Making a case for easily accessible electronic health records

- A patient perspective on lack of availability of health information in critical situations

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ABSTRACT
More and more county councils in Sweden are now in the process of making electronic health records available for patient access. Studies have already been performed both in Sweden and abroad highlighting e.g. the potential in patient empowerment and the problems encountered with norms and regulations. It does not, however, seem like many of the arguments put forward are based on real-life scenarios. Through this position paper I am trying to make a case for easily accessible electronic health records. A real-life scenario, concerning myself, is described illustrating a situation in which the lack of access to electronic health records could have caused big problems both for my own health and for my safety. The described scenario is used as an argument for showing why it could be highly beneficial for patients to be in access of their own records online, especially with regards to results from regular check-ups.

Author Keywords
eHealth; electronic health records; patient safety, real-life scenario; critical incident.

ACM Classification Keywords
H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous; J.3 Life and Medical Sciences: medical information systems.

BACKGROUND
During recent years county councils in Sweden have begun to make patient records available online for the patients to see. The first county council to open up the electronic health records to patient access was Uppsala county council and in the beginning of 2016 about half of Sweden’s 20 county councils had done the same [1].

Making electronic health records, or at least parts thereof, available to patients has not been without controversy. Many issues, both positive and negative, have been brought to light and according to [1] “Aspects such as laws and regulations, digital divides, trust, equality and vulnerability issues, changed power distribution, patient integrity and safety, technological security, ethics, the work environment of health professionals, health communication and enhanced transparency need to be addressed to obtain a rich understanding of eHealth.”.

According to an extensive review of more than 150 studies on patients’ online access to their own health records in the US, patients were generally positive [2]. Results indicated improved satisfaction and self-care as well as improved communication with clinicians. Since the idea of patients accessing their health records electronically is fairly new in Sweden not many evaluations have been performed of the systems in use. Most Swedish studies performed to date seem to focus mostly on clinicians’ attitudes towards the idea of opening up access to health records and norms that are being challenged [1, 3, 4]. Concerns that have been brought to light in these studies e.g. relate to laws and regulations, patient safety and clinicians viewing health records as more of a working document where e.g. they are using a very specific language being strange to most patients. Only a few studies performed in the Swedish context relate to patients and their understanding of medical records (see e.g. [5] about how patients perceive printed records).

As can be deduced from the discussion above there are many different views on eHealth services and in this paper I will try to make a case for easily accessible electronic health records by using a scenario of a critical incident in my own life as a starting point. Overall, it seems like scenario based arguments are not used so much within this fairly new research area. The main aim of this position paper is not to discuss a specific design, but rather to use a real life scenario to show how problematic it can be if it is not possible to access one’s own records. The following section will describe the critical incident on which my line of reasoning in this paper is built.

THE SCENARIO
Back in 2006 I was diagnosed with a rheumatic disease and a few years later in 2009 I got a treatment that has worked fairly well ever since. The disease I have is auto-immune which means that the immune system attacks healthy tissue
causing inflammations. The medication I take lowers the immune system to counteract this. A side effect of this particular medication is that it is easier to get sick and that it takes longer time than usual to get well after an infection. Additionally, it could be very problematic to get infections caused by bacteria when the immune system is suppressed by this medication, since the body cannot handle it and antibiotics is necessary.

In the beginning of the last week of June 2009, I went to one of my quarterly checkups mostly to make sure that everything was fine, and four days later I should attend a conference in Portugal. I felt fine, so I saw really no reason to call the hospital and ask for the results from the blood tests (which I always do if I’m not at good health when the tests are performed). One day before the journey to Portugal my doctor called me during the usual calling hours and let me know that more tests were needed since the immune system was at an unusually low level – obviously due to the medication I take. I then asked if it was advisable that I travelled to Portugal for the conference. The response I got both scared me and caught me by surprise – I should definitely not travel anywhere until new tests had been evaluated. It was no problem for me to cancel the trip due to health issues, but what if my doctor’s calling hours had been when I was already at the conference?

**DISCUSSION**

Here, I will discuss the scenario and its implications regarding electronic health records accessible by patients.

**About the scenario**

The scenario itself does not relate to any particular eHealth service since no such service was implemented at the time of the incident described. This is, however, the main point of the scenario and of this position paper – the lack of access to such a service could have had severe consequences for my health and safety. In this regard the scenario can still be used to discuss design of eHealth services and as a reason for why making electronic health records available to patients could be beneficial.

The situation described in the scenario did not result in any harm – the message about not leaving for a long journey was received in time. But the important thing to consider here is what could have happened if it was not.

Last, the scenario description may seem to imply that the hospital made a mistake not communicating information about the test results the minute they were received from the lab. This is, however, not the case since the health status revealed by the blood tests did not prevent living an ordinary life taking the extra precautions that patients using Humira normally do. It was the long journey abroad, of which the doctor was not aware, that posed a threat.

**Implications for health and patient safety**

As already implied above, the critical incident never caused any real harm. It does, however, give rise to the critical question: What could have happened if I had not got the call, or missed the call, from my doctor before departure? It is commonly known that cabin air circulates in aircraft in flight, making passengers with degraded immune system even more exposed to infection risk. If I had gotten sick during the flight or, more likely, during the conference period, I would most probably have been forced to commit myself to a hospital with no one familiar with me or my medical history.

Also, the scenario has implications for patient safety. Particularly, it highlights a situation where I, as a patient, was totally dependent on receiving critical information in time. This dependency is most severe for patients taking medication that could potentially induce health problems not noticeable until they get sick (and it is too late to act preventionally). If I had not been informed about my status in time, I would never have realized the potential danger I was in, since I felt indeed fine.

**Implications for eHealth services**

Even though the scenario does not relate to an existing eHealth service, it still presents implications for design since it shows how problematic it can become if information is not easily accessible in time. At least, it makes doubtless that there are situations in which patients’ easy access to online health records would be highly beneficial. Earlier studies have focused mostly on patient empowerment (see e.g. [1] and [2]) and the effect on norms and clinicians’ attitudes, but fewer studies have focused on real scenarios in which access to these kinds of records could make all the difference. If I had been able to log in to my own medical record and see that e.g. some results were flagged or deviating conspicuously from normal values, I would have called the hospital instantly and got the situation cleared out.

What is needed to avoid similar occasions is first and foremost the possibility, as a patient, to access one’s own medical health records. This possibility is already a reality (although limited) in a few county councils in Sweden and all county councils are due to implement eHealth solutions within the next few years [1]. For patients like myself, who take immune repressive medications and thus could get in bad shape without realizing it, the possibility to access the results of blood work from regular check-ups could make a big positive difference especially in situations like the one described in the scenario which could hardly be regarded unique. Today there is a large patient group using immune repressive medication for various reasons and these patients are, as it is today, dependent on the doctors’ informing them about their status. The sense of security for this patient group would most probably improve if we got access to our own health records online, especially regarding results from the regular check-ups.

A problem one has to address is the one e.g. studied in [4] – that physicians see the health record as their work tool. One implication of this, also discussed in [1], is that patients do not necessarily understand the information presented in the
electronic health record – patients and physicians do not share a common ground regarding e.g. specific medical terms used or names of specific blood analyses. When it comes to the scenario brought up to discussion here the solution, given that access to the records is granted, could be to highlight test results that are deviating and perhaps show reference values. This visual information could be enough to inform patients about the overall results and especially values that are way below or above reference values. If we go beyond the scenario and consider the entire journal containing e.g. CT-images, questions to radiologists, notes from patient consultations and so forth, it becomes of course much more of a challenge to establish a common ground between clinicians and patients regarding the content of the medical record.

As a concluding point, it is rewarding to relate back to a quote about patient safety from [1]: “As in most cases, access to correct information at the right moment is crucial for the decisions taken and actions performed among and between healthcare professionals and the patient. From what we know about adverse events, deficient communication and information transfer – on their own or in combination with other causes – contributes to more than half of all adverse events”. This can be directly applied to the chosen scenario and indicates the potential of opening up access to electronic health records for patients.

REFERENCES
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