Is ‘patient’s online access to health records’ a good reform?  
– Opinions from Swedish healthcare professionals differ

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Abstract

Patients’ access to their own electronic health record is a controversial issue. Many care professionals are concerned about negative effects deriving from patients reading their record information without support from clinicians. Patients on the other hand often think their concerns are outweighed by the benefits. In Sweden a pilot county has provided the health record online to its 350 000 patients for 2.5 years. This study highlights one of the most important questions to handle before and during implementation of such public eHealth services; the opinions of the care professionals regarding online records as a good reform. Results from three questionnaires to various care professions show that opinions from healthcare professionals differ not only between the professions but more importantly also between those who have experience from their patients reading their health record online and those who to date have no real experience. The experienced staff was more positive. This study concludes that in order to provide for successful national implementation, it is important to quickly elicit and disseminate opinions of care professionals with real experience to their unexperienced peers. Healthcare professionals should also be more involved in the implementation of Public eHealth services that regard electronic health records and their work processes.

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1. Introduction

As a means to address current challenges for and demands on health and social care, e.g. quality of care and patient empowerment, information and communication technologies (ICT) are being used to supply citizens with various health services\(^1\). One example is to give patients online access to their own electronic health record (EHR)\(^3\). The conditions for investments in public eHealth services are good in the Northern European countries. Regarding the introduction of region-wide EHR systems, Sweden has reached far; county councils have introduced EHRs to 100% of hospitals, primary care and psychiatry. In Europe, the corresponding figures are 65% in total and for hospitals alone, 81%\(^4\).

Further, patients in Sweden have a right to take part of their health records\(^5\). The National eHealth Strategy states that patients should be able to take part of their health records also via Internet\(^6\). Thus, all county councils or healthcare regions in Sweden have decided to make EHRs available online for patients by 2017 i.e. online records as a national eHealth service\(^4\). Also in European directives such a solution is sought for to gain increased patient safety and security\(^7\).

Within the scope of an EU-project, the Uppsala county council in November 2012 deployed such a public eHealth service to its 350 000 patients as the first trial in Sweden\(^8\). Access to your own eHealth record is however a controversial issue, as many healthcare professionals are concerned about negative effects, such as lack of patients’ privacy, increased workload and patient safety, e.g. in terms of how the information will be understood by patients when reading the record without support from their clinicians. To date, this pilot county has provided the health record online for 2.5 years. The aim of this study is to highlight one of the most important questions to handle before and during implementation of such public eHealth services, i.e. whether the care professionals regard online records as a good reform.

1.1. Development and deployment of online records in Sweden

Already in 1997 Uppsala County Council in Sweden started a project with the aim to give patients access to their medical data. The project was called Sustains and had financial support from the European Commission\(^9\). A health information system was developed where patients had direct access to their clinical notes as well as to several other eServices through a “Healthcare account” similar to a bank account over Internet\(^9\). The system was introduced and used on a solo family practice in Uppsala and tested in clinical practice\(^10\). The fast digital development and experiences from the Sustains project pushed forward a change of the Swedish legislation in 2008\(^5\), which permitted the healthcare organizations to give patients direct access to their EHRs including laboratory values and the doctor’s notes.

As part of the EU-project Sustains\(^8\) (ICT-PSP 297206, during 2012-2014), Uppsala County Council extended the deployment of public eHealth services to a national pilot. The 350 000 patients were given access to their health records through the national Internet patient portal “My Healthcare Contacts” (www.minavardkontakter.se) and in November 2014, 56 480 patients had used the eHealth service\(^11\). From 2015, the national eHealth organization (Inera) has taken the responsibility for the public eHealth service. The development and deployment are ongoing processes in every healthcare region and county council. To date four of 21 regions in Sweden offer parts of their EHRs as online services for their citizens and four more have planned to introduce the service during 2015 and five more in 2016, including Örebro region\(^12\). Currently, almost 2 200 000 citizens (22%) have chosen to create and administer their own account on the patient portal, and the online record service has approximately 200 000 active users\(^12\). It is evident that increased knowledge is essential for successful deployment of public eServices and such services tend to be challenging to put into practice. Consequently, there is a great interest in evaluation studies regarding the development and deployment of public eHealth services in general and online records in particular.

1.2. Studies within the research project DOME

The study presented in this article is part of a larger study in the research project, DOME, Deployment of Online Medical Records and eHealth services in Sweden\(^13\). The project was created in July 2012 in order to connect the first
European deployment project to a purposive research group consisting of 16 nationally spread researchers from various scientific fields. This multi-site and multi-disciplinary composition provided 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. Different evaluation studies are taking place within three work packages, where this work is part of comparisons of surveys directed towards care professionals in the work package that regards professions and management. Currently other statements from the data-sets are jointly being analyzed by statistics, clinical and healthcare informatics researchers and students.

The statement handled in this study aims to discover whether care professionals agree on this eHealth service being a good reform. And, do experiences from the pilot county result in other opinions compared to the regions where online records are not yet implemented?

2. Methods

This study collected data from three similar 5-graded Likert scale web questionnaires to Swedish healthcare staff and was focused on opinions of physicians (Q1), nurses (Q2) and all licensed professionals (Q3) that document in the EHRs. Ethical approval for Q1 was made by the Uppland County’s research units. Q1, Q2 and Q3 were conducted according to the principles of the Declaration of Helsinki.

Q1 was sent out in June 2013 to 1600 physicians in Sweden with a response rate of 25% (399 respondents). Q2 was sent out in March 2014 to 8460 registered nurses and midwives in Sweden with a response rate of 35.4% (2867 respondents) and Q3 was sent out in December 2013 as a pilot study in the Örebro region to 100 licensed staff, with a response rate of 45%. The questionnaires consisted of background questions and about 5 sets of items and free text fields to each set. To deliver the web questionnaires the regions’ and the Swedish Association of Health Professionals’ internal web survey tools (Webropol and esMaker) were used. The missive letter stated e.g. that responding was voluntary and that time spent to respond according to the strongly agree (5) - strongly disagree (1)-scale was approximately 10 minutes.

To analyze data, standard data reports were initially created for each questionnaire with charts showing the most prominent differences in each statement. The statement “Is online patient access to health records a good reform?” was posed in all three questionnaires and was hence selected for further analysis in this paper. Differences and similarities between professions regardless of geographical sites as well as between different regions were possible to analyze here as a first step of a complete comparison of the content of the three questionnaires. The Mann-Whitney ranksum and CHI2 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 [10].

3. Results

The results show how statement responses differed between staff that had experience of patients using online records and those who were unexperienced. In general, professionals’ opinions of patients reading their health record online were neither entirely positive nor negative (nurses median=3), although physicians were generally more negative to the reform (median=1). The specific statement analyzed in this study was “Is online patient access to health records a good reform?” The responses were summarized from the national surveys (Q1 and Q2) in table 1, and validated by the pilot study (Q3) regarding answers from nurses and physicians.

<table>
<thead>
<tr>
<th>Table 1. Is online patient access to health records a good reform?</th>
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<tbody>
<tr>
<td>Strongly disagree:</td>
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<tr>
<td>Q1: Physicians (385)</td>
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<tr>
<td>Q2: Nurses, all other (2729)</td>
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<tr>
<td>Q2: Nurses, Pilot (241)</td>
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Nurses in the pilot county with experience of the online records were significantly more positive to the reform (p<0.001) than nurses outside the pilot. 40% stated they agreed or strongly agreed to patients receiving free online access to health records compared to nurses in the rest of the country (25%) as well as to the physicians where 82% strongly disagreed or disagreed. As a response of the background questions of the web questionnaire, 61 doctors of 399 (15%) stated that they for themselves or their relatives had personal experience of using this eHealth service. A sub analysis revealed that the own usage was equal between hospital and primary care physicians, females and males, but the users were younger (p=0.0004). Physicians using the eHealth service themselves, compared to non-users, found the eHealth service being a good reform to a greater extent (p=0.003) and found the launch of the reform better (p=0.019).

4. Discussion

The professionals with personal experience of the online record were significantly more positive to the reform than their peers without experience. A hypothesis is that the experienced staff in the pilot county has not experienced an increased workload or has noticed that access gives a positive effect when meeting the patient. This needs to be studied further, possibly via interviews with the experienced staff. There were also differences between the professions: the nurses with experience of the service were generally more positive compared to the physicians in the same region.

However, the questionnaires were implemented on three separate occasions which need to be taken into consideration when analyzing the data. Further, the statement as written in Swedish differed a little between the pilot questionnaire and the other two, i.e. Is online patient access to health records a good service respectively reform? Here we considered the responses comparable, whereas the time spent between the questionnaires (9 months) does cause an uncertainty regarding comparability between the professions. The longer usage for nurses compared to physicians may have given the nurses a more positive attitude to the eHealth service. Future work would be to perform another national survey where physicians and other care professionals respond in parallel. Extending the Örebro pilot study (Q3) to a region-wide survey would also be interesting.

Knowledge about the context in which this deployment process took place is worth mentioning. During the deployment project, representatives of the physicians’ local union in the pilot county have expressed a distrust of the online record service whereas the Swedish Association of Health Professionals (for the nurses and midwives) has embraced the development and deployment of such eHealth services. It is possible that the differences in the opinions held by the unions on a governing level shines through in the responses by their respective professionals.

Regarding the non-response analyses; the statistical analysis of Q2 showed that non-negative and negative towards the eHealth service as a reform were evenly spread among all responding groups, which indicates that there is no systematic loss depending on whether the respondent is negative or non-negative to the eHealth service as a reform. In the Q2 study only 5% of the physicians answered the questionnaire and there should be a non-response analysis; maybe the physicians who responded were all negative towards the eHealth service? On the other hand, the sub analysis of physicians who used the eHealth service for themselves or their relatives is interesting. The users differ significantly from physicians not using the service. Probably the own usage has a positive influence on the attitude. The sub analysis indicates that there was no systematic loss due to a specific opinion.

Future work: Regarding the entire questionnaires, physicians and registered nurses generally left more comments in free text compared to other professions. The comments regarding this statement are still to be analyzed together with the results of this first analysis. We will also perform analyses of the complete data-sets in order to better delve into why each profession was supportive or unsupportive of personal access to health records. More results will also be published based on other research questions.

5. Conclusion

This study aimed to discover whether care professionals agree on this eHealth service being a good reform. Results from three questionnaires to various care professions show that opinions from healthcare professionals differ not only between the professions but more importantly also between those who have experience from their patients having personal access to the health record online and those who to date have no real experience. The former held a
more positive opinion. The recommendation based on this study is therefore to use results of studies like this one as a basis for information to unexperienced staff, e.g. by delving into the opinions of the proper staff that is about to be involved in the deployment process of the service. Further, the information could be used when teaching care professionals and patients how to use the service when the patient wants to take part of it. It is therefore important to quickly elicit and disseminate opinions of care professionals with real experience. Healthcare professionals should also be more involved in the implementation of Public eHealth services that regard electronic health records and that will affect their work processes. As ICT is increasingly used to supply citizens with various health services, the challenges for and demands on health and social care organizations need to be studied further, as well as the impact on healthcare personnel. The main outcome of this study is that healthcare professionals with personal experience of the new eHealth service are more supportive to online records as a good reform than healthcare professionals without experience.

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