Support USers To Access INformation and Services
(Grant Agreement No 297206)

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Intermediate Pilot Evaluation
Uppsala
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Abstract
This document presents the intermediate evaluation of the introduction of SUSTAINS services in Uppsala.

Key Word List
Pilot evaluation, e-services
Executive Summary

Introducing e-health services needs a key service that will attract citizens / patients. This service will function as a door opener for other services. When the citizen / patient is surfing around for the key service, they will also try other e-services when they pass by. In this way, all e-services will be used and become popular when there is a key service.

We have found that the key service for the citizen / patient is to look at their EHR through the internet. When this service was introduced, it rapidly reached an extensive use by many citizens / patients, leading to increased use of other related e-health services.

Use of the SUSTAINS services has already exceeded the project expectations at the start of the project.

Introducing the service “Examine the EHR” was not smooth. The main reason was that the Swedish Medical Association, the union for medical physicians, opposed to the introduction.
Change History

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Version Changes
0.1  Initial proforma document with table of contents
0.2  Preliminary version
0.3  Preliminary statistics
0.4  Statistics
0.5  Pictures
0.6  Proofreading
1.0  Minor changes prior to issue
1.1  Correction of a few statistics

Outstanding Issues
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1. Introduction

1.1 Purpose of this document

This document sets out the results of the intermediate evaluation of the deployment of Sustains services in Uppsala. It will be followed by a final evaluation report at the end of the project period.

1.2 Glossary

<table>
<thead>
<tr>
<th>CCU</th>
<th>County Council of Uppsala</th>
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<td>EHR</td>
<td>Electronic Healthcare Record</td>
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<td>NLL</td>
<td>County Council of Norrbotten</td>
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<td>SMA</td>
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</table>
2. Implementation of services

2.1 Background

In 1995 an administrative data system for the University Hospital in Uppsala was introduced. This system included among other things data for booked visits, laboratory results and medication. In 1997 these data were made visible for a pilot group of patient through the internet in an EU project called Sustains.

In the evaluation of this project, it was shown that the patients did not use the service as it did not contain the notes from the medical record.

In 2002, the next step was taken when three GP pilot surgeries gave their patients access to the EHR. This project was financed by “KK-stiftelsen”, the Swedish Knowledge Foundation. However, in 2003 the Data Inspection Board judged it illegal to give patients direct access to their EHR, and further deployment was therefore stopped. The project continued in one GP surgery in Uppsala as a research project.

As a consequence of the position taken by the Data Inspection Board, new legislation came in place 1st July 2008 which allowed direct access to their EHR by citizens / patients.

In 2005, Uppsala County introduced a joint EHR system for all medical care, GP surgery, ambulatory care, hospital care, intensive care and so on. This system made it possible for HCPs to read notes made in other parts of the healthcare organisation in the County.

At the political level in Sweden, in both the County Council of Uppsala and the national Government, the issue of direct access to the EHR was looked upon as a matter of empowerment of patients, and the project was initiated and supported from the political levels.

2.2 National web portal

In Sweden there is a national web portal for citizens / patients called Mina Vårdkontakter (My health care contacts). This portal has been running in Uppsala County since October 2011, and has mainly the following services: secure log in, secure communication with care giver, and booking service for those units that have decided to use the service.

In the County of Uppsala, the use of the web portal “Mina Vårdkontakter” has had a relatively slow start. In November 2012, there were 22,790 user accounts. When CCU launched the SUSTAINS service, there was a quick rise in the number of users. On 9th December 2013, there were 48,664 user accounts.

As the log in to Sustains services is through the national web portal, we judge that the quick rise in users of the national web portal is a consequence of the popularity of the SUSTAINS services introduced. See Figure 1 below.
2.3 Services available at start of project

2.3.1 National web portal for healthcare

In Sweden there is a national healthcare web portal called “Mina Vårdkontakter”. This web portal contains:

- Secure log in through two alternative ways: e-legitimation, or password and a one-time password to your cell phone. These ways to log in have been found secure by the Data Inspection Board, and are used by all healthcare in Sweden.

- Secure message communication between patient and HCP for units that have introduced this service.

- Booking service for units that have introduced this service.

2.3.2 Change GP (when moving or similar)

This service was in place before the start of the project. The service is reached through the web portal “Mina vårdkontakter”, My health care contacts.

When the SUSTAINS project started, the use of the portal “Mina vårdkontakter” increased and thereafter the service was used with increasing frequency. The frequency of changing GP through the web portal is shown in Figure 2.
2.3.3 **Book or rebook a consultation/diagnostic exam**

This service was introduced as part of the national web portal Mina vårdkontakter. Through a template on the web portal, the citizen/patient can fill in his/her wishes for booking or rebooking. The HCP then has to book in the EHR and confirm to the patient.

Date of introduction: August 2011

Service usage: See Figure 3 below. As can be seen, the number of events has been tripled from project start to September 2013.

Problem encountered: It has been a choice for every healthcare unit whether or not they shall use the service. This has resulted in a slow start which in part is due to lack of manpower.
The next step in development is to use the functionality in the EHR system. The EHR system has four levels of functionality:

- Show all bookings for a specific patient.
- Make a cancellation.
- Rebooking.
- Book a new visit.

The services above will be fully automatic, and the citizen/patient will use the service without any contribution by HCP.

Deployment of this extension to the service according to above will start Q1 2014.

2.3.4 **Ask a question to a physician/nurse**

This service includes sending a question to physician or a nurse through a secure connection. The service is included in the web portal and was in use before the SUSTAINS project started.

As a consequence of the introduction of the SUSTAINS services, the general use of the web portal has increased, and also the use of this question.

Service usage is shown in Figure 4 below.

The service was introduced October 2011, when Mina Vårdkontakter was introduced.

Problem encountered: none.

![Ask a question usage statistics](image-url)
2.4 Services implemented during project

2.4.1 Pay a service fee

This service was started in the department of psychiatry when moving to a new building for psychiatry. When the patient signs up at the department, an invoice can be produced automatically and sent to the patient by ordinary post. This invoice is paid in the regular way, for example through e-banking. The new building for psychiatry was meant to be cashless. However, the County Council is able to receive cash, so for the moment there is a mixture of cash and invoices sent to the patient.

Date for introduction: Spring 2013

Service usage: No statistics are available for the moment.

Problem encountered: The fee is determined according to complicated rules with many exceptions. It is therefore not possible to have a computerised system to establish the fee. This is done manually by HCP.

In the County of Värmland, the politicians have decided that there will be a unit fee for all appointments. In the County of Värmland, payments of fees have been fully automated, saving time for HCP. If the same rules could be introduced in the County of Uppsala, this service will be changed to the way it works in Värmland.

2.4.2 Update phone number and name of close relative

In this service, the citizen / patient can update telephone numbers and e-mail addresses. This means that the HCP will have correct data more frequently when contacting citizen / patient. Before introduction of the service, the HCP always had to ask if data was correct and if needed had to change the data. The service saves time for HCP as the patient is taking over the work to update the data.

It is also possible for the citizen / patient to introduce name, address, telephone numbers and emails of close relatives. The patient can also rank and change the ranking list of close relatives so the HCP knows in what order the relatives shall be contacted. This service is time saving for the HCP, as the citizen / patient takes over the job from the HCP. It also means better quality, as the right person will be contacted when the HCP contacts a relative when, for example, the patient is seriously wounded after a car accident.

Service introduced: March 2013.

Service usage: The module for statistics released in December 2013 will incorporate these figures. Figures will be presented in the final evaluation report.

Problem encountered: no problems encountered.

2.4.3 Consult audit trail

In this service, the citizen / patient can view a list of all HCPs and delegates who have looked at their EHR. When an unexpected access of their EHR has taken place, the citizen / patient may have a suspicion which can be checked by this
service. This is important, not only to find the unexpected access, but also to remove such a suspicion.

In addition to the citizen/patient control of the audit trail, this is also checked by sampling by the care giver. However this sampling is very unlike to find any unexpected accesses.

Service introduced: February 2013, but had to be shut down after 10 days. During the period 22nd February 2013 – 11th April 2013, the service was not available. The reason was that the presentation of the audit list was not understandable and caused a lot of questions. A revised version of the service was released 12th April 2013.

Service usage: Until 6th December 2013, 14,274 unique citizens/patients have used the service 67,168 times, see Figure 5 below.

![Consult audit trail statistics](image)

**Figure 5: Consult audit trail statistics**

Problem encountered: The audit trail display to begin with was not understandable and had to be revised. This halted the service for 1½ months.

### 2.4.4 Delegation of access

In this service, the citizen/patient can delegate access to his/her EHR. The person who is given delegated access will be notified about this, and has to accept the delegation. After this, the person can, when logged in to his/her own EHR, change to the delegated EHR.

This service is meant to be used for example for older persons who can delegate access to their EHR to their children or other persons they trust. In this way they can receive support in their contacts with healthcare.

Service introduced: February 2013.

Service usage: Until 6th December 2013 only 105 unique patients have delegated access to their EHR. In total, 39 delegates have accessed an EHR 257 times.
Problem encountered: This service has not been used as much as expected. The service is not reached in a natural way in the application, and the information about the rationale for the service has not been sufficient.

2.4.5 Mask sensitive data

The citizen / patient in Sweden has the legal right to mask information in their medical record to prevent other healthcare providers from reading data.

This is done by a contact from the patient to HCP either by phone or through the web portal Mina vårdkontakter, announcing that masking is desired. The HCP then introduce the mask in the system.

The first step in self-service is that the patient him/herself can through SUSTAINS view if there is a masking introduced for the patient and the extent of the masking.

The service to order a masking through web portal Mina Vårdkontakter was introduced October 2011.

Service usage: in 2011, number of maskings, 38; in 2012, 220 maskings, and in 2013, 166 masking. Masking by month is shown in Figure 6.

![Number of masking of EHR](image)

**Figure 6: Masking statistics**

Since the start, 38 citizens / patients have canceled their masking of EHR.

The service to view masking through SUSTAINS was introduced in December 2013.

Problem encountered: The masking is too extensive, which means a medical risk. From the perspective of the patient, a more fine grained masking is desired. The main interest is to mask against a specific HCP (former wife/husband working in Health Care, etc.), and/or a specific notation in the EHR.
2.4.6 Track referrals

A recurring comment from healthcare professionals is that patients call and ask if a referral has been sent, if it has arrived at the recipient, and when the visit will take place.

In SUSTAINS, the citizen/patient can view the status of the referral: when it is sent, when it is received, when the answer is sent, and when the answer is received. In this way, the citizen/patient does not have to call the HCP to receive the information, and time is saved.

Service introduced: February 2013.

Service usage: When a citizen/patient logs in to Examine the EHR, he/she has access to track referral. We do not, however, have statistics on the numbers using the function tracking referrals.

Problem encountered: none.

2.4.7 Notification services

In this service, the patient will get an SMS 24 hour before a booked visit. In this way, the number of “did not shows” will be reduced, and the health system will be more efficient.

In CCU, this service is a part of our EHR system.

To activate the service, an HCP has to ask the patient if he/she wants a reminder by SMS. If the answer is yes, the HCP has to insert the mobile number to which the SMS will be sent. After this activation of the service, any visit to healthcare in the County will be reminded by SMS.

Service introduced: March 2012.

Service usage: Usage has gone up since the start. During summer 2013, there was a dip, but in the autumn 2013, the number of SMS reminders has risen to 45,000. See Figure 7.

Problems encountered: It takes time for the HCP to activate the service for the patient.

A development is planned where the patient can activate the service him/herself through SUSTAINS. This will probably raise the use even further, and save time for HCP.
2.4.8 Consent for the export of EHR data to the epSOS Patient Summary

It has not been possible to implement this service, as a specification from epSOS is lacking.

2.4.9 Examine the EHR

This is the main service and the reason for the SUSTAINS project.

During the introduction of this service, there has been a great deal of discussion, mainly with the doctors union. During the first year, more than 100 news articles have been published on the subject.

During spring 2012, the service was technically tested by approximately 40 persons from the staff of the County Council. In August 2012, all 11,000 employee at the County Council were given access to the service. During three months, 550 employee used the service. Before entering the service, these employees had to fill in a questionnaire about expectations with the service. The result is found in D6.4.

On the 11th November 2012, the service was introduced to all inhabitants in the County of Uppsala, and on the 3rd December to all Swedes who have an EHR in the County.

The rise in the numbers of users has on average been 102 new users every day. On average there have been 522 log-ins every day. Every user has on average made 5.1 log-ins.

Evaluations of this service have been carried out by the Dome research consortium. So far, attitudes of the medical doctors in Uppsala County and patients at the Department of Oncology have been studied. This has been done by questionnaires and in-depth interviews with patients autumn 2013. The results are not yet published, but can be summarised: Medical doctors do not think this service is of any value for the patients, and think the service should not have been introduced.
Patients are overwhelming positive to the service even though the patients were seriously sick with cancer.

Service introduced: November 2012.

Service usage: 40,441 unique users have used the system, and they have made 206,305 log-ins (6th December 2013). See Figure 8 below.

![New users "Examine EHR"

Figure 8: New users for Examine EHR

Looking at the figure above, it is evident that usage falls during major holidays and vacations.

The distribution of log-ins per day during the period is shown in Figure 9 below. As can be seen, the number of log-ins is lower during major holidays such as Christmas, New Year and Easter. It is also lower during summer when people in Sweden have their vacation. The distribution is similar to the distribution of new user above.
Figure 9: Log-ins per day

Looking at log-ins by day of the week in Figure 10 below, it is evident that usage varies during the week. On average, there were 623 daily log-ins Mondays through Fridays, and 270 daily log-ins Saturdays and Sundays.

Figure 10: Log-ins by weekday

Besides the user of the service, a total of 84,000 citizens / patients have tried to use the Examine the EHR service, although they did not have an EHR in the system in Uppsala County. These citizens / patients received a message that they do not have a record in the EHR system of Uppsala, and therefore the service is not available.
2.4.10 Fill out a Health Declaration Form

Following a political decision, all healthcare units in the County Council of Uppsala have to collect life style questionnaires. These are sent to the patient before a visit, for the patient to fill in at home and bring to the visit. There the HCP collects the paper questionnaire, and types the answers into the EHR.

With the SUSTAINS service, the patient fills out the life style questionnaire at home through the web portal; the data is then automatically stored in the EHR. Time is saved for the HCP.

The system is generic, and any form of questionnaire can be constructed for the citizen / patient to fill in. It is anticipated that this will be used by HCPs to follow the care of patients.

Service introduced: December 2013.

2.4.11 Print out drug and lab list before travelling abroad or outside their region

This is a service that was introduced at the same time as the service Examine the EHR.

Service introduced: November 2012.

Service usage: No data is available, as the print out is handled by the individual computer.

Problems encountered: None.

2.4.12 Patient’s input into EHR

In Sweden, patients have a legal right to have a dissenting opinion recorded in the medical record. Through this service, the citizen / patient may enter a dissenting opinion. A flag in the EHR marks that the citizen / patient has written a dissenting opinion, and HCP can click and read it.

This service makes it easier for the citizen / patient to have a dissenting opinion introduced. It also saves time for HCPs, as they do not have to enter into the EHR what the patient has said or written in a note.

Service introduced: December 2013

2.5 Procurement of equipment, software and services

2.5.1 Equipment

Servers to house the services have been purchased by public procurement, frame agreement upph2012-0266.

Citizen / patients have not had to purchase any equipment; they only need a connection to the internet, and any PC, tablet, etc. able to surf the net.
2.5.1.1 Lessons learned

The equipment is not a problem. This project is not a technical project so standard equipment is used.

2.5.2 Software

The interface between the EHR system and patients' computers was developed by the consulting firm Evry in close cooperation with the project. Evry was engaged through a suborder agreement (ref nr 2010-092).

The development method used was Scrum with development and implementation in short phases (typically three weeks).

In the County of Uppsala, a direct connection between the EHR and the interface presented to the patient is used.

When the service is scaled up to national level, information will be extracted from the different EHRs, and presented to the citizen / patient. This is because the patient may have visited healthcare in several counties.

2.5.2.1 Lessons learned

Although the nine years of pilots had provided a lot of experience, there were still continuous questions to answer and problems to solve. We used Scrum method with "sprint demos" every three week. On these occasions, decisions were taken for the development during the next three weeks. We judged that this model of work was a prerequisite for the smooth and quick development.

2.5.3 Services

When the SUSTAINS services are transferred to regular operation, the service will be handled by the County Council's IT department.

2.5.3.1 Lessons learned

Before the project starts, it is wise to have a strategy for transferring the services from the project to regular operation.

2.5.4 Implementation activities & process

Implementation of the different services has been as soon as they have been developed and tested. Since spring 2013 there have been seven releases containing new functionality.

Information about new functionality has been given to users when they log in to the service. No advertising has taken place.
2.5.5 Lessons learned

2.5.5.1 Main success factors

EU project

Being an EU project with support from politicians in the government and county, there was a clear message sent to all levels of the organisation that the project would be realised.

The label EU project gives a quality signal.

As an EU project we have to stick to the time table which gives it priority.

Experience with extractions

Experience with a total of 60,000 EHR print out requested by patients.

Experience with a real pilot

Nine years of experience from a pilot at a GP surgery. With this experience and research, we knew that the main interest of patients was reading their EHR, and that the patient wanted to read everything, and not just a limited version.

One single EHR in the County

One single EHR system in the County for all healthcare organisations, for example GP surgery, open care, hospital care, psychiatry.

Timing

The time is ripe for the service, and the public expects it.

2.5.5.2 Other critical issues

Swedish Medical Association tried to delay and reduce the introduction

Throughout the process, the doctors union maintained a number of objections:

- There will be a rush of patient questions that will hinder work.
- Patients will not understand.
- Patients will be concerned.
- Risk that healthcare workers will be threatened when patients are reading the log list / audit trail.

Other issues

- Far more complicated to design and set up.
- Dissemination to citizens needed more visibility.
- Reports sent to different supervisory authorities.
- Large number of users.
- An error in the technical design could lead to a violation of a user’s integrity.
3. Launch of services

3.1 Trialling

The services were tested in a pilot project including one GP surgery for nine years, see above.

After a six month test period when the service was open only to every County Council employees, it was directly introduced in the whole County.

3.2 Publicity

3.2.1 Press

There has been an overwhelming interest in the SUSTAINS project in Sweden. Over 120 articles have been published in national newspapers all over Sweden.

The Swedish Medical Association (SMA) has been critical of citizens / patients reading their EHR; representatives of the union have acted to have this opinion published in the press. When the press described the situation as a conflict between the project and SMA, this has been a perfect medical drama, and the press has articles to reinforce the perception of such a conflict. As soon as there were articles in the press about this conflict, the number of new users increased.

3.2.2 Radio broadcasting

There have been over 30 spots in news, interviews and programmes about the SUSTAINS service to access the EHR though the web.

3.2.3 TV

The SUSTAINS project has also attracted attention on TV. It has mainly been in local TV stations, but also at national level.

3.3 Training

No training for citizens / patients has taken place, and there has been no demand for training from them. The service is so intuitive that no training has been needed.
4. Uptake of services

4.1 Usage volumes (actual v. target), key indicators

4.1.1 Examine the EHR

The service with the main focus has been reading the EHR. We had estimated the total number of users at 25,000 by the end of the project (December 2014). This number was reached already the end of June 2013, after 8.5 months.

On the 12th December 2013, more than one year before the end of the project, the number of users has reached 42,081.

Citizens / patients interest in and acceptance of the service has exceeded all our expectations.

The expected percentage of citizens to whom the service had been offered who use the service was 5% for year 2013 (year 2). On 10th September 2013, this percentage was 6.41%, well above expectations.

4.2 Patient Empowerment Questionnaire completion

At their first visit to the service, citizens / patients were asked to take part in the Patient Empowerment Questionnaire. If the questionnaire had not been answered the question was repeated on the following ten occasions when citizen / patients used of the service. As the questionnaire was answered at one of the first ten times of use, the answers reflect the expectations of citizens / patients.

The Patient Empowerment Questionnaire was finished in the beginning of November 2013. A total of 167 citizens / patients answered the questionnaire. No further patients have been asked to complete the questionnaire.

These citizens / patients also gave their email address, and are willing to complete a new questionnaire after one year of use. This second questionnaire should reflect how the citizens / patients found the service.

4.3 Analysis of population

This analysis reflects the users of the SUSTIANS service in total.

4.3.1 The material

Only citizens / patients with a record in the EHR system (named Cosmic) in CCU can read their EHR through the service.

In total there are 865,133 identities in the system (September 2013).
184,289 individuals had no records in the EHR. When CCU introduced the EHR, all old paper medical records were scanned, and the papers were destroyed. The scanned old medical records were accessed by the person number and the EHR. This group represents patients with old journals, but no medical notes in the EHR. They represent patients who cannot use the service, and do not represent the cohort to which the service is offered.

92,741 individuals were registered as dead. Only patients who have died at a unit that uses Cosmic will be registered as dead in the system. This means that there are probably a number of patients who have died outside the units in CCU that use Cosmic (for example, other places in Sweden). We judge this error is minor. These individuals do not represent the cohort to which the service is offered.

The service is not open to young individuals up to 17 year of age. The number of persons in this age group was 110,023. They do not represent the cohort to which the service is offered.

There were 152 individual that did not have year of birth notated. They could not reach their EHR and were exclude from the cohort.

In total, 477,928 individual were offered the service and statistics are related to this number unless otherwise noted.

4.3.2 Total number of users

In total up to 12th December 2013, we have had 42,081 unique users. This number is increasing by approximately 100 new users every day. This is still the case after one year.

4.3.3 County affiliation

Every person in Sweden can read an EHR in the Cosmic system in the County of Uppsala. Uppsala has approximately 25,000 students who study at the university. Most of these come from other parts of Sweden, and they can read what has been written in the EHR system of Uppsala County.

The 477,928 individuals have a code for county. Of these, 280,639 individuals live in the County of Uppsala. Further analyses have been done on this cohort, as this cohort represents a typical county with all types of patients. Individuals from other counties are mainly referred for specialist treatment at the university hospital or are students; these groups are not representative of the general population.

The share of individuals from other Counties having a medical record in Uppsala County’ EHR system and using SUSTAINS in relation to County is shown in Figure 11.
As can be seen in Figure 11, the share is highest in CCU with 6.49% and lowest in Stockholm County with 2.19%.

It is notable that the share is relatively similar, which means that patients from all over Sweden with an EHR in the system in CCU use the system in Uppsala to the same extent.

4.3.4 Age of user

Here the % of users in different age groups accessing their EHR is presented. As can be seen in Figure 12, the % of users is the same up to 72 years of age. For older patients the % of users falls.
4.3.5 Gender of user

Females use the system relatively more than males, 7.37% versus 5.54%.

Younger females use the system more than males, while older males use the system more than females. See Figure 13 for % of users by gender and age.

![Share of Sustains user in relation to gender and age](image)

**Figure 13: Use by gender and age**

4.3.6 Latest entry in Cosmic in relation to use

The date for the latest entry in Cosmic is registered. All users of SUSTAINS were analysed according to when their latest entry in Cosmic was made. As can be seen in Figure 14, the vast majority (82%) had their latest entry in Cosmic during 2013. The conclusion is that citizen / patient use the system when they have a current illness.

![Sustain users and latest notation in EHR](image)

**Figure 14: Usage analysed by latest entry**
4.3.7 Number of entries in Cosmic in relation to use

The total number of entries in the EHR system was analysed in relation to use. As can be seen in Figure 15, citizens / patients with more notations use the system more than citizens / patients with only a few.

![Share of Sustains user in relation to number of notations in EHR](image)

Figure 15: Usage analysed by number of entries

4.3.8 Use of respite

The citizen / user can choose if they can to see an entry as soon as it appears in the EHR, or if there should be a respite of 14 days. (See section 5.1.2 below for further details).

98% of citizens / patients did choose not to have a respite. 2%, corresponding to the 760 individuals, chose to use this respite of 14 days. These might represent individuals that could not handle worrying information given over the internet.

4.3.9 Use of “Early hypothesis”

What is written under the keyword “Early hypothesis” is not shown to the patient, although it is included when a paper copy is sent to the patient. This keyword has been introduced to meet demands from the medical doctors, see section 5.1.3 below.

In total, the key word Early Hypothesis was used 554 times. It was mainly used by GPs (476 times) compared to specialists (78 times). Distribution is shown in Figure 16, Figure 17 and Figure 18 below.
Figure 16: Use of Early hypothesis, total

Figure 17: Use of Early hypothesis, by GP

Figure 18: Use of Early hypothesis, by specialists

The low frequency of use can be partly due to the fact that information on the keyword did not reach all doctors.
5. Initial evaluation

5.1 Attitudes of different actors

5.1.1 Politicians

The politicians at local level in CCU have been engaged in the project for several years. Three of the local politicians have been in Brussels to argue for the project at EU level. All political parties in CCU are united in the support of the project.

At national level, the government has supported the project with a recommendation letter. The government was represented by EU minister Birgitta Ohlsson at the Kick-off meeting for the project in January 2012.

![Image of Benny Eklund, EU minister Birgitta Ohlsson and Leif Lyttkens at the kick-off meeting for SUSTAINS in Uppsala.]

5.1.2 Patients

The different patient associations have been united in their support for the service, especially reading EHR.

The patient associations also strongly argued for a patient choice regarding a respite of 14 days before an EHR entry is visible to the patient.

They also were united in their wish to see entries immediately, and not wait for signing.

Altogether, patients and their organisations have been in strong support for the project.
5.1.3 Swedish Medical Association

The local division of the Swedish Medical Association represents approximately 1,200 medical doctors. They have during the whole project been acting strongly against the project. They have reported the project to nine legal authorities, so far with no success.

The Swedish Medical Association has opposed the project on the following grounds:

- The project has been run with great urgency, and the doctors have not been sufficiently engaged.
- There will be a rush of patient questions that prevent doctors from working.
- The patients will not understand what has been written in the EHR.
- The patients will be concerned.
- Risk that healthcare workers will be threatened when patients are reading log list.
- Risk that there will be health and safety problems when patients can write their own comments.

5.1.4 Health Professionals – union for midwives, biomedical scientists, radiographers and nurses

The official opinion of Health Professionals was declared in a press release on 10th June 2013 after a spot in the news in the Swedish Broadcasting Cooperation.

*Health Professionals welcomes patients’ ability to read their journal online*

*The Echo reported this morning about the project in the County of Uppsala, where patients have access to their medical record via the internet. Unfortunately, it focuses on the problems and difficulties that some doctors experience.*

*It is obvious that it is painful when going from a guardianship culture to care where the patient is regarded as an authority and an involved participant in their own care. This enhances patient power, improves safety and quality of care says Sineva Ribeiro, president of the Health Professionals.*

*The integrity problems that may exist are essentially already solved. For the sake of the patients, we hope that the opportunity to read their journal online will be introduced as soon as possible in the whole country.*

*Health Professionals have long pushed for a paradigm shift in healthcare that moves from a hierarchical hospital-centred care to a care based on the individual needs where team work is essential and the patient is involved in their own treatment.*

As can be seen from the press release above there is a great difference in attitude between the medical doctors and the nurses.
5.1.5 Media

There has been a lot of focus on the project in national and regional media. More than 130 news articles have been published and more than 30 radio and TV spots have been broadcast.

The initial focus has been on the opinion of the local branch of the Swedish Medical Association which has opposed the project. The articles have presented the situation as a conflict between the project management and the medical doctors, who themselves are said not to speak on their own behalf but out of concern for the patients.

Later focus has changed to a discussion between the doctors and representatives for the different patient groups. Representatives for the patients have argued that they speak for themselves and do not accept that the doctors make themselves advocates of the patients.

There has also been a growing interest in results from the research taking place.

5.1.6 Initial conclusions

If you offer a service that is perceived as urgent, than the service will be demanded and the number of users grows. That is what has happened in Uppsala.

The typical user of the service Examine the EHR though the net is a citizen / patient with a current disease with many contacts with healthcare.

5.2 Further deployment in Sweden

This is outside the contract for SUSTAINS but is clearly within the scope of the project.

After release of the SUSTAINS services, especially Examine the EHR, all counties in Sweden are united to launch this service for their inhabitants. This has resulted in a new project (outside SUSTAINS but as a result of SUSTAINS) to make the service available to all citizens / patients in Sweden.

CCU has received the assignment to realise this project. Norrbotten, NLL (which is a partner in SUSTAINS) have tested the service for one patient (December 2013) and the County of Skåne will launch the service in February 2014. Before the end of 2014, another three Counties will have launched the service. These Counties are Stockholm, Jönköping and Västmanland.

Before the end of 2015 all Sweden is expected to have the service.

5.3 Prizes and awards

The SUSTAINS project, and especially the service Examine the EHR have been the focus for development of e-Health services in Sweden.

The project has received the following prizes and awards.
5.3.1 The special prize of the jury 2012

On 6th December 2012, the project was awarded the special prize of the jury at the Days of e-Health in Stockholm. The prize was handed over by representative of the government, Anna-Karin Hatt of the Swedish Minister of IT and energy.

Figure 20: Special prize of the jury at the Days of e-Health, December 2012

5.3.2 The “Grand Prix” 2013

One year later, the County of Uppsala was awarded the “Grand Prix” at the Days of e-Health in Stockholm. The prize was awarded for the successful SUSTAINS project. The prize as handed over by a representative from the government, Lena Furmark, Secretary of State at the Ministry of Health.
5.3.3 **Prize for best system developer bachelor thesis**

From the Dome research consortium, see section 5.4 below, Johan Andersson and Viktor Kjerrman were awarded winner of Jusek’s and Computer Sweden’s prize for best bachelor thesis in Computer Science. The thesis described the introduction of SUSTAINS service *Examine the EHR* and suggested how the service can be further developed.
5.4 Research

Research is not an object for the project. However the Commission has encouraged all sites to initiate research where results will be published in scientific journals with a system of referees.

In Sweden, a research consortium called Dome has been founded with senior researchers from the Uppsala University, Skövde University and Lund University. The research consortium is independent of the project and is funded by separate funds. The SUSTAINS project has been available to researchers, and results are currently starting to be published. The research consortium will continue with the research for at least three more years.

The consortium and its research is presented on:
http://www.it.uu.se/research/hci/dome/