SUSTAINS - Direct Access for the Patient to the Medical Record over the Internet

Ingrid Joustra-Enquist, Benny Eklund
County Council of Uppsala, Sweden

ABSTRACT

The main objective of this project has been to encourage the patient’s involvement in his own health and medical care. A further aim has been to make the work of the health care providers more effective and efficient.

SUSTAINS (Support Users To Access Information and Services) is a system that can be considered as analogous to Internet banking, but for health care. Instead of an “Internet Bank Account” the user has a “Health Care Account”. Here the user (patient) can read essential information from his medical record. He can also obtain a list of prescriptions, laboratory results and so on. The system also allows easy exchange of written information between doctor and patient.

The patient logs in, using a One-Time Password which is sent to his mobile phone as an SMS, three seconds after username and PIN code has been entered. Thus personal information can be transferred both ways in a secure manner with acceptable privacy.

So far, SUSTAINS has been shown to be very satisfactory to many of the patients and beneficial for the physicians.

Keywords:
E-health and clinical communication, Patient education and self-care, Internet applications.

INTRODUCTION

Medical and technological advances have meant that citizens, with even relatively severe medical problems, today are able to live a more normal life than earlier. Such citizens are high consumers of Health Care and if they want to be mobile and live where they like, they also need to be in control of their personal data concerning treatment and health.

1. Would patients benefit from instant access to their own medical record?
2. How would the doctors react to such a scenario?

These were two of the questions asked when the County Council of Uppsala initiated a project to study the effects of giving the patients access to their own medical record via the Internet. Other questions concerned implications for security and integrity and the availability of sufficient technology.

One of the most important objectives was to encourage the patients’ involvement in their own health and medical care. A basic condition for such involvement is that the patient should have access to the same information as the care providers.

Through this project and its two pilot studies, a system was developed which took into account the technical aspects as well as security and integrity issues. The name, SUSTAINS, is short for its general purpose “Support Users To Access Information and Services”.

The basic idea of SUSTAINS could be understood as a copy of Internet banking, but for Health Care. Instead of an “Internet Bank Account” the user has a “Health Care Account”. The user logs in using an One-Time-Password. Thus personal information can be transferred in a secure way, with acceptable privacy. The patient can explore the medical record in detail and see the complete list of prescriptions, lab-result etc. It also provides a way of exchanging written information between the doctor and the patient.

The SUSTAINS project started with an EC funded trial in 1997 (Esprit IV Project 22994) and was followed 1999 by a nationally funded trial [1]. These two pilot studies were based on two different information sources (Hospital Information System Database and GP Medical Record Database) and each had a population of 100 patients. The trials were thoroughly evaluated with questionnaires and also led to further improvements of the system. Since November 2002 the SUSTAINS system has been available to a larger population in the municipality of Uppsala. So far it has been offered to 2.300 patients. The plans are to make it available to all inhabitants of the region (300.000) within the next two years.

The Swedish Federation of County Councils has recently published a book to show the benefits of similar services [2]. There are other projects concerning Internet access for patients. One is PCASSO where doctors as well as patients can access medical records from an intranet [3]. In Boston medical data from several sources are made available via the web in a safe way [4]. Other projects try to distribute data wireless [5] [6].

A presentation of SUSTAINS could be found at http://www.lul.se/sustains
METHODS

In this project we have utilised several phenomena and typical characteristics of the society of today:

Technological – society
- High coverage of Internet access and use of webs at the average citizen level.
- High coverage of PCs at home and in public places
- A mobile phone in almost everyone’s pocket

Financial
- EC funding
- National funding by the Swedish Knowledge and Competence Foundation.

Organisational
- Fast transition from paper-based information to computer-based, at back offices (hospitals and GPs)
- Good network of professionals, allowing cultural and technological difficulties to be bridged.

Under the basic conditions described above, we set up the two trials and implemented them. We focused on security and privacy, benefits for the citizens and the care provider, and accessibility of information irrespective of time and place. The results from the two pilot studies where combined in a specification for a system which has been launched to a limited extent since November 2002. We now aim to provide access to all the citizens in the region, within two years. This plan is included in, and thus depends upon, the implementation plan of the new regional Electronic Health Care Record (EHCR) system. A system that will be common to all hospitals and GP surgeries in the region.

Evaluation

The two trials (Sustains I and II) were evaluated with questionnaires given to the participating patients. Since the response level was very low in SUSTAINS I, we made complementary interviews with some of the patients after the trial.

We also interviewed the different health care providers (doctors and nurses) before, under and after the trials. Today, when the service is in limited production, we regularly have follow-ups with the GP in charge.

Risk management

To display the medical record to the patient is a delicate matter of risk management, at high level.
- How great are the risks of hackers getting access to very private data?
- Is there a risk that the patient misunderstands the information regarding his condition?
- Can physicians be more cautious when recording observations and by that making the notes less useful for future use?
- How great are the risks of users getting access to other user’s Medical Record?

Such questions must be carefully explored before implementing the concept. The risks and benefits must be thoroughly explained to both patients and professionals. The SUSTAINS project has so far included three different, independent security analyses made by experts. Prior to their consent of participating, all patients were given a folder of information to read.

DESCRIPTION OF THE SYSTEM

The pilot studies

SUSTAINS I
This was an EC-funded Esprit IV project that was divided into two parts: Italy – concentrating on public kiosks (not addressed in this paper) and Sweden – using Internet. The latter gave 100 patients personal access to information from the Hospital Information System (HIS) at Uppsala University Hospital.

The patients were identified with username and PIN code. In this trial, only information of when the patient has visited the hospital, at what department and under what diagnosis, was displayed. The trial was finished in 1999 and its evaluation very clearly indicated that the users wanted more information, including their medical record.

SUSTAINS II
The second pilot project (1999-2001) concerned the patient’s request for access to the medical record. For this purpose we engaged three different GP surgeries which had EHCR implemented and wished to participate in the trial. The information now available was therefore the patient’s medical record (produced at the GP surgery), laboratory results, prescriptions and referrals made by the GP, and so on. All information stored in the EHCR database.

Here we increased the degree of security up to an “Internet banking level”, including authentication with PIN code together with One-Time Password, generated from a token. This security level was considered to satisfy to the average citizen’s demand for privacy and integrity.

A substantial part of the efforts made in this pilot project consisted of providing information to the newspapers and participation in conferences. This was not only because of some obstructive cultural barriers in the professional organisation, but also to inform the patients, who were unused to think outside the customary health care routine. This activity has been very successful.

The SUSTAINS system of today

Since November 2002 the patients, who have Health Care Accounts, can access data from three different sources. The system also has a built-in communication channel between GP and patient, as requested in the evaluations of the two pilot studies.
The patient’s utilization of SUSTAINS can be explained with the above scheme, which include the following steps:

1. Patient entering username and password
2. Receiving One-Time Password on the mobile phone.
3. Entering the One-Time Password (OTP).
4. Requesting information from Health Care (HC) account.
5. Getting access to the overviews from the Hospital Information System (HIS) and the laboratory database (LAB).
6. Getting access to the Electronic Health Care Record (EHCR) from the GP centre.
7. Sending a message to the GP to ask for medical advice, an appointment, a prescription etc. The message is stored in the Message Database (DB). A notification of the incoming message is automatically sent to GP.
8. GP answers into the Message DB and a notification is sent to patient.

**Technical description**

SUSTAINS is built as a multi tier solution. This is mainly for security reasons, but also reasons of performance and flexibility. The user is only required to have a reasonably up-to-date web browser to access the service. He simply connects to a specific URL belonging to the County Council. The web server then establishes a secure connection to the system application proxy server through the corporate firewall. After authentication, the user is granted access to his medical record in the health care database. Totally the system uses four different hardware tiers and even more software tiers.

The connection uses PKI and X.509 certificates to ensure privacy and authenticity. After contact has been established between the proxy and the web server, the proxy tells the web server to ask the user to identify himself. An external RADIUS server then performs the authentication on behalf of the proxy, which includes granting access to a certain medical record. The proxy then sets up a session key to keep track of the authenticated user and whose medical record he is authorised to access. In order to ensure that no one can interfere with the safe running of the medical record server, the proxy always checks every question or statement sent from the web server to the medical record server.

The external RADIUS server uses a strong authentication protocol to ensure the identity of the user. This includes an ordinary user name and PIN code as well as a randomly generated One-Time Password. The password is generated by the server and is sent to the user’s mobile phone as an SMS message through the GSM network. This of course requires that the user is registered in advance together with his mobile phone number. This is considered to be strong authentication, since the user is identified using something he knows, the PIN, and something in his possession, the SIM card in the mobile phone.
RESULTS

Our principal objective of the whole project has been to help the consumers of health care to have more control over their personal data concerning health and treatment. A further aim has been to make the work of the care providers more effective and efficient. We felt that the concept of a Health Care Account could be the solution. Therefore two trials were made, investigating the implications of a Health Care Account. From the patient’s point of view as well as the health care provider’s. Some of the results are highlighted below.

The number of users was 100 in each trial, but the persons were not the same individuals. Today, when the system is in limited production, the number of users is 350.

The response to the questionnaire was very low in the first trial. So therefore, the results below refer to the second trial. It should also be mentioned that the trial period differed for the users, from 15 months down to 2 months. The length of the period depended on the different approaches, in announcing for participants, at the three GP surgeries.

The questionnaire was divided into 4 different categories;

**User profile (1)**

Focusing on the patient’s age, gender, education, occupation and experience in using computers and the Internet.

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<th>The average age of the users (patients) was 55 years. The gender distribution was equal. Different educational levels were relatively well represented.</th>
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<td>89% have had a computer at home for at least two years</td>
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<td>70% had experience of computers at work.</td>
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<td>30% used the Internet 3-5 times a week.</td>
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<td>70% of the users had previous experience of service on the Internet such as Internet banking and purchasing.</td>
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<td>23% had used an “Ask the Doctor on the Net” service</td>
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**Use and utility of the Health Care Account (2)**

Concerning the frequency of use and the users’ opinions of the different services, any technical problems etc. It is assumed, but not yet surveyed, that there is a higher use frequency for people with more health care visits.

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<th>On average, the users accessed the system less than 5 times during the trial period.</th>
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<td>We tested three slightly different technical solutions for the three GP surgeries. It was noted that the less complex the technical environment, the more stable the solution for the users.</td>
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**Estimated value of different e-services (3)**

Measuring the patients’ expectations of e-services of the Health Care Account. Both existing and new services, both read-only and interactive services, were analysed. As seen in the figure below, the patients would most appreciate to see their medical records and to be able to communicate with the health care providers.

![Figure 3: Estimated value of e-services](image)

82% of the users had not been at all worried about security risks during the trial, while 15% expressed “some concern”.

Would they be anxious about security risks in event of full scale service? 73% answered “Not at all”, while 2% stated “Yes, very concerned”.

**Observations by the health care providers**

During the pilot studies and since start of production, we regularly have had interviews with the health care providers involved. Below, some of the conclusions are listed.

Concerning the relationship between patient and HC provider:

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<th>No extra calls from patients who had not understood the information. It had been suspected before the project that there might be an overload of calls from patients with access to their medical record.</th>
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<td>Patients were showing a better understanding for the complex and time consuming health care processes.</td>
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<td>Increased demand from the patients for:</td>
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<tr>
<td>- Fast processing of notes, signing etc.</td>
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<td>- Use of a more precise language in the records</td>
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Concerning technical and administrative issues:

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<th>No effect on performance of back office EHCR systems with 350 users today (which was a suspected risk).</th>
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<tr>
<td>Too much administration and too expensive with distribution of Secure-Id tokens in full scale. This solution is only possible in smaller projects. The solution with One-Time Password to the mobile phone is better, but is obviously only applicable for owners of mobile phones, which some have found to be unfair.</td>
</tr>
<tr>
<td>With the present system in production, the GPs’ estimate of time saving for staff is 1 hour/patient and year. But it is far too early to measure this objectively yet.</td>
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<tr>
<td>The present uptake of the service today is about 15% of the population. Still the general awareness that such services exist is rather low in Sweden, compared with Internet banking.</td>
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DISCUSSION

The basic idea of SUSTAINS is very easy to understand. It’s simply analogous to Internet banking. Instead of an Internet Bank Account you have a Health Care account. But it has been easier for banks to apply this concept, for several reasons. The information in the bank world is better structured. The most active bank customers are at their most capable age. They can easily, and are willing to pay for the service. The bank customer and the bank professionals are at almost the same “level”. None of them are considered as the typical “weak” party.

A comparison between Health Care and Banking can be useful in understanding what impact e-services in banking or health care can have on private economy or health, respectively. Is e-service in banking a way to create economic wealth for an individual? No, just as little as the described e-services are a guarantee for good health. Many other factors determine whether individual will be wealthy or healthy. But with efficient e-services available, the individual can be helped in making decisions when such can be made. It is easier to see relations between income and expenditure, and between way of living your physical condition and, the closer you are involved in the case. Interactive e-services make it easier to supply information of your past and current medical status to the HC professionals involved in your case, as well as to express your wishes and preferences. The professionals making decisions on your behalf can then act on this information. Thus, the e-service can substantially improve the quality of such decisions. But there is a need to improve systems such as SUSTAINS with structured ways of getting such information from patients. Now we are half way – trying to present functions that consumers of health care find valuable to use.

Another area that we found important to further explore is the patients’ role as co-ordinators and auditors of their own health care. But why should the patients and relatives bother about that? Isn’t that the responsibility of the care provider? Yes, indeed it is, but the processes will be more efficient with involvement of persons who are present all the time and have a real interest in the case. The situation may be compared with that of a parcel delivery company providing the customer with a “tracking number”. Why make all this effort to keep the customer informed in detail of the process of delivering a parcel across the Atlantic? There are of course a number of reasons. But by this means the company also achieves two things that are less obvious: First they avoid calls from customers making inquiries about the parcel. Secondly, they also get a free auditor, someone who will immediately call if the delivery goes in the wrong direction, gets held up for a longer period, and so on. The help of the customer increases the quality of the delivery. Why shouldn’t health care systems take advantage of such phenomena? Hitherto, the assistance of relatives and patients as such resources has been underestimated in the business of health care.

LEARNING POINTS AND CONCLUSION

What is the strength and what is the weakness of the project?

<table>
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<tr>
<th>WEAK POINTS</th>
<th>STRONG POINTS</th>
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<tr>
<td>Needs national patient identifier</td>
<td>Recollection of “doctor’s orders” is facilitated</td>
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<td>Who benefits-who should pay?</td>
<td>New tool for supporting relatives of elderly patients</td>
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<td>“For wealthy only”</td>
<td>Patient can be a powerful resource in HC and patients can act as quality controllers</td>
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<tr>
<td>Security/privacy risks</td>
<td>Self-service will be facilitated</td>
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<tr>
<td>Doctors feeling uneasy when displaying their documentation</td>
<td>In case of illness while travelling, patient can display essential medical data to other health care provider.</td>
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Figure 3: Table of weak points – strong points.

The strongest points are of course the empowerment of the patients and the relatives, both as information resources and as quality controllers. The patient can also, by himself, display his medical data to other health care providers in case of health problems when in another location, or in case of a request for a second opinion from another doctor. A possible weakness is that e-services are labelled as being only for people with means (money to buy a computer and the skills to use it). This issue must be properly addressed in the information preceding introduction of the service. Another issue that has to be dealt with is that some of the HC-providers experience discomfort when presenting “their” documentation on the Internet, both for personal reasons and reasons of security and privacy for the patients. Technically, use of the Health Care Account, in other countries than Sweden, can find an obstacle in the lack of a national identifier. It can also be difficult to determine who should pay for the service, the patient (as in banking), or the health care organisation. Concerning the issue of security and privacy we know, that even if the technical aim is set ever so high, we never can guarantee total security. The patients must be thoroughly informed of the possible treats, before agreeing to be users of the service. Thus, one can assume that there always will be people that after balancing the risks and the benefits choose not to have a Health Care Account.
SUMMARY

PATIENT BENEFITS
The basic idea of SUSTAINS can best be understood by using the concept of Internet banking as a model. Before Internet banking became a widespread service, it was available only to the staff of the banks. In the same way as bank customers today have access to their own bank accounts; patients can access their own medical record over the Internet.

Whether the patient wants to read the doctor’s notes at home or needs the information when visiting another doctor while traveling, SUSTAINS can be a useful tool. By being able to access the information in the medical record, the patient is likely to have better knowledge of his own condition and therefore to have a better chance of participating in planning and treatment of the condition. It also makes it easier for the relatives of the elderly patients, to participate in the care without having to be present at every meeting with health care professionals.

SECURITY AND INTEGRITY
The system is built up of several tiers of hardware and software. The patient authenticates himself by means of his civic registration number, a personal PIN code and a One-Time Password. The authentication server generates a new password every time the patient logs in and is transferred to the patient’s mobile phone as an SMS. In addition, advanced proxy firewall technology is used to keep the communication and information safe.

By comparing e-health services with the Internet banking, their impact on the health care industry can be more easily understood. Just as the e-services of a bank cannot alone appreciably increase the economic wealth of their customers, of course the e-health services will not improve the health of the patients. But the availability of efficient e-services will help individuals to make decisions when such can be made. The more you are involved in the management of a health problem, the easier it will be to see relations between your way of living and your physical condition. Through e-services it is also easier as a patient to express wishes and preferences end to give information to professionals dealing with their health care. For the latter purposes, however, systems such as SUSTAINS need to be improved further with structured ways of obtaining such information from the patients.

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Address for correspondence
Benny Eklund, +460705 101306, Benny.Eklund@.lul.se