Building Continents of Knowledge in Oceans of Data: The Future of Co-Created eHealth
A. Ugon et al. (Eds.)

doi:10.3233/978-1-61499-852-5-336

Timing It Right - Patients' Online Access to Their Record Notes in Sweden

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Abstract. In Sweden, and internationally, there is an ongoing debate about the effects of national implementations of Patient Accessible Electronic Health Records (PAEHRs). The purpose of this paper was to describe the current situation in Sweden and compare this with the expectations on reasonable waiting time for information access of users of the Swedish PAEHR. Data were collected from publicly available resources regarding current implementation in the 21 county councils, contrasted with patient experiences, gathered from a national online survey. The results indicate that patients have high expectations on immediate access to information, while this varies greatly in implementation across Sweden.

Keywords. Patient portals, Electronic health records, Health Information Exchange, Patient Accessible EHR

1. Introduction

Transparency and patient participation in healthcare are becoming increasingly important. eHealth has been highlighted as a potential tool to empower patients and shift the power balance from healthcare professionals to patients [1]. Giving patients online access to their electronic health records (EHRs), through e.g. patient portals or personal health records, is seen as one of the most important and most debated eHealth services today [2][3][4].

The health system in Sweden is founded on the principles of equal access and regional autonomy. The responsibility for healthcare provision is shared between the central government, county councils and municipalities, with the county councils the principal providers. Private care providers also operate throughout Sweden, but most often they are also publicly funded and an integrated part of the national healthcare system. This decentralized organization of healthcare also means that each county council (or private care provider) decides which information technology, e.g. EHR system, it uses [5]. Consequently, many different EHR systems are in use and interoperability between them has traditionally been low [6]. To facilitate communication between different health information systems and eHealth services, a national Health Information Exchange (HIE) platform has been implemented and used

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since 2013 [7]. The national HIE platform enables a single point of connectivity for client applications. The patient accessible EHR (PAEHR) is one of the e-services using the platform to make information gathered from possibly many EHR systems appear as one continuous record to the patient accessing it.

So far, 19 out of 21 regions or county councils have connected to the PAEHR (*Journalen*) through the national HIE platform. The e-service is accessed with a high level of security through the national patient portal, 1177.se. Sweden has approximately 10 million inhabitants and in Sep 2017, 43 percent (ca 4.3 million) had logged in (using their eID) to use personal e-services on the national patient portal. The total number of unique users of the PAEHR e-service had reached 1.5 million in Sep 2017 [8].

One of many key issues when giving patients access to their record notes has been the timing [9], [10]. Should clinical notes be available immediately or with a waiting period to give healthcare professionals time to validate the text and the results (e.g. after a dictated note has been transcribed), or to contact the patient?

According to the first version of the Swedish National Regulatory Framework (NRF) for giving patients direct online access to their electronic health records, each region or healthcare provider could choose whether or not to give immediate access or use a delay of 14 days, as well as whether or not to give access to unsigned notes [11]. The electable paragraphs resulted in important differences in *when* patients get access to their information depending on where they received care, as the regions chose different solutions [11]. This was clearly not good for the individual, and the new national regulatory framework (from 2016), states that all residents aged 16 or over should have access to all health-related information documented in county-funded health and dental care by 2020 [12]. This study focuses on *when* patients actually get access to their clinical notes. The differences between Swedish healthcare providers regarding this issue are presented, and these results are contrasted to what patients who are using the PAEHR think is a reasonable waiting time to access their clinical notes.

2. Methods

This study uses data from two sources**:** (1) publicly available resources provided by Inera, the owner of Swedish e-health services, regarding the national regulatory framework, current implementation of the national e-service and decisions made by different healthcare providers [8], and (2) results from a national survey among patients using the PAEHR *Journalen*. The survey data was collected from June to October 2016, after ethical approval by the Regional Ethical Review Board in Uppsala, Sweden (EPN 2016/129). Participants were recruited through the national PAEHR service *Journalen*. Upon log-in they were presented with information about the study and could choose to fill out the survey. Thus, only active users of *Journalen* could find the survey.

In this study, we focus on the following questions from the survey; (1) reasonable waiting time, or delay, to access the notes and (2) patients' overall satisfaction with the PAEHR. The results from the survey regarding these questions are analyzed and discussed here in relation to decisions about delay periods made by healthcare providers.

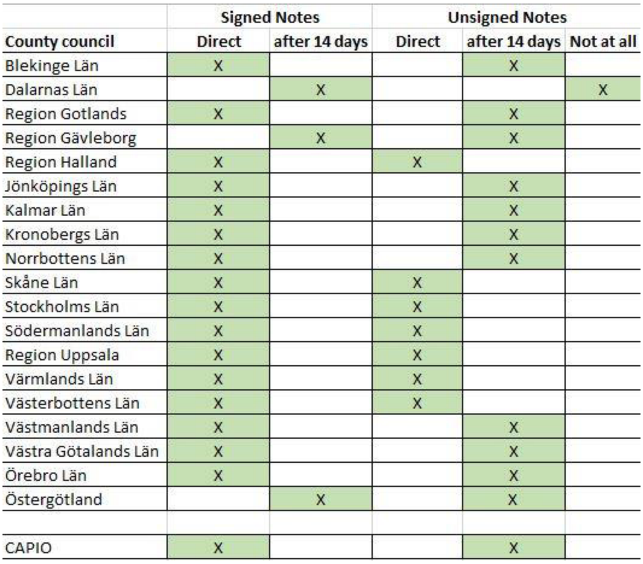
3. Results

Two electable paragraphs in the first version of the NRF guided the healthcare providers in their implementation of delays in access. The paragraphs related to the implementation of a 14 day delay of all notes, and the handling of unsigned notes, that is notes that have been entered into the EHR but not yet validated or confirmed by the healthcare professional. With regards to patient access to signed notes, healthcare providers could choose to either give immediate access to the notes, or to implement a 14 day delay. With regards to unsigned notes, the same options apply; immediate access, or with a 14 day delay, but healthcare providers could also choose not to give access to these notes at all.

3.1. Current implementation of access time in Sweden

An overview of access to record notes implemented by Swedish healthcare providers is presented in Table 1; immediate or with delay, for signed and unsigned notes.

Table 1. An overview of when patients get access to their notes in Sweden.



	Signed Notes		Unsigned Notes		
County council	**Direct**	**after 14 days**	**Direct**	**after 14 days**	**Not at all**
Blekinge Län	X			X	
Dalarnas Län		X			X
Region Gotlands	X			X	
Region Gävleborg		X		X	
Region Halland	X		X		
Jönköpings Län	X			X	
Kalmar Län	X			X	
Kronobergs Län	X			X	
Norrbottens Län	X			X	
Skåne Län	X		X		
Stockholms Län	X		X		
Södermanlands Län	X		X		
Region Uppsala	X		X		
Värmlands Län	X		X		
Västerbottens Län	X		X		
Västmanlands Län	X			X	
Västra Götalands Län	X			X	
Örebro Län	X			X	
Östergötland		X		X	
CAPIO	X			X	

When it comes to signed notes, most care providers (17/20) give immediate access, but 3 implement a delay of 14 days for signed notes. Regarding unsigned notes, 12 of 20 healthcare providers implement a 2 week waiting period (after 14 days the note is accessible to the patient even if it has not been signed yet). One healthcare provider have chosen not to give access to unsigned notes at all, whereas 7 healthcare providers give immediate access also to unsigned notes. The healthcare providers that give immediate access to unsigned and/or signed notes let the patients choose whether they want the immediate access or the delay.

3.2. Patients' experiences and opinions

From the analysis of data from the patient survey of 2016 where 2587 patients responded, some parallels may be drawn. When asked about how long the respondents were willing to wait until information is available after a visit, the majority wanted access to new information within 24 hours (Table 2). The respondents were informed that the alternatives "Same day" and "After a day" would mean that the healthcare professional may not yet have signed the notes. Additionally, when being presented with the statement "I believe that access to *Journalen* is good for me", a large majority of the respondents gave a positive response (89% strongly agreed and 8% agreed). This indicates a strong positive attitude towards the system.

Table 2. Respondents' responses to questions about reasonable waiting times, and whether *Journalen* is a useful service for them.

Reasonable waiting time (N=2539)		**Access to *Journalen* is good for me (N=2528)**	
Same day	438 (17%)	Strongly agree	2256 (89%)
After a day	1299 (51%)	Agree	199 (8%)
Two weeks	488 (19%)	Neutral	39 (1%)
One month	36 (2%)	Disagree	15 (1%)
Other	278 (11%)	Strongly disagree	19 (1%)

4. Discussion and Conclusion

The results presented in this study show that the majority of patients accessing their clinical records in Sweden thinks it's a good reform. Most prefer to have access to information within a day after a doctor's visit and this goes for both signed and unsigned material. Thus, the majority of the patients seem to accept that information they read has not been signed by a physician. Immediate access to signed notes appear to be broadly supported among healthcare providers in Sweden. Yet, some implement a 2 week waiting period. This is likely due to concerns about how patients receive potentially troubling news, to allow healthcare professionals to have time to inform the patient in person before reading the record. A limitation of this study is that we have not analyzed if there are differences in patient satisfaction with *Journalen* between regions that provide direct access and those that implement a 14 day delay.

Unsigned notes are however more controversial, with a greater discrepancy between healthcare providers. Notes are often unsigned in the record when they have been dictated (often by a physician), then transcribed and entered into the record, and awaits validation by the original author. These notes may contain errors that have not yet been corrected, which is the argument for why these notes should not be shown to the patient. However, in Sweden there is a problem with notes remaining unsigned for a long time. In 2015 e.g. when one county moved from one EHR system to another, 1.4 million notes were found to be unsigned (ranging between 3 and 48% of all notes depending on the specialty) [13]. Situations such as this is likely what has motivated regions to give access to unsigned notes after 2 weeks (as chances are high they may never be signed). There is however limited research into this issue both nationally and internationally.

Compared to the table from Scandurra et al (2016) where only 9 regions were connected to the PAEHR service, there has been a shift in the healthcare providers' decisions, generally towards a more open, i.e. direct access, provision. This is in line with the aim on a national level to ensure that all patients have immediate access to all information by 2020.

This study raises a number of questions around the timing of patients' access to their record notes. Further knowledge is needed regarding the delay of documentation in healthcare. How long does it take for notes to actually be entered into the record system?

How long does it take for unsigned notes to be signed, what proportion of notes are never signed and what are the consequences for the patient? What underlying factors affect this, and how can time from event to documentation be reduced?

Not surprisingly, patients' expectations on immediate access are high. Further research is needed regarding how delays in access affect patients' experiences, trust in healthcare and relationships with healthcare professionals. Comparing the responses to the survey between regions that provide direct access to all notes and regions that implement a delay on all notes may give us a deeper understanding of this issue, yet more in-depth qualitative studies are also required. Since this is the first time patients' views on waiting periods for accessing their record notes have been elicited, this discussion will guide future decisions regarding delay periods within Sweden and internationally.

Acknowledgement

This research was performed by researchers from the DOME consortium http://projectdome.wordpress.com/. The study was partly funded through the PACESS project (2016-00623) supported by FORTE – the Swedish Research Council for Health, Working Life and Welfare. We would also like to thank Inera AB (www.inera.se) for providing the data and managing the survey and data collection through *Journalen*.

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