) from undesirable side effects of his medical treatment or drugs.

## *Otto*

---

**Age:** Old

**Marital/Family Status:** Widowed, 4 children

**Profession:** Non-medical

**Technology/Internet Experience**

1. He has no cell phone
2. No computer or other technology experience

**Additional Considerations**

1. He is not able to see small fonts and his hands are a bit shaky. He also tends to forget things very quickly.
2. As he is often very ill he would like to check his online health account regularly.
3. He has difficulties remembering things so a username and password would be hard to remember.
4. He does not feel that it would be secure using only a username and password since he would probably have to write it down on paper.

## *Sven*

---

**Age:** Adult

**Marital/Family Status:** Single

**Profession:** Non-medical

**Technology/Internet Experience**

1. Uses a cell phone regularly
2. Well experience in internet applications and computer technology.

**Additional Considerations**

1. He legally represents his father.
2. He would like alerts when an appointment is upcoming so he can plan his schedule.

## *Mia*

---

**Age:** Adult

**Marital/Family Status:** Married

**Profession:** Non-medical

**Technology/Internet Experience**

1. Uses a cell phone regularly
2. Well experience in internet applications and computer technology.

**Additional Considerations**

1. A modern business woman with almost no free private time. She is also very often on business trips.
2. She wanted access to her husband's health record while they were on vacation, because he has had a medical emergency in the past.

## *Kylie*

---

**Age:** Adult

**Marital/Family Status:** Single

**Profession:** Non-medical

**Technology/Internet Experience**

1. Uses a cell phone regularly (no internet access available)
2. Low level of experience in internet applications and computer technology.

**Additional Considerations**

1. Low level of education and currently jobless. She can only access the internet at her father's or at public access points.
2. She is concerned about her high cholesterol so she likes to receive her test results quickly.
3. Not concerned enough with other medical issues to check her account regularly.
4. She does not want anyone else to access her account except for medical staff.

## *Fred*

---

**Age:** Non-Adult

**Marital/Family Status:** Single

**Profession:** Non-medical

**Technology/Internet Experience**

1. Uses a cell phone regularly (no internet access available)
2. Well experience in internet applications and computer technology.

**Additional Considerations**

1. Does not have a good relationship with his parents and moved out at the age of 17.
2. He is not particularly concerned with his medical record.

## *Miranda*

---

**Age:** Adult

**Marital/Family Status:** Married

**Profession:** Non-medical

**Technology/Internet Experience**

1. Uses a cell phone regularly
2. Some experience with internet applications (for example email) and computer technology.

**Additional Considerations**

1. Her husband currently has access to her online health account but she does not have a good relationship with him. She does not want him to have access to her account but he threatens her to keep her from excluding him.

## *Mikka*

---

**Age:** Adult

**Marital/Family Status:** Divorced, one child

**Profession:** Non-medical

**Technology/Internet Experience**

1. Uses a cell phone regularly
2. Some experience with internet applications (for example email) and computer technology.

**Additional Considerations**

1. His wife has primary custody but he visits the child on occasion so he would like access to his son's record in case of a medical emergency.

## *Andreas*

---

**Age:** Adult

**Marital/Family Status:** Married, two children

**Profession:** Medical

**Technology/Internet Experience**

1. Uses a cell phone regularly
2. Some experience with internet applications (for example email) and computer technology.

**Additional Considerations**

1. Likes to "control" everything in an account's record.
2. Rarely checks his own account or those of his family.

# Appendix E

## Survey

The ALOHA project usability survey asked users a variety of questions about their background. These covered basic demographic information, computer & technology experience and their interest in an online health account. Survey respondents were asked to indicate whether they would or would not be interested in having online access to their health record. The respondents were then provided with questions about why they would like access and what they would like access to, or why they would not and why they would not want access.

### Survey Questions

Prior to beginning the survey respondents were asked to select between English or Swedish as the language.

#### Demographic Questions

##### Age (Required)

- <18
- 18-30
- 31-50
- 51-70
- >70

##### Sex (Required)

- Male
- Female

##### Marital Status (Required)

- Single
- Married
- Divorced (no children)
- Divorced (do not have custody of children)
- Divorced (have partial custody of children)
- Divorced (have full custody of children)
- Widowed
- Other (fill in the blank)

##### Education (Required)

- Some high school or below (did not finish)

- Currently enrolled in high school
- High school diploma or equivalent
- Currently enrolled in college
- Some college (did not finish)
- Associate's degree
- Bachelor's degree
- Higher education (Master's, Ph. D., M.D., etc.)

### **Profession**

- Retail / sales
- Education
- Law enforcement
- Health Care
- Student
- Homemaker
- Farmer / other agricultural
- Retired
- Other (fill in the blank)

### **Technology Usage**

#### **Do you have access to the internet?**

- Yes
- No

#### **How much time do you spend on the internet each day on average?**

*Please answer this question only if you answered yes to having internet access*

- <1 hour per day
- 1-3 hours per day
- 3-5 hours per day
- 5-7 hours per day
- >7 hours per day

#### **Do you use a cell phone regularly (Required)**

- Yes
- No

#### **Do you use text messaging (SMS) on your phones?**

*Please answer this question only if you answered yes to using a cell phone.*

- Yes
- No

#### **Do you have internet access from your cell phone?**

*Please answer this question only if you answered yes to using a cell phone.*

- Yes
- No

#### **What kind of online systems do you use? (Required)**

*Please check all that apply*

- Email
- Internet banking
- Online bill payment



- Job-related services (timesheets, calendar, etc.)
- None

**Do you feel secure authenticating with these systems with just a username and password combination? (Required)**

*Please answer this question only if you checked an option other than none above.*

- Yes
- No

**What other authentication devices would you feel comfortable using? (Required)**

*These devices related to logging in to a system. Additional authentication devices provide an added layer of security, usually by providing the user with a one time access code to be used in addition to the typical username / password combination used in login systems. Please check all that apply.*

- Cell phone: Authentication code via SMS
- Cell phone: Authentication code via voice call
- Authentication token: Authentication code via standalone device
- Certificates install on your computer
- Any kind of biometric device (e.g. a fingerprint scanner)
- None

**Would you be interested in accessing your health care record online? (Required)**

- Yes
- No

### Usage Frequency

The question asking how often users would utilize the online health record will only be displayed if they answer yes to being interested in accessing the record online.

**How often do you anticipate accessing an online health care record system? (Required)**

- Daily
- Weekly
- Monthly
- Other (fill in the blank)

### Desired Online Health Care Record Features

This section is only presented if the respondent indicated that they are interested in accessing their health care record online.

**What information should be displayed online for viewing? (Required)**

*Please check all that apply.*

- Records from your last doctor / hospital visit
- Emergency information (blood type, allergies, etc.)
- Prescription information
- Laboratory test results
- Other (fill in the blank)

**Would you be interested in accessing health care records of family members online? (Required)**

*Example: Records of your child, spouse or parents.*

- Yes
- No

**Please explain your response to the question above. (Required)**

**What other functions would you like to have? (Required)**

*Example: Pre-defined search functions, notification service, making appointments online, etc.*

## **Online Record Access Permissions**

This section is only presented if the respondent indicated that they are interested in accessing their health care record online.

**Who would you be comfortable with accessing your online health care record? (Required)**

- Medical staff (e.g. a hospital or a doctor)
- Immediate family
- Pharmacists
- Any other authenticated users
- Other (fill in the blank)

**Are you uncomfortable with all of your doctors having access to your full medical record? (Required)**

*Example: Doctor having access to records from your psychiatrist*

- Yes
- No
- Other (fill in the blank)

**Would you be comfortable with emergency information being available to non-primary medical staff? (Required)**

*Example: Medical staff in a foreign country in case of an emergency*

- Yes
- No

**Please explain your response to the question above. (Required)**

**Even if you do not have online access would you like your family to have online access in an emergency? (Required)**

- Yes
- No

**Are you comfortable with your health care records being accessible online even if you do not have online access? (Required)**

- Yes
- No

**Are you concerned that your health care records will not be secure if they are available online? (Required)**

- Yes
- No

## **Your Objections**

This section is only presented if the respondent indicated that they are not interested in accessing their health care record online.

**What is the reason that you do not want to access your health care record online? (Required)**

- I do not need it
- I have doubts regarding the security
- I cannot see the advantages for me
- Other (fill in the blank)

Even if you do not have online access would you like your family to have access in an emergency? (Required)

### Further surveys

Would you be willing to participate in further studies? (Required)

- Yes
- No

## Survey Results

Age	Overall	<19	19 - 30	31 - 50	51 - 70	>70
Internet Usage	100%	100%	100%	100%	100%	100%
Cell Phone Usage	83%	100%	92%	88%	75%	0%
SMS (Text Messaging)	69%	100%	96%	71%	40%	0%
Cell Phone Internet	35%	0%	79%	30%	20%	0%
Username / Password Sufficient	73%	100%	71%	73%	81%	100%
Interested in Personal Access	77%	0%	83%	75%	81%	50%
Not Interested: Not Needed	43%	100%	75%	44%	17%	0%
Not Interested: Security	46%	0%	50%	44%	50%	100%
Not Interested: No Explanation	29%	0%	0%	33%	50%	0%
Not Interested in Personal Access, Interested in Family Emergency Access	32%	100%	50%	25%	25%	0%
Interested in Personal Access, Interested in Family Emergency Access	85%	0%	80%	83%	100%	100%
Interested in Access of Family Records	79%	0%	45%	96%	85%	0%
Comfortable with Doctor Having Full Access	70%	0%	60%	73%	85%	100%
Comfortable with Non-primary Medical Staff Having Emergency Access	78%	0%	80%	77%	85%	0%
Comfortable with Information Visibility Without Personal Access	68%	0%	70%	58%	77%	100%
Concerned about Security	47%	0%	40%	52%	38%	100%
<b>Participants</b>	<b>119</b>	<b>1</b>	<b>24</b>	<b>64</b>	<b>28</b>	<b>2</b>

Table E.1: Results of the online survey

# Appendix F

## User Interface Requirements

The User Interface Requirements and Design Guidelines provide future online health account developers with a basis for their system. These requirements and guidelines were developed based on the user survey and prototyping process.

### 1 General Design Guidelines

1. The system will be based on a consistent framework for each page and subpage.
2. All of the information about users, patients, doctors, etc. should be presented in a consistent manner.
3. The system will have a default interface targeted to an inexperienced technical user with the ability to be expanded for further functionality by a technically advanced user.
4. Users will have a better interface and reaction to the system if all different pages of the system are designed in a consistent fashion with only the content changing.
5. Users will be able to quickly access the most important information of their health care record.
6. Text within system should be abstracted from functionality.
  - Allows for easy language translation
  - Allow adjustment of the text size on any page
7. Users should be able to report any discrepancies in their record through the system.
  - These reports should be sent to a health record administrator for verification.
8. Each page that contains a large amount of information should have a consistent search field with customized filters based on content.

### 2 Health Care Record Guidelines

The basic setup of the user interface will allow for users of various technical levels the ability to accomplish the tasks they want. The home screen will consist of several predetermined buttons that will provide quick access to the essential parts of their health records. In addition to these buttons, there will be a sidebar that has many different features and settings that more advanced users will be able to use. The sidebar will be consistent on each screen and expand and contract based on the page the user is currently viewing.

#### 2.1 Health Care Record Login Functions

##### Acceptance of Terms of Use

1. Users must be presented with a “Terms of Use” screen upon their first login.
2. Each section of the terms of the terms of use shall have a checkbox. The user must agree to the statement by checking the box before continuing.

## **Login Using Electronic Identification**

Users will have four different types of login options available to them.

1. Username and password
2. Electronic ID
3. One time password distributed through SMS
4. Other sensors, e.g. finger print sensor

## **2.2 View Health Care Record**

Viewing of one's health care record using ALOHA will provide better capabilities for the users, as well as a much more user friendly and convenient manner.

### **View Medical History**

The overall viewing of one's health care record will provide the user their entire records just as they would in a hard copy of the file. The user can view each specific incident on their health care record. They are available in a quick summary view broken down into Date, Reason for Visit, Department, and Doctor columns. The user also has the ability to go into each specific incident for full details of the event. This could include a doctor analysis, a list of tests done, medicines prescribed, or other relevant information.

### **Search for Incident**

Users will have the ability to search their entire health care record to find specific item. The search fields include Doctor, Department, Reason, Date, and a Free Text search field. This will allow the user to quickly find the event or list of events they wish to see and provide quick access to the full details of the record.

## **3 Health Care Record Access Privileges**

### **3.1 Access Privilege Management**

#### **Provide Access to New Person**

1. Patients shall be able to designate other users who are able to access their online health record.
2. Patients should be able to search by a national identification number to locate a person to provide access to.

#### **Manage Existing Access**

1. A table listing each person with access to the patient's online health record shall be the default view.
2. Patients shall be able to click on the name of a person who has access to their online health record.
3. Clicking on the name of a person with online health record access shall display at minimum that person's contact information, relation to the patient, and access privilege controls.
4. Access privilege controls shall consist of providing full online health record access, access to individual items, or removal of access to the online health record.
  - Elements of the online health record should be enabled and disabled via a checkbox next to their description.
  - Elements of the online health record should be grouped by areas of functionality that the patient will throughout the system to maintain consistency.

#### **Health Care Record Access Log**

1. A table of all access attempts for an online health record shall be available to the user.

2. The table shall list the user making the attempt, the date and time, all actions performed, and any other system messages.
  - To reduce information load on the initial screen all logs for an individual attempt by a user shall be reduced to one with the option to view more details.

## **4 Administrative Information**

### **4.1 Appointment Management**

1. All appointment information should first be presented in a calendar format.
2. An alternative view, such as an agenda view, may be provided.
3. All actions for an individual appointment should occur in a commonly designed screen.
4. All appointments should be searchable.
5. All appointments should provide a link to a health record entry if the entry exists.

#### **Book New Appointment**

1. Users shall be able to select a date and time from a calendar and click an appointment booking button.
2. Users should be able to select the physician type from a drop-down list to filter the doctor selection list.
3. Users should be able to select a doctor from a drop-down list.
4. Users should be able to enable a message notification for the appointment.

#### **Cancel Upcoming Appointment**

1. Patients shall be able to view a list of upcoming appointments and select a cancel button for an individual appointment.
2. Patients shall be able to select a cancel appointment button when viewing an individual appointment's details.

#### **Change Upcoming Appointment**

1. Patients shall be able to view a list of upcoming appointments and select a change appointment button for an individual appointment.

#### **View Past Appointments**

1. Past appointments should be displayed on the main appointment view and greyed out.
2. Users cannot edit a past appointment.
3. Users can view all information from a past appointment.

### **4.2 Billing Management**

ALOHA should provide an online payment option, this subsystem should support:

#### **Pay Outstanding Bill**

1. Pay bills via credit card or by online bank transactions.
2. Print bill if patients want to pay it through a post office.
3. Be able to choose the options of getting bills sent to their home address.

#### **Check Bill Status**

1. Control status of paid bills.
2. Display billing history.

### **4.3 Contact Information**

1. All contact information should share a common design.

### **4.3.1 Patient Information**

#### **Basic Personal Information**

1. User shall be able to view and edit their basic contact information which will include things such as address, birthdate, name, etc.

#### **Emergency Contact Information**

1. Users shall be able to designate emergency contacts.
2. Emergency contacts can be found by searching the system.
  - Data for these contacts should be kept up to date with that users contact data.
  - Medical data for the emergency contacts shall not be available through this interface.

#### **Family Information**

1. Users should be able to access relatives' basic information to find trends within families.

### **4.3.2 Physician Information**

#### **Family Doctor**

1. Users shall be able to change their family doctor by using a search function to retrieve a list of possible doctors.
2. Changes to the family doctor must be approved by a health care system employee.

#### **Lookup Doctor**

1. Users shall be able to search for a doctor by name, location, department.
2. Users shall be able to view the availability of a doctor.

## **4.4 Messaging**

1. Users will receive a new message whenever a new test result, referral, entry in the health care record, etc. happens.

#### **View Existing Messages**

1. Users will have access to an inbox which will contain all their messages with doctors.
2. Ability to view incoming and sent mail.

#### **Create New Message**

1. Users can select another user to message through a search function.
2. Users should be able to message a doctor directly from a health record entry.
3. Messages should have a recipient, subject, and body at a minimum.
4. Users should be able to provide a reference to a health record entry within a message.

## **5 Health Care Functions**

### **5.1 Prescription Management**

#### **View Current Prescriptions**

1. All current prescriptions should be listed in a table which provides the name of the prescription, the prescription start date, the prescription end date, and the number of refills.
2. Additional information, such as dosage, can be viewed through a detailed prescription view option.

#### **Download Current Prescription Details**

1. Download prescriptions details for printing, in case a patient would like a paper copy of the prescription. This could include information such as medication names, dosage, and other information.

#### **Renew Existing Prescription**

1. Users should be able to click a renew prescription button when viewing a prescription.
2. Users should be able to receive a message notification when the prescription is ready for pickup.

#### **Check for Prescription Interaction**

1. The system should automatically generate a list of interactions between all active prescriptions.
2. Interactions with common over the counter drugs should be listed as well.
3. Users may select other over the counter drugs to search for interactions with.
4. Users may select to have an over the counter drug permanently included in the prescription interaction check.

## **5.2 Test Results**

Since all patients in Sweden have the right to see everything in their health care record, all test results should be available in the ALOHA system. Therefore these functions should be supported:

#### **View Test Results**

1. View test results posted by doctors with attached comments and analysis.
2. Get notified when new test results are posted.

#### **Report Test Results**

1. Upload test-result in case of self-treatment.

#### **Censor Test Results**

1. The ability to change the information available to medical personnel.

## **5.3 Referrals**

1. The users should have the ability to book an appointment directly from a referral.

#### **Settings Options**

1. Users should be able to adjust privacy levels.
2. Users should be able to manage the notifications they receive and how they receive them.
3. Users should be able to customize the layout. This includes simple vs. advanced, color layouts, etc.



# Appendix G

## Pidoco Prototype

### 1 About the Prototype Software

The ALOHA project obtained a free trial of a software prototyping tool which made it possible to develop a working prototype for potential users to view. A German software tool called Pidoco allows for wireframe prototype in a collaborative environment. This was a great tool because it allowed several designers to work with it simultaneously. In addition, it allowed many other users to test and give feedback about the system and how it was being implemented.

### 2 The Design of the Prototype

While creating the prototype, the design guidelines as well as basic requirements and functionality of the report were followed to an extent.

### 3 Limitations of the Software

There were some aspects of the software that limited the ability to implement every design guideline. The prototyping tool only allows for working with the wireframe and no actual functionality of the system. This meant that instead of features being fully implemented, most buttons were links to another page that attempted to mock up functionality. An example of this was the login screen where an authorized username and password did not need to be entered to view the rest of the prototype.

Another aspect that was limited due to the software was the ability to make sidebar menus. The side menus were decided upon to be expandable/collapsible menus based on what section of the system you were currently looking at. This was overcome by creating separate tabs on each page instead of an expanded sidebar, which was initially intended. The ALOHA project is also considering having both the expanding sidebar and tabs in a final system because the tab received good feedback in the prototype.

The last limitation of the software was that it did not allow for readjustment of text size. The implementation contains a text size slider for users to change the size of the text to best fit their needs. Pidoco would not allow the slider to change the text size on the page but it did allow a good example of how the system will potentially work.

### 4 Screenshots

Below are several screen shots with brief descriptions of design decisions and other unique features of our system. To view the prototype, please visit <http://www.it.uu.se/edu/course/homepage/ITisam/ht09/aloha09/prototype/pages/index.xhtml>.

## 4.1 Common Components for all pages

### 4.1.1 Side Menu Bar

One of the recurring components on every page is the side-bar (see Figure G.1). The bar is divided into three general areas consisting of Main, Medical Functions, and Additional Functions. Under each of these sub bars there are further selections available. The design is consistent across all pages and allows the user to become well acquainted with it, providing a better overall user experience.

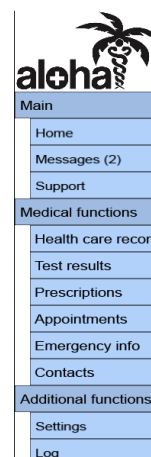


Figure G.1: The prototype side menu bar.

### 4.1.2 Top Bar

The top bar (Figure 4.1.2) provides several aspects of the functionality that are essential to the final system. In the upper right corner there are options to view the system in a different language. Currently the only ones the prototype supports are English and Swedish, however other languages could definitely be accommodated. The text size slider is also present so the user will have the ability to increase or decrease the text size based on the content of their current page. It will also allow you to logout at any time to make it more convenient for when a user is done looking at their record and wants to leave. Finally, there is a universal search bar that allows the user to do a free text search over their entire health record and system. This will allow the user to quickly find whatever they were looking for. The ease of use and quickness that one can complete tasks will improve with the user's experience.

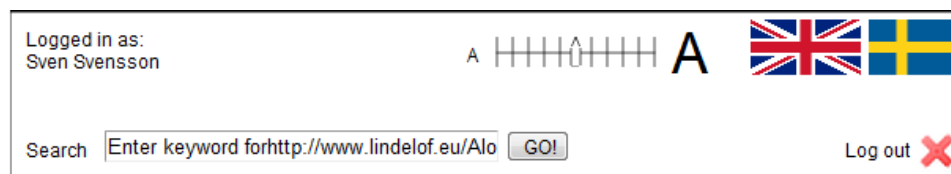


Figure G.2: The prototype top menu bar.

### 4.1.3 Search Filters

Another aspect that appears on a majority of the pages within the prototype is a search pane (shown in Figure 4.1.3) with specific filters. This generally appears below the content on the pages. It allows users to fine tune their searches to produce more accurate results. The filters vary from page to page depending on what content is there and how it can be broken down. For example, on several pages the user can distinguish which doctor and department they want to search in. The increase search efficiency will give users better results and generate an overall better experience they get when using the system.

## 4.2 Pages within the Prototype

### 4.2.1 Introduction Page

Upon the first time logging into the system, the user will be presented with an introduction to the system (Figure G.4). This will give them the option right away to choose between a simple home screen interface and an advanced one. Also, it will briefly explain to the user some general information about the layout and how to change the settings.

### **4.2.2 Simple Home Page**

The simple page (Figure G.5) is geared towards users that have bad eyesight or have limited computer experience. This homepage consists of large buttons with increased font size accompanied by a picture to describe the link. This will make it easier and quicker for people with limited technical background to find what they want right when they login to the system. The user can also customize which buttons show up on the home screen and the order which they appear.

### **4.2.3 Advanced Home Page**

The advanced page (Figure G.6) is aimed at users that are more comfortable with computers and systems on the internet. The page will consist of previews of each of the parts of the system chosen by the user. For example, the calendar could show what is scheduled for the upcoming days. This will allow the user to see their information right away while still allowing them to go to the specific page for more information.

Search Filters			
Doctor	<input type="text"/>	From	<input type="text"/>
Department	<input type="text"/>	To	<input type="text"/>
		Free Text	<input type="text"/>
			<input type="button" value="Search"/>

Figure G.3: The sample filters a user may search with.

Figure G.4: The screen introducing the user to the pages.

Figure G.5: The simple page which provides access to commonly used functions in an easy to read manner.

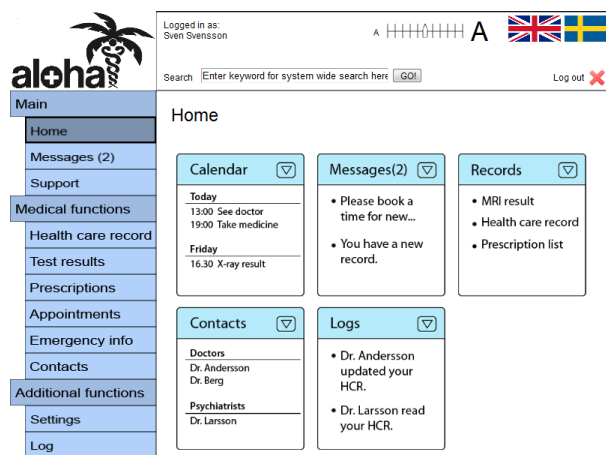


Figure G.6: The advanced page screen which provides quick access to commonly used functions.

# Appendix H

## OHA System Communication Standard

The interface for accessing an online system can be defined in different ways. The term “interface”, in this context, means the valid ways of accessing the system. In the following sections different standards for defining and creating this interface are discussed. Some factors that are important to look at when choosing a standard to use:

- Is it a widely used standard, because if it is, there are probably a lot of people that know how to use it,
- Is it an open standard that can be used without restrictions, because restrictions can hinder the development and increase costs,
- Does it support the requirements of the system.

The following sections contain two communication technologies that are options for the Online Health Account (OHA) system. In the end, it is a discussion section that will try to find out which is most suitable for the OHA system.

### 1 Web Service

The World Wide Web Consortium [W3C Web 1, 2009] has published the following definition of the term Web Service:

A software system designed to support interoperable machine-to-machine interaction over a network. It has an interface described in a machine-processable format (specifically Web Services Description Language WSDL). Other systems interact with the Web Service in a manner prescribed by its description using SOAP messages, typically conveyed using HTTP with an XML serialization in conjunction with other web-related standards.

The W3C has also published a number of recommendations for for using the technologies involved in web services [W3C Web 2, 2009]. One organization, Open Oasis, is publishing a standard for web services with different modules [WS-I Web 1, 2009]. Modules are used so web service related software can choose to support a subset of the modules. E.g. with the module “WS-Addressing”, it is possible to define different destinations which may answer a request and to specify another destination for the error response. The following diagram summarizes the different parts of a Web Service communication. The different parts are described in more detail in the following sections.

#### 1.1 Web Service Definition Language (WSDL)

Web Service Definition Language (WSDL) is a formal language that is used to define how a web service can be talked with. It defines all operations and the messages that may be sent or received, as well as the

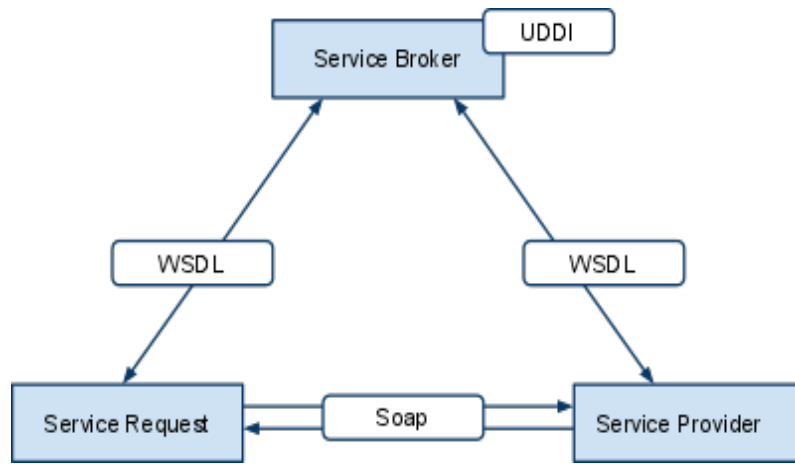


Figure H.1: Web Services

type of the possible answer messages. Many computer programs exist that can automatically generate a skeleton for implementing a web service defined by a WSDL file. These programs may generate a skeleton for programming languages such as Java and C++ etc.

## 1.2 Simple Object Access Protocol (SOAP)

SOAP is one of the possible message formats that can be used in web services, and the one that is most widely used. A SOAP message is a XML-document. One module in the Open Oasis Web Service specification is called WS-Security. It contains a specification for encrypting the content of SOAP messages. The SOAP message standard makes it possible to use datatypes such as integer string and list etc.

## 1.3 Universal Description, Discovery and Integration (UDDI)

An open industry registry for businesses all over the world to list themselves on the internet. It was initiated by the OASIS organization.

## 2 CORBA

The Common Object Request Broker Architecture [CORBA Web 1, 2009] is a means of interchanging data between different systems. It can be compared to the Java RMI (Remote Method Invocation) system. One of its main features is a definition of different data types such as integer and string, but also combined types like struct or sequence. A programmer who wants to use CORBA to interface to another CORBA compliant application has to define methods and data types that their side of the application uses.

More abstractly, you could say the following, taken from wikipedia [Wikipedia CORBA Web 1, 2009]:

CORBA is a mechanism in software for normalizing the method-call semantics between application objects that reside either in the same address space (application) or remote address space (same host, or remote host on a network) ... CORBA uses an interface definition language (IDL) to specify the interfaces that objects will present to the outside world. CORBA then specifies a mapping from IDL to a specific implementation language like C++ or Java

Benefits of this approach are for example language or operating system independence and freedom from a specific technology, as well as strong data typing. Problems are often implementation incompat-

ibilities, firewalls and last but not least the design of CORBA itself since it was designed by committee and sometimes provides too much freedom to the user.

### **3 Comparison and Discussion**

CORBA and the Web Service specifications are very similar in many aspects. The main difference is that the Web Service specification is more modular. E.g. the formatting of messages in the Web Service specification is not fixed and can be exchanged and extended to use several message formats. XML might be preferred as a message format over a binary format in many situations because it is easier to implement, but in some cases a binary format has to be used because of performance reasons. Support for both CORBA and Web Services appears to be implemented for most programming languages. To conclude this discussion, one can say that both the Web Service specification and CORBA would probably work well as interconnection technology for the Online Health Account system. To determine which of the two standards the online health care system should use, one can look at how the two technologies support the more advanced operations that should be supported.



# Appendix I

## International perspective

The overview over countries provided insight into the medical practices of them. These insights were obtained through interviews and background research. Examinations of the culture of medicine, their use of technology, how social status affects health care and the overall impact these factors have on medical care are presented here.

### 1 Sweden

#### Introduction

Thanks to Benny Eklund at the Uppsala County Council and Per Olof Egnell at Luleå University of Technology for providing information about the Swedish health care system. Additional information has been obtained from [Swedish Health Care Web 1, 2009], [World Internet Institute Web 1, 2009] and [Uppsala Nya Tidning Web 1, 2009].

#### Overview of Health care System

The Swedish health care system is available to everyone equally. It is government-funded and is, much like the other Nordic countries, heavily decentralised. The central government sets the general guidelines by means of law and ordinances and the National Board of Health and Welfare acts as an expert and supervisory authority to it. At the level beneath, Sweden is separated into 20 county councils (plus the municipality of Gotland) that are responsible for the health care in the county. A county council is a political body whose representatives are elected by the public every four years. The county councils are by law obliged to provide good health care to its residents and 90% of their budget involves health care. The 290 municipalities in turn are responsible for care of the elderly.

Supporting a population of 9 million people, Sweden has 60 hospitals with specialist care around the clock. Eight of these are regional hospitals that provide highly specialised care. Sweden has been divided into six health care regions for advanced care and, for the most advanced specialist care, the entire county is considered a service region.

About 9% of Swedens gross domestic product is spent on health and medical care. Only 3% of the total cost is payed through patient fees. The main source of funding, 71%, comes from local taxation and the rest comes from contributions, sales and other sources.

One of the major drawback of the system is that there are long waiting times. A care guarantee which states that no patient should have to wait more than three months after the type of care has been determined was agreed upon as a countermeassure to this.

## Technology

Internet is widely spread and computer skills are on average high. As of 2009 86% of the population over 16 years of age has a computer at home and 97% of these are connected to the internet. From an international perspective, this is very high. Medical personnel at a majority of the hospitals are used to handling medical data electronically, mainly through the use of a system called Cosmic. Cosmic offers a variety of features digitally but the most used is the function that provides for electronic health care record access. A survey done 2006 showed that 95% of the medical personnel were using cosmic. 60% claimed that it worked good and 20% claimed that it did not work very good.

An EU collaboration that allowed 100 patients access to their health data online, called Sustains project, was carried out in Uppsala. The project got positive feedback and a child project called Vårdkontot was developed and executed at a private clinic in Uppsala. As of 2006 almost 500 patients had access to Vårdkontot and a survey of the project showed that 49% of the users felt that it was useful or very useful to be able to view their health care record online.

## Culture of medicine

The health care record is owned by the patient and they are entitled to view it upon request in most cases. The only exception is if the information contained within could affect the treatment or a person mentioned negatively. A recent change in the law addressing the access to health care records made it possible to put it online.

Privacy of medicine is highly valued, but people in general trust technology. System with sensitive data, such as online banking, is widely appreciated for its convenience with a method of authentication that provides for high security.

## Conclusion

With the success of internet banking as well as the positive results of the pilot projects in mind the conclusion is that Sweden is very well suited for an online health care system. Digital systems are already being used within the health care and the next step is to involve the patient in the care in order to provide an efficient health care service.

## 2 Norway

### Introduction

Thanks to Steinar Pedersen at the Department of Telemedicine at the University Hospital of Troms for providing information about the Norwegian health care system. Internet sources include [Norwegian Board of Health Supervision Web 1, 2009], [Norwegian Institute of Public Health Web 1,2009] and [Health Systems in Transition Web 1, 2009].

### Overview of Health care System

Health care in Norway is publicly financed, mainly through tax revenues, and is well-developed. Through the national insurance, or social security, everyone has the right to economic assistance in case of illness, old age and unemployment. A basic principle of Norwegian authorities is that health services should be distributed according to need, not according to pay.

The Norwegian health care system is decentralised and divided into three parts. Several departments act on a national level, for example The Ministry of Health and Care Services that are responsible for forming and implementing the national health policy. Norway is then divided into five regional health authorities that are responsible for specialist care. At the lowest level each of the 434 municipalities are responsible for primary health care.

## Technology

Similar to other Nordic countries, the accessibility of technology and internet penetration is very high. Large parts of the health care system has been digitalised and one of the systems used is Norhealth. Norhealth is one of the leading systems for public health information in Europe. It is a web based system that monitors health and health related conditions. It was developed in order to create a knowledge base for health promotions and disease prevention strategies. The main user groups consist of politicians, student and health care professionals, among others. Users can view and create tables and diagrams of the health care data provided.

## Culture of medicine

It is legally possible to view a health care record online. However, there is no portal for online health care records in development at the moment and there has publicly been little discussion about this. Health care professionals are beginning to realise the advantages of such a system though. The privacy of medical information is highly valued in Norway as well.

## Conclusion

Norway has a good health care system as well as high technological standards. The people should, similarly to the other Nordic countries, be open to an online health care portal.

# 3 Finland

## Introduction

Thanks to Jaakko Lhteenmki and Niilo Saranummi VTT Technical Research Center of Finland for providing the information about the health care in Finland as well as the information about the Feel-Good project. Additional information was obtained from [Finnish Health care system Web 1, 2009], [Kela Web 1, 2009], and [Feelgood Web 1, 2009].

## Overview of Health care

The Finish health care system was in bad shape before the latter half of the 1960s and the life expectancy of men were one of the lowest in Europe. A series of improvements to the health care system have increased the health of the people and today Finland is among the top European countries in many areas within health care, much the same as the other nordic countries.

Finnish health care is publicly owned and operated; everyone is entitled to the health services regardless of the financial situation. It is financed mainly through tax revenues and is heavily decentralised. General health policy guidelines are set by the national administration and the national Ministry of Social Affairs and Health which also sets the broad development goals among other things. The majority of the health care is carried out by the municipal health care system. Each of the 348 municipalities in Finland are required by law to either provide health care themselves or to cooperate with one or many other municipalities in order to provide sufficient care.

Economically the health care system has a low expenditure per capita, partly through effective health care but also because the salaries of health care professionals are realtively low. The system is liked by the people and according to a survey carried out by Eurobarometer 70% of the Finns claim to be quite satisfied with the system.

## Technology

Technology in Finland is high and the country is world leading in cell phone development among other things. Internet is widely available. Work is being done in order to realize a system that lets the patients

view their health care record online, though it is important to stress the fact that this kind of system should be a complement to any existing services and not a replacement. The health record service, called KanTa, is based on a centralized repository that stores EHR documents which all health care providers are mandated by law to send. Besides being able to store data about a patient such as EHR, the system also supports other features such as ePrescription which keeps track of a patient's prescriptions. This project is financed through various national sources such as ministries but also through EU-funding which can be applied to this type of activities.

FeelGood is an exciting project that is currently in development. This is an online health care portal which allows patient interaction; it is referred to as a personal health record, or PHR. This kind of system allows the patients to manually store information on their account or even directly from personal wellness devices. An outline for setting up the system has been presented.

## **Culture of medicine**

Privacy of medical information is highly valued. However, many think that the current rules are too tight. A balance between flexibility and security is preferred and the hope is that this can be achieved by providing online access.

The health care record is owned by the organization which maintains it. However, the patient has certain rights concerning access and control as dictated by law. As mentioned earlier, there are projects under development that allow for online access to the health care record and it is important to note that this is legally possible.

## **Conclusion**

Finland is one of the foremost countries when it comes to online health care. It is legally possible and several systems are nearing completion. As concluded by national studies, the citizens would benefit from such a system. e.g. from reduced costs as a result of automatization.

# **4 Greece**

## **Introduction**

George Dafoulas, the e-health services coordinator for e-trikala SA, and Evangelos Stamatiadis of the IT department of the 5th Regional Health Authority of Thessaly and Sterea were the largest contributing sources for this cultural view of the health care system of Greece. Additional resources include articles found on the Internet [Greece Guide Web 1, 2009],[Iason Athanasiadia Web 1, 2009].

## **Overview of Health care System**

The public health care system in Greece is IKA. IKA is available to any individual who contributes to the Greek social security system and their families. It provides low cost, and sometimes free, medical coverage to these individuals. Members of IKA pay small fees for prescriptions, non-essential medicines, eye care, and some dental care. If an individual does not qualify for IKA, they must seek private health insurance.

Greece has one of the worst health care services[Greece Guide Web 1, 2009] in Europe despite their high standards for medical training. There are limited health care facilities in some regions of the country, the island areas being one example. The article claims that this is largely due to insufficient funding. It also claims that there are substantial efforts underway to improve the overall level of health care in the nation.

Social security numbers in Greece, as in the United States, are used to associate medical records with an

individual. Within a hospital these medical records can be accessed using an online system by medical professionals. There is no such system specifically for patients.

## **Technology**

The Internet is widely available in Greece, with a penetration of 45.9% as of 2006 [Greek Internet Usage Web 1, 2009], and the use of the Internet has been increasing rapidly amongst the Greek population. Thanks to projects such as SYZEYXIS, all metropolitan government networks, including hospitals and health centers, have been connected. There are also projects underway, such as SYZEFXIS2, to bring broadband Internet access to all households. The idea of allowing online access to medical information for patients, however, is still quite new in Greece. There are currently no projects underway to address this issue to the knowledge of the subjects that has been interviewed.

## **Social Status**

As mentioned before, the medical standards for doctors in Greece are quite high. This suggests that doctors also hold a high status in society. However, doctors in Greece are the worst paid in Europe [Iason Athanasiadia Web 1, 2009], earning anything from 8,052 to 39,360.

## **Culture of Medicine**

Medical information is very important to the people of Greece. The privacy of this information is a major issue and the literature is unclear as to who is considered to “own” the health care record. It is also unclear about the steps an individual would have to take in order to view their own health care record.

## **Conclusion**

Similarly to that of many other countries, since the people of Greece regard their medical information as being extremely personal, any system allowing access to this information would have to ensure the strictest security precautions are taken. After researching the matter and conducting a limited number of interviews the consensus is that the people of Greece would welcome the implementation of such a system.

# **5 Spain**

## **Introduction**

The majority of the information below was provided by Jon Gardner, a Rose-Hulman Institute of Technology professor, who has lived in Spain several times. A portion of the information comes from friends of his who are located in Spain.

## **Overview of Health care System**

Spain has a national health care system. Every Spanish national, as well as their family members, is entitled to free health care in Spain. Furthermore, non-nationals who participate in the social security system may also obtain free health care in Spain. Tourists from other European Union countries may also obtain free health care for up to three months in Spain.

Each individual in Spain is assigned a primary doctor. Unfortunately, due to the relatively small number of doctors, the time a patient waits to see their doctor is relatively long, unless the patient is facing an emergency. One strategy Spain has chosen to help alleviate this strain is to give pharmacists a high degree of freedom. A pharmacist can give out medications without a prescription from a doctor at their own discretion. This helps lower the load on doctors, but also results in some people attempting to get

medicine they do not need for unauthorized uses.

Major hospitals in Spain are often overcrowded, and do not appear to be very well funded. Dr. Gardner described a visit to a hospital with a friend, in which he said that the waiting room reminded him more of an old bus station and furthermore in the exam rooms there were unsanitary items such as rusty cabinets. The low level of funding was also reflected through a lack of personnel. Some patients in the emergency room who had been deemed to have less-urgent needs had been waiting there for as long as three days.

The Spanish people seem to have mixed feelings about their health care system based on the interviews and recorded experiences. Most find the level of care to be sufficient and enjoy not having to worry about finances when they are in need of medical attention. Most Spaniards also have complaints about the waiting time and some have complaints about the quality. Since many Spanish people have never experienced higher quality medical attention or facilities they only dislike the long waiting period for less urgent needs.

Spanish citizens have a social security number, similar to those used elsewhere in the world, which is the main method of identification used to associate medical records with an individual.

## **Technology**

Spain is quickly becoming more modernized. As described by Dr. Gardner, Spain had very few computers and other technology only ten years ago, but recently has been advancing very quickly into the 21st century. Computers and internet access are now relatively available in Spain, though not as well as in a country such as the USA.

The primary users of technology seem to be the younger generation. Technology is being increasingly used in education and for accessing the internet for research and personal use. Many of the elderly in Spain do not use computers on any sort of regular basis. Citizens cannot view their health care records online, and in general there seem to be very few services offered online by the government.

## **Social Status**

Doctors are considered to be a prestigious profession in Spain. People respect doctors, and treat them well. Doctors also earn a decent salary, but not nearly as high as a doctor in the United States. This lower salary is the result of the limited budget, which restricts the amount that may be spent on doctor salaries.

## **Culture of Medicine**

The people of Spain in general are very open to using medicine and life sustaining devices to treat citizens. Dr. Gardner states that Spanish citizens definitely have a right to view their medical records, but that it is somewhat unclear as to who the “owner” of the records is. Privacy is valued to an extent in Spain, but it is not as highly valued as in some other countries such as the United States or the United Kingdom. Most Spaniards have a small town philosophy where “everybody knows everything about everyone else”.

## **Conclusion**

Research seems to indicate that the Spanish people would be open to a system to view their health care records online. Currently there would probably not be a large amount of enthusiasm for such a project simply because many people do not use the internet on a regular basis. However as time progresses their desire for such a system will increase.

## 6 United Kingdom

### Introduction

Many thanks to Helena Bernald of the United Kingdom for her help in researching a cultural view of the health care system of the UK. Additional resources include surveys and articles found on the Internet, [National Health Service Web 1, 2009], [NHS Careers Web 1, 2009], [World salaries Web 1, 2009], [Tech Crunchies Web 1, 2009].

### Overview of Health care System

The health care system of the United Kingdom is often referred to as the National Health Service (NHS). The NHS is a national health care system funded by the government by means of taxation. The NHS entitles individuals, even people who are not residents, to many medical services free of charge.

When seeking medical care, an individual first visits their General Practitioner (GP). The GP is normally the first place to turn when seeking medical attention. If the GP deems it necessary, they will refer the individual to a specialized unit or hospital.

The NHS seems to be a very popular system amongst the people of the United Kingdom; however, there have been difficulties financing the system. The NHS is quite generous with its services, but it also seems that some individuals tend to take advantage of the many free services, such as scheduling many trips to the doctor. Individuals are linked to medical records through the use of their NHS number, which is a national identification number.

### Technology

The United Kingdom is a developed country and has much of the same technology as the United States and Sweden. The Internet is widely available throughout the country and can be found in nearly every household. As with most new technology, the primary users are the younger generations. Most Internet users in the United Kingdom are between the ages of 18 and 49. However, even with widespread access to and use of the Internet, citizens have no way of viewing their health care records online. Sources were not aware that any projects for implementing a system allowing online access to health care records have been debated.

### Social Status

Sources suggest that doctors in the United Kingdom are probably viewed in much the same way as they are in the United States. Working as a doctor is considered a prestigious career. Doctors are well paid in the United Kingdom with salaries ranging from 33,285 to 69,369 for doctors of all types.

### Culture of Medicine

Medical information is regarded as very private and personal in the United Kingdom. These records are controlled by the Department of Health. If an individual wishes to view their own records they may do so; however, they must submit a request in writing and pay an administrative fee to do so.

### Conclusion

As previously mentioned, the people of the United Kingdom regard their medical records as being very personal. Any system allowing access to these records over the Internet would have to undergo rigorous design to ensure the safety of this very sensitive information. However, it seems that the people of the United Kingdom as a whole would be quite receptive to such a system, if it adheres to the strictest security precautions.

## 7 United States of America

### Introduction

The majority of this information was provided by Brenon Smith and Logan Price, both project members and US citizens, and by some medical professionals directly related to them. Due to the relative difference between the United States health care system and that of most countries in Europe, a longer than normal overview is provided.

### Overview of Health care System

The United States of America has a private health care industry. Individuals purchase insurances from insurance companies and in general, hospitals and clinics run without governmental funding. There are some public programs for health care but they are almost exclusively for senior citizens. Such programs include Social Security, Medicare, and Medicaid. Every US citizen has a Social Security Number, which is used to relate medical records to the individual. This is very different from the majority of systems in Europe, and it has different advantages and disadvantages.

Currently the focus is on the negative aspects of the private medical system. One of the discussed disadvantages is that some people are unable to afford health insurance due to an extremely low income, or due to insurance companies charging very high rates due to pre-existing medical conditions an individual might have had and which make them more susceptible to needing health care. These persons are unable to get health care without paying the full price for the service which they are often unable to afford. An exception to this is any urgent care. By US law, any person in need of a medical procedure to save their life must be treated by the hospital regardless of their ability to pay. For example if a person is involved in a car accident and needs a life-saving surgery but does not have a health insurance, the hospital must perform this surgery by law.

There are also advantages to this health care system. One advantage is an extremely high quality of health care. While there are a few areas where the United States does not have the best in medical care, it does rate the best in the world for very many treatments including heart surgery, cancer treatment, brain surgery, etc. Also, the United States is responsible for the vast majority of medical breakthroughs and new medical technologies developed each year. In fact, the United States is responsible for more than 80% of the medical research and development done in the entire world. The private system that gives an economic incentive for medical breakthroughs is responsible for this progress which saves countless lives across the world as the new technologies are shared. If the United States reduced its contribution to research, the rate at which medical breakthroughs occur would be greatly decreased. Also, many drugs become more widely available and less expensive due to the research that improves the efficiency of creating that drug. Prices and technologies would almost stagnate without the constant research and development.

### Technology

Technology is available throughout the United States. Almost every home has internet access and there exist many places where you can get free internet, such as coffee shops, throughout the nation. Computers are used for a wide variety of purposes, from business to entertainment and everything inbetween. While the primary users of technology are probably between about 16 to 50, many young children as well as the very elderly are also beginning to use technology at an increasing rate.

The patient currently cannot view his health care record online. Part of the reason for this is that since the hospitals are not controlled and run by the state, but rather independent businesses, they do not always have direct access to records created at another hospital. They can always get the records from another hospital by law, but the data is not stored in a central location. Things such as internet banking and many similar services can be accessed online by individuals.



## **Social Status**

Medical Doctor is a very prestigious profession in the United States. Many children grow up wanting to be doctors, as they not only save lives, but are extremely well compensated. In fact doctors in the United States are the best paid in the world. Salaries for a doctor in the average hospital average well over \$200,000 per year.

## **Culture of Medicine**

US citizens are very open to the use of technology and medicine in order to sustain and to save lives. However, Americans are very sensitive to privacy. Americans mostly consider themselves to own their health care record. Some Americans even keep a hard copy of their medical records and carry it with them when they travel. Though the process for obtaining your medical record varies from hospital to hospital, due to each hospital being a private owned business, Americans have the right to view their health care record.

## **Conclusion**

The majority of Americans would most likely embrace an online health care record system, as it very much fits with the American values of efficiency and convenience. It also has the potential to be useful for the hospitals as many features could allow the customer to do things such as make an appointment without needing to contact a hospital employee. However, the most recent security protocols would be a must, as Americans are very concerned about privacy and identity theft.

# **8 Germany**

## **Introduction**

Most of the information is gathered from interview with Christian Hauser who is a project member and from Germany.

## **Technology**

Internet is widely available to the extent that an Online Health Account would be possible to implement. Although the connections are not as fast (on average) as for example Sweden.

It is legally possible to view the HCR on-line in Germany.

So far there has been only little debate about a system such as an Online Health Account in Germany. The only debate has been between the politicians and the parties involved. The general public is not aware of possible benefits.

There is an ongoing project about getting the HCR to your insurance card. This project has almost failed for technological and economical reasons and low acceptance from the doctors. The low acceptance from the doctors is because they would have to invest in part of the reading devices needed.

## **Culture of Medicine**

The German people trust the medicine. Very often they go to the pharmacy directly instead of going to the doctor first, simply because it is faster. Brands of certain medicine is not important.

The doctor owns the HCR. The patient can access everything in it if requested.

Privacy is very important for the German people. Some will be afraid of putting the HCR online but most will not be. Security must be high enough.

## **Conclusion**

Germany has got a bad situation with the almost failed project of insurance cards. They need to get the right ideas and see the benefits in to actually get on the right foot. The public in general would probably accept this kind of system with open hands.

## **9 Italy**

### **Introduction**

This information was gathered from answers from Silvia Mancin from Arsenà.IT, the Telemedicine Consortium, and [Health Care in Italy Web 1, 2009], .

### **Overview of Health care System**

Italy is considered to have one of the best health care services in the world. Yet many hospitals are overcrowded and underfunded. Though it is adequate for emergencies.

Italy has a national health plan called “servizio sanitario nazionale”. That plan provides for hospital and medical benefits. The eligibility for the plan depends on certain criteria (e.g. your nationality or working permit).

If you are a resident of Italy and covered by the national health plan, you and your dependents will be provided hospital services free of charge. Visitors are expected to pay full hospital charges and claim reimbursement from their insurance provider.

Most hospitals have emergency rooms open 24 hours a day. Ambulance is called by dialing 118.

### **Technology**

Internet is spread to the extent in Italy that the OHA is possible to implement.

It is legally possible to view the health care Record online in Italy.

There are many projects in Italy which have as their ultimate goal the creation of the health care record. The Ministry has established a central board to agree on common standards but currently nothing is realized. The Telemedicine Consortium, Arsenà.IT, has “discussed a study” to understand the situation in Italy. Now they are developing a project that primarily involves networking of primary care practitioners and later the constitution of Personal health care record.

The debate about this kind of system has been up for ten years. It is a very sensitive matter. Though Italy is in the process of creating a health network infrastructure to link all health care providers involved in patient care. This seems to be the closest goal in Italy so far and the most important aspect for the Italians.

### **Culture of Medicine**

Privacy of medical information is highly relevant to the Italian people.

Italy makes a difference between documents and clinical data. The documents that contains the health care record are the property of those who created them. The clinical data therein is property of the patients so they can incorporate them in his health care record.

## Conclusion

The Italians would benefit from an Online Health Account system. The necessary security measures are needed to ensure that the Italians keep their medical data private. Italy seems to want an infrastructure for the medical personnel done first. The current projects are more focused on that. But Italy has Internet penetration high enough to begin implementing an OHA system. As the debate is very sensitive, some tension might have to be loosened and perhaps there are uncertainties needed to get straightened out.

The system would be good in Italy for a few reasons:

- Historical data are an important memory storage for the citizens and an important support for decisions for the hospital staff and the general practitioner.
- For the citizen to obtain an insight into their own situation.
- For hospital staff and general practitioners to know the entire history of the patient to facilitate the process of decision making.
- For the hospital staff in emergencies or in case of hospitalization during the night or if the patient is unconscious.

# Appendix J

## Authors

This report is authored by the members of the ALOHA project. The ALOHA project which stands for Achieving Large-scale Online Health Accounts is a joint collaboration between Uppsala University and Rose-Hulman Institute of Technology. The twenty nine project members consists of twenty one students attending the course IT in Society at Uppsala University in Uppsala, Sweden and eight student attending the course Computing in a Global Society at Rose-Hulman Institute of Technology in Terre Haute, United States of America. On a mandate from Uppsala county council, the goal the of the project has been to produce a report addressing the usability, system architecture, economics, ethics and international and cultural issues of an online health account system where patients have access to their own medical record.

The project was initiated in September 2008 and the majority the project members have either software engineering, computer science or information technology backgrounds. Research and interviews have mostly taken place in Sweden and United States of America but the countries of Belgium, Denmark, Estonia, Finland, Germany, Great Britain, Greece, Italy, Norway and Spain has also been taken into consideration. The ALOHA project has strived towards delivering an end product that is comparable with trade standards, but the academic background of the project should not be disregarded.

Joachim Andersson	Nadim Moued
Johan Byggnings	Andreas Olsson
Jonathan Cody Collins	Drew Paine
Marcus Fredriksson	Andreas Pehrson
Kai J. G. Hatje	Logan D. Price
Christian Hauser	Kenny Pussinen
Henning Hellquist	Joseph M Salisbury
Kristoffer Hellstrand	Henric Salomonsson
Matthew M. Iverson	Dennis Sandmark
Markus Jonsson	Brenon T. Smith
Björn Lindelöf	Adam Viklund
Christian Lindquist	Israel I. Wilson
Dari Luukka	Kjell Winblad
Timothy S. Marriner Jr.	Martin Wrangenby
Sebastian Mendez	