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# Experiences of Healthcare Professionals to the Introduction in Sweden of a Public eHealth Service: Patients' Online Access to their Electronic Health Records

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**Abstract**

*Patients' increasing demands for medical information, the digitization of health records and the fast spread of Internet access form a basis of introducing new eHealth services. An international trend is to provide access for patients to health information of various kind. In Sweden, access by patients to their proper electronic health record (EHR) has been provided in a pilot county since November 2012. This eHealth service is controversial and criticism has arised from the clinical professions, mainly physicians. Two web surveys were conducted to discover whether the opinions of healthcare professionals differ; between staff that have had experience with patients accessing their own EHR and those who have no such expericence. Experienced nurses found the EHR more important for the patients and a better reform, compared to unexperienced nurses in the rest of the country. Similarly, physicians with their own experience had a more positive attitude compared to non-experienced physicians. The conclusion of this study is that healthcare professionals must be involved in the implementation of public eHealth services such as EHRs and that real experiences of the professionals should be better disseminated to their inexperienced peers.*

***Keywords:***

Electronic Health Records; Health Personnel; Online Systems; Professional-Patient Relations; Doctor-Patient Relations; eHealth; Access to Information; Healthcare Survey; Patient Participation

## Introduction

The increasing demands of patients to read medical information pertaining to themselves, the digitization of health records and the fast spread of Internet access form the foundation of the implementation of a service giving patients direct online access to their electronic health records (EHR). All Swedish patients have a right to obtain a part of their health records [1] and the national eHealth strategy states that all health records should be accessible via Internet (i.e., online electronic health records) by 2017 [2].

Also in European directives, such a solution is sought to gain increased patient safety and security [3]. As the introduction of access to health records by patients and their families is an international trend, findings from research on pilot sites with real experience are of wide interest.

However, patients' access to their own health record is a controversial issue with many aspects. It is since a long time stated that the computerization transforms the accountability of professionals in relation to different actor groups: patients as well as managers, politicians and auditors [4]. The autonomy of the medical profession in relation to organisational governing and control systems has been discussed [5]. A common fear among the professionals is that the autonomy of the medical profession is expected to change and decrease. Less attention has so far been drawn towards professional transparency versus autonomy in relation to the patients, for which this kind of studies provides a basis. With this study, we want to focus on the impact on professionals due to patients new EHR transparency.

In Sweden, EHR systems were adopted quite early. Internet access as well as mobile phones have been widespreaded in the population from the early 1990's. In 1997, Uppsala County Council in Sweden started a project with the aim to give patients access to their medical data. The project called Sustains had financial support from the European Commission [6]. A system was developed to allow patients to have direct access to their clinical notes as well as to several other eServices through a "Healthcare account" similar to a bank account, over the Internet [6]. The system was introduced and used on a solo family practice in Uppsala and tested in clinical practice for many years [7].

The fast digital development and experiences from the Sustains project [6,7] pushed forward a change of the Swedish legislation in 2008 [1], which permitted the healthcare organizations to give patients direct access to their EHRs including the laboratory values and doctors' notes.

All hospitals and primary healthcare centers, except community nurses and some private doctors, in Uppsala County Council, used the same system developed by Cosmic, from a Swedish healthcare IT company: Cambio Healthcare Systems.This facilitated the initial integration work between the region-wide EHR and the public eHealth services.

Within the scope of an EU-project [8] Uppsala County Council in august 2012 introduced a new eHealth service called "My medical record" with the content from the Cosmic EHR. With this eHealth service, the patients from the age of 18 years old have access to all written text, including doctors' notes, on the Internet. The system was tested with employed health personnel in Uppsala County Council before it was launched [9].

In November 11th 2012 the e-service was offered to all 350,000 registered inhabitants in Uppsala County Council and soon later, in December 3rd, to all Swedish inhabitants with EHRs in the Uppsala County. As the first region-wide trial, the patients were given access to their health records through a secure log in to the national eHealth patient portal "My Healthcare Contacts" (www.minavardkontakter.se). People log in to the portal using the same general electronic ID as they use for banking and government e-services. Other e-

services successively introduced in the pilot county through the national patient portal were to:

- book, re-book/re-schedule or cancel an appointment,
- request certificates,
- extend sick leave,
- create safe messages with nurse or doctor,
- update personal data,
- change house physician/family doctor,
- renew medical prescriptions and assistive tools,
- and to order a written copy of the proper medical health record [10].

Apart from reading the medical text, the patient also has access to the audit log, block access to their records, give access to a friend or relative, order, get a SMS reminder of appointments, get a written list of prescriptions and laboratory values, can fill in a health declaration form saved in their records, and see the status and entire flow of their referrals to specialists or hospital. Both authors of this paper have access to their own health record and current version of views of data starts with either a time line or a calendar view, of the patient's choice.

From the release of the eHealth service in the pilot county, the number of users was growing with about 100 new users every day and in September 2013 6.4% of the eligible patients (n=477,928) were users [10]. By the end of 2014 the service had 48,664 unique users that could access their own and/or their family members' records [10]. In March 2015 there are 80,000 users who have had an average of four accesses to their health record and 800 patients accessed their health records every day [11,12].

Although the eHealth service is popular among patients, it is controversial among many professionals, especially physicians [13]. It is evident that increased knowledge of how the e-service influence users, both patients and clinicians, is essential for successful deployment of public eHealth [14] and that such services in general are challenging to put into practice.

This was the first region-wide trial in Sweden. The introduction of patients' access to their EHR creates an unique possibility to examine both longitudinal changes as well as momentary aspects related to professional transparency, patient relations, and patient empowerment.

The study presented in this article is part of a larger research project, DOME, Deployment of Online Medical Records and eHealth services in Sweden [15] with the aim to highlight experiences and effects related to the introduction of public eHealth services. The project was created in July 2012 in order to connect the first European deployment project, Sustains [8], to a purposive research group consisting of 16 nationally spread researchers from various scientific fields. This multi-site and multi-disciplinary composition provides a unique opportunity to highlight the issues from various research aspects through different methods and studies. Currently the senior researchers cover the areas of information management, human-computer interaction, IT and work environment, management and business studies, information security, healthcare informatics, medicine, organization theory, eGovernment, information technology, engineering education and statistics [15].

Different evaluation studies are taking place within three work packages, where this work is part of comparisons of surveys directed towards health care professionals in work package B, professions and management. The research questions for this study were:

- Which were the attitudes of the nurses and the physicians after they had been working some time within the pilot county compared to professionals that were not yet experienced with the eHealth service?
- Do experiences from the pilot county differ from regions where patient access to Electronic Health Records are not yet implemented?

## Materials and Methods

Patients from Uppsala County Council who were treated in hospital and primary care and patients from other counties who had received care in Uppsala County Council all have direct access to their EHRs since December 2012. The service is optional to use for patients and there is no requirement for staff or patients to talk about the usage of the service.

The two web surveys of this study were distributed to the physicians in Uppsala county 6 months after the deployment of the new e-service and to the nurses 9 months after the deployment. Data were collected from two similar 5-graded Likert scale web surveys (S1 and S2) to Swedish healthcare staff and is focused on attitudes and opinions of physicians (S1) and nurses (S2). To each set of statements, there was also a possibility to give answers in free text.

S1 was sent out in June 2013 to 1,602 physicians in the pilot county with a response rate of 25% (399 respondents, 52% women, age 25-71 years, median worktime 14 years, 78% worked inhospital and 22% in primary care, 85% native in Swedish language).

S2 was sent out in March 2014 to 8,460 registered nurses and midwives in Sweden with a response rate of 35,4% (2,867 respondents, of whom working as nurses were 84%, midwives 6%, chief position 5%, in projects 2% and other 3%). The questionnaires consisted of background questions and five sets of items with free text fields to each set. To deliver the questionnaires the Uppsala County Council's and the Swedish Association of Health Professionals' internal web survey tools were used. The accompanying letter stated that responding was voluntary and that the time spent to respond according to the strongly agree (5) - strongly disagree (1) - scale was approximately 10 minutes.

Ethical approval for S1 was granted by the Uppsala County Council's research units as well by the Swedish central ethical committee. S2 was conducted according to the principles of the Declaration of Helsinki.

Standard data reports were created for each survey with charts showing the most prominent differences in each statement. As the questionnaires were jointly developed and contained some identical statements, this first analysis expects to discover differences between nurses and physicians that have experience of patients accessing their EHRs online and those working in regions where the eHealth service had not yet been implemented. The two different questionnaires distributed to the nurses and physicians contain more statements to analyze, however the responses handled in this study are consistent between the two surveys. Currently other statements from the data-sets are jointly being analyzed by statistics, clinical and healthcare informatics researchers and students and will be published in the near future.

The statements analysed in this study regard to which extent patients' access to EHRs online is considered useful for the patients, if their relatives were given access to their EHRs and whether the professionals consider the new eHealth service being a good reform. In the questionnaires the statements read:

*- To which extent do you consider it a benefit for the patients that their relatives have a possibility to take part in their EHR?*

*- To which extent do you consider the eHealth service "online health records" a good reform?*

Simple statistics were used for analysis. The Mann-Whitney ranksum and $\chi^2$ tests were used for evaluating the statistical significance for ordinal and nominal data, respectively. The data was analyzed by the Stata statistical package 13.1 [16].

## Results

The responses of the physicians to the multiple choice questions are presented in Table 1 based on a 5-graded scale from strongly disagree (1) to strongly agree (5). The responses of the nurses are presented in Table 2 and Table 3. In general, professionals' opinions of patients reading their health record online were negative (grade<2.5) among physicians and positive (grade>2.5) among nurses. Physicians were negative to giving relatives of the patients access to the EHR and they were also negative to the reform as such. Both pilot nurses and those outside the pilot county were generally more positive than the physicians.

Nurses in Uppsala County Council with experience with EHRs were significantly more positive to reform ($p<0.001$) than nurses outside the pilot county. 40% stated that they agreed or strongly agreed to 'patients receiving online access to their EHRs being a good reform' compared to nurses in the rest of the country (25%) as well as physicians, where 82% disagreed or strongly disagreed.

*Table 1 – Physicians working in the pilot county (Uppsala County Council) Responses to the statement "To which extent is it a benefit for the patients that their relatives have a possibility to take part in their EHR?" and whether the eHealth service "is a good reform".*

Five-graded Likert scale 1-5 where 5 = strongly agree.

| | Access for relatives | A good reform |
|---|---|---|
| **N** | 381 | 385 |
| **Mean** | 2.22 | 1.66 |
| **SD** | 1.08 | 0.97 |

In one of the background questions of the web questionnaire, 61 physicians of 399 (15%) stated that they for themselves or their relatives had personal experience of using this eHealth service as patients.

A sub-analysis revealed that their own usage was equal between hospital and primary care physicians, females and males, but that the users were younger ($p=0.0004$).

Physicians using the eHealth service themselves, compared to non-users, regarded the eHealth service:

- more important for patients ($p=0.0001$),
- to improve quality in care ($p<0.0001$),
- to contribute more to equality in healthcare ($p=0.0003$),
- they experienced less change in their working conditions ($p=0.014$),
- found the eHealth service being a good reform to a greater extent ($p=0.003$),
- thought their medical noting had improved since the eHealth service was introduced ($p=0.021$) and
- found the launch of the reform better ($p=0.019$).

*Table 2 – Nurses working in and outside the pilot county (Uppsala County Council). Responses to the statement "To which extent do you consider it a benefit for the patients that their relatives have a possibility to take part in their EHR?"*

Five-graded Likert scale 1-5 where 5 = strongly agree.

| | Pilot county | Outside Pilot | P (Mann-Whitney) |
|---|---|---|---|
| **N** | 234 | 2495 | |
| **Mean** | 3.08 | 2.92 | 0.0454 |
| **SD** | 1.16 | 1.12 | |

*Table 3 – Nurses working in and outside the pilot county response to the statement "To which extent do you consider the eHealth service "online health records" a good reform?"*

Five-graded Likert scale 1-5 where 5 strongly agree.

| | Pilot county | Outside Pilot | P (Mann-Whitney) |
|---|---|---|---|
| **N** | 235 | 2494 | |
| **Mean** | 3.17 | 2.71 | <0.0001 |
| **SD** | 1.27 | 1.17 | |

Again, nurses from the pilot county were far more positive (35% agree and strongly agree) to the importance of this eHealth service for the patients, compared to nurses outside the pilot (25%) as well as physicians (64% disagree or strongly disagree).

## Discussion

This study aimed to investigate the opinions of health professionals related to the introduction of a new eHealth service: giving patients direct access to their EHRs, in Sweden. The main outcome of this study was that many professionals were reluctant with the proposed eHealth service, and that professionals with personal experience with the innovation were more positive as to the benefit for patients than healthcare professionals without experience.

Nurses with experience with the service were significantly more positive to reform ($p<0.0101$) than nurses outside the pilot region. The physicians within the pilot region were generally more negative compared to nurses in the same region. However, the time spent between the questionnaires (9 months) does cause an uncertainty as to comparability between the opinions of the professionals. The longer use time for nurses compared to physicians may have given the nurses a more positive attitude.

The authors' knowledge about the context in which this deployment process took place is worth mentioning. During the deployment project [8], representatives of the physicians' local union in the pilot county expressed a distrust of the eHealth service, whereas the Swedish Association of Health Professionals (the union for the nurses and midwives) embraced the development and deployment of such eHealth services. These different statements could have affected the respondents of this study.

However, in another study, free text responses from the survey of the physicians were analyzed and revealed that the physicians in general were negative and many also upset over the deployment of an eHealth service giving all patients digital access to their medical records. The physicians were especially concerned about increased workload and patients' risk of misunderstanding the notes and laboratory findings. These findings are further presented by Erlingsdottir et al [13].

These findings correspond to the hypothesis that physicians have a wider knowledge and a stronger patient relationship

than nurses. Thus they feel a greater threat to their autonomy and thus get a more negative attitude to online EHRs for patients.

As the patients become more knowledgeable, the privileged position of the professionals changes. As early as in 1985, Freidson argued that computerization may contribute to the decreasing of the knowledge gap as more and more information becomes easily accessible [4]. According to Freidson, the key question is whether laymen are able to mobilize sufficient motivation to become knowledgeable to the extent that they will be able to challenge professional actors. Possibly, the resistance that is noted in this study could be related to the intrinsic conflict when patient empowerment encounters professional autonomy [17], which needs to be further investigated.

It appears that the overall trend in the results of this study is that a negative attitude predominated among the professionals. However, the difference between experienced and inexperienced nurses, as well as physicians, was significant. As the introduction of electronic access to patients' health records and other similar eHealth services is on the eHealth agenda of many countries, we find it important not only to display the attitudes of the majority of professionals to the idea of patient access to EHRs, but also to show the findings from real experience. Although the results from the pilot county are not strong enough to translate into real qualitative changes in attitude, we found the changes to be statistically significant and therefore worth discussion.

Again, the difference between experienced and inexperienced nurses as well as physicians, was significant. Possibly the nurses in the pilot county have not experienced an increased workload and no harm to the patients, which was stated as a fear by physicians in the free text responses [13]. Moreover, the eHealth service may have a positive effect on the patient consultation. The opinions of physicians who used the eHealth service for themselves or their relatives were remarkable. They differed significantly from physicians not using the service. They found that the eHealth service more important for patients and that it improved quality in care to a greater extent. Probably their own usage has a strong positive influence on their attitudes.

In previous studies on giving patients web access to their own health data, patients regard the online access as a step towards increased quality of care and patient empowerment [18,21]. Other studies indicate that patients think privacy concerns are outweighed by benefits [22] and physicians do not experience significance increase in work load [23]. Checkland et al. argue, somewhat in opposition to Freidson, that direct access to information over the Internet may contribute to enhanced trust in the patient-doctor relationship as the patient becomes knowledgeable and enlightened [19].

Information and communication technology innovations are being increasingly used to supply citizens with various health services which will lead to new demands on health and social care organizations. There is a strong need for further studies to investigate how this new trend will influence patients and health personnel. Knowledge that experienced staff hold a less negative attitude is a factor that could support future deployment processes and may lead to an increase in acceptance [24,25]. Therefore, it is important to disseminate these results to the inexperienced peers that today are standing on the verge of the deployment process of such eHealth services in their organizations.

It is in line with the interest of action researchers to address the challenge of overcoming the clash between patient empowerment and professional autonomy. One means could be to emphasize the introduction method of an innovation in a socio-technical way [18]. Different methods of measurement around the introduction of a system can be integrated with each other, e.g., TAM, Theory of Planned behavour and Innovation Diffusion Theory [24,25]. Yi et al. [24] offer a set of measurement criteria required for a specific intervention, which could be the deployment of a public eHealth service. Based on the suggestions from Yi et al. [24], an adaptation has previously been applied to support the introduction of an eHealth system in a Swedish county council, with successful results [18]. Such an adaptation would be interesting to repeat, when innovations like this eHealth service are to be implemented in other regions.

## Conclusion

The main outcome of this study is that many professionals are reluctant when faced with patients having access to their EHR and that professionals with personal experience of the innovation are more positive as to the benefit for patients than healthcare professionals without experience. The study shows that health personnel have concerns about patients' direct access to their EHR in terms of the benefit for patients if their relatives also have access. Physicians and nurses having their own experience with online EHRs demonstrate a positive attitude towards the benefit for patients to a greater extent. The success of the introduction of reforms from the patients' point of view is accompanied by the possibility for professionals to get used to the eHealth services. We therefore recommend that healthcare professionals should be more involved in the implementation of Public eHealth services such as online EHRs and that real experiences of the professionals should be better disseminated to their inexperienced peers.

These findings, based on real experiences, are of interest in the upcoming introduction of similar eHealth services in Europe [25], as well as in other countries with a public eHealth strategy agenda.

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## References

[1] Patient Data Act (SFS 2008:355) http://www.riksdagen.se/sv/Dokument-Lagar/Lagar/Svenskforfattningssamling/Patientdatalag-2008355_sfs-2008-355/ Retrieved 2014-12-21

[2] Ministry of Health and Social Affairs. National eHealth – the Strategy for Accessible and Secure Information in Health and Social Care, 2010. http://www.nationellehalsa.se/Content/Cms/img/temp/National%20eHealth%202010.pdf. Retrieved 2014-12-21

[3] European Commission, eHealth Action Plan 2012-2020 – Innovative healthcare for the 21st century,

http://ec.europa.eu/health/ehealth/docs/com_2012_736_en.pdf Retrieved 2014-12-21

[4] Freidson, Eliot. The Reorganization of the Medical Profession", *Medical Care Research and Review*, 1985: 42:11-35

[5] Kurunmäki, L. A hybrid profession – the acquisition of management accounting expertise by medical professionals, *Accounting, Organizations and Society,* 2004: 29, pp. 327-347.

[6] Eklund, B. and I. Joustra-Enquist. Sustains--direct access for the patient to the medical record over the Internet. *Stud Health Technol Inform* 2004: 100: 182-189.

[7] Ålander, T. Eklund, B. and I. Joustra-Enquist. Projekt Sustains – Journaltillgång över Internet. AllmänMedicin 2004: 6: 11-13.

[8] Lyttkens, L. SUSTAINS Intermediate trial evaluation – Uppsala, Report D6.1 v1.1, 14 Jan 2014. Available from: http://www.sustainsproject.eu/. Retrieved 2014-12-21.

[9] Lyttkens L. D6.4 v1.0 SUSTAINS Uppsala patient questionnaire. Uppsala County Council. Public Report. 2013-03-18

[10] Lyttkens L, Eklund B, Pettersson M. Rapport om införande av e-hälsotjänster. Min journal på nätet. Sustains. Landstinget i Uppsala län. Gov report 2014.

[11] Eklund B. Sustains, project leader. IT-dep.Uppsala County Council. Oral information 2015-04-02.

[12] Inera. Monthly report citizen eServices (in Swedish) Journalen. http://www.inera.se/TJANSTER--PROJEKT/Journalen/Inforande/ Last updated 2015-03-23. Retrieved 2015-04-03.

[13] Erlingsdottir, G., Lindholm C, Ålander T. (2014). eHealth services, patient empowerment and professional accountability – An empirical study on the changing patient-doctor relationship in the digital world. Conference paper, Edinburgh.

[14] Melin U., Axelsson K., and Lundsten M., Talking to, not about, Entrepreneurs – Experiences of Public e-service Development in a Business Start Up Case*, in eChallanges*, P. Cunningham, Editor. 2008

[15] Scandurra I, Åhfeldt, R-M, Cajander Å. Towards National Deployment of Medical Records and eHealth Services. *In Proceedings of VITALIS – Nordic leading eHealth meeting.* 2014: 14-17. Göteborg. Göteborgs Universitet; 2014. Retrieved 2014-12-21. https://gupea.ub.gu.se/bitstream/2077/35435/2/gupea_2077_35435_2.pdf

[16] Stata Statistical Software. Release 13.1 ed. College Station, TX: Stata Corporation 2014

[17] Erlingsdottir G, Lindholm C. When patient empowerment encounters professional autonomy. The conflict and negotiation process of inscribing an eHealth service. *Scandinavian journal of public administration*. 06/2015; 19(2)

[18] Hägglund M, I. Scandurra I, and Koch S, Empowering patients and relatives in elderly care by information access, in *the 6th International Conference on Information Communication Technologies in Health*, 2008, pp. 218–223.

[19] Checkland, K., Marshall, M. & S Harrison, 2004, Rethinking accountability: trust versus confidence in medical practice, *Qual Saf Health Care*. 2004; vol 13, pp 130-135 doi:10.1136/qshc.2003.00972

[20] Koch S, Improving quality of life through eHealth-the patient perspective., *Stud. Health Technol. Inform.*, vol. 180, pp. 25–29, 2012.

[21] Delbanco T, Walker J D, Darer, Elmore G, and Feldman H J. Open Notes : Doctors and Patients Signing On, *Ann. Intern. Med.*, vol. 153, pp. 121–125, 2010.

[22] Vodicka E, Mejilla R, Leveille S G, Ralston J D., Darer J D, Delbanco T, Walker J, Elmore, J. G. Online access to doctors' notes: patient concerns about privacy. *J Med Internet Res* 2013: 15(9): e208.

[23] Delbanco T, Walker J, Bell S K, Darer J D, Farag N, Feldman H J, Mejilla R, Ngo L, Ralston J D, Ross S E, Trivedi N, Vodicka E, Leveille S G Inviting patients to read their doctors' notes: a quasi-experimental study and a look ahead. *Ann Intern Med* 2012: 157(7): 461-470.

[24] Yi M.Y, Jackson, J.D., Park, J.S., and Probst, J.C. Understanding Information Technology Acceptance by Individual Professionals: Toward an Integrative View, Information & *Management* 2006 (43:3), pp. 350-363.

[25] Venkatesh V, Thong J Y L, Consumer Acceptance and Use of Information Technology: Extending the Unified Theory of Acceptance and Use of Technology. *MIS Quarterly 2012*: Vol. 36 No. 1 pp. 157-178.

[26] SUSTAINS: Support User Access to Information and Services http://www.sustainsproject.eu/ . Retrieved 2015-03-01

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