

Patients' Online Access to Electronic Health Records: Current Status and Experiences from the Implementation in Sweden

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Abstract

The number of eHealth services for patients is rapidly increasing worldwide. This paper describes the status of a very important eHealth service for patients in Sweden, the Patient Accessible Electronic Health Record (PAEHR). As many countries are facing an introduction of national eHealth services providing health information to the patients, lessons learned from Sweden may improve the deployment and use of PAEHRs and similar eHealth services. Challenges that remain in Sweden relate to local differences in the implementation that lead to fragmentation and unequal access to information. Initiatives have been taken to reconcile some of the problems, e.g. an updated national regulatory framework for PAEHR. To date, evaluations are often performed from a healthcare provider perspective, focusing on aspects that are considered important by healthcare professionals and decision makers. Based on experiences of this nation-wide implementation we argue for the need to also base evaluations of eHealth on the perspective of the patients.

Keywords:

Patient Portals; Electronic Health Records; Health Information Exchange

Introduction

eHealth is often suggested to have the potential to revolutionize the way healthcare and prevention is provided, shifting the balance of power and responsibility from healthcare professionals to patients and citizens [1], [2]. Yet, many of the applications developed for patients are either designed from a healthcare providers' perspective, or completely independent from healthcare. Patient involvement in the design of eHealth has been stressed as important to achieve usable and useful eHealth solutions [3]. Experiences of the nation-wide implementation of one of the most important eHealth services for patients in Sweden accentuate the need to also base evaluations of eHealth on the perspective of the patients, rather than, as it today often is, only perform evaluations from a healthcare provider perspective, focusing on aspects that are considered important by healthcare professionals and decision makers.

Patients' online access to EHR

Sweden recently updated the national eHealth vision that now states that all residents from 16 years of age should by 2020 have access to all health related information documented in county-funded health and dental care [4]. However, implementing these eHealth services are controversial for the

healthcare professionals [5] and it is challenging to realize on a national scale [6].

Internationally, there is also a drive towards providing Patient accessible EHRs (PAEHRs), but it has been limited in part by professional resistance and concerns about security and privacy [7][8], legal constraints [9] and low uptake of other online resources for patients. In a systematic review from 2014 [10], a lack of evidence from high-quality studies about the impact of online access was noticed, yet it was clear that the tensions between the growing consumer demand to access data and healthcare systems not yet ready to meet these demands have increased in recent years [10]. Many of the studies identified in the review originated from the USA, from large health plan-based programmes, whereas a minority of studies originated from Europe. The review indicated that patient online access to their EHR and other services offer increased convenience and satisfaction [10]. However, professionals are often concerned about impact on workload and risk to privacy, which is also the case in Sweden [11]. The authors of the review article conclude that a redesign of the business process to engage health professionals in online access and of the EHR may be required to make it easier to use and provide equity of access to a wider group of patients. Another review published in 2015 called for more empirical testing regarding the effect of PAEHRs on health outcomes for patients and healthcare providers [12].

Aim

The purpose of this paper is to present the current state of the nation-wide PAEHR implementation in Sweden, to describe the challenges in the implementation, and finally to discuss the need for patient-centered evaluation of PAEHRs as proposed in the PACESS project.

Methods

The results presented in this paper are based on a retrospective analysis of national projects in Sweden focusing on the design, implementation and evaluation of PAEHR. The authors have been engaged in the research projects described below over the past 7 years, and have had opportunity to observe the debate and decision making processes both in national and regional organizations. We base our description of the implementation projects and e-services on our participation in the projects as well as on publicly available resources provided by e.g. Inera regarding the current usage of the national e-services [13]. Over the years, the authors have also organized several international workshops, where challenges of implementing these types of eHealth services have been

discussed [14], [15], leading up to the analysis presented in this paper. The authors are part of the DOME consortium from which researchers of six Swedish universities to date have published over 50 articles on the introduction of the PAEHR (<https://domeprojekt.wordpress.com/>).

SUSTAINS

Already in 1997 Uppsala County Council (UCC) 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 [16]. In 2002 a pilot study of PAEHR was run in Uppsala County, however it ran into legal problems and was shut down by the Data Inspection Board as the legislation at the time did not allow individuals to have online direct access to their medical records [17]. However, ensuing discussions resulted in the introduction of the Patient Data Act in 2008, which solved this problem. Work continued, and as part of the EU-project Sustains [17] (ICT-PSP 297206, during 2012-2014), UCC extended the deployment of public eHealth services, and all 300 000 patients were given access to the PAEHR in 2012.

The PAEHR Journalen

'Journalen' was originally developed and deployed in Uppsala County [17]. From 2015, the national eHealth organization (Inera AB) has the responsibility for development and maintenance of all public eHealth services and the national patient portal, further described in the Results section. Through this portal 'Journalen' is currently (December 2016) accessible by the citizens of 17/21 county councils.

My Care Pathways

The Swedish research project "My Care Pathways" [18] was another project running in parallel with the EU Sustains project also focusing on giving patients access to information from their medical records. This project aimed to create new mobile public eHealth services that allow patients to follow, own, and manage their care process-related information. The project also aimed to adapt and further develop the National Health Information Exchange (HIE) platform for citizen e-services and provide an open software development kit (SDK) for developing new e-services [19]. Several patient groups were involved in a patient-centered design process; stroke patients [20], lung cancer patients [21], and hip surgery patients [22].

Vårdhändelser

In parallel with the Sustains project, the My Care Pathways project also developed e-services for patients, the most notable called 'Vårdhändelser'. This service included similar health information as 'Journalen', but presented it to the user in the form of a time-line that was intended to be both backward and forward looking, indicating planned events, and including information from the patients' own health devices.

Results

In this section, a brief overview of the Swedish implementation of the PAEHR is presented, followed by challenges identified as essential during the implementation process. Finally, we introduce the PACESS project, which proposes that a patient-centered evaluation approach of PAEHRs is necessary to complement research in this area.

One way to access healthcare for the citizens – 1177.se

Although the county councils are autonomous and could prioritize which eHealth services to focus on, there is a national decision that patients should only have one way in to healthcare [4]. Thus, a patient portal '1177.se' is available for everyone seeking healthcare or health-related information in Sweden. The patient portal consists of three parts;

1. *1177 on the phone* - a telephone advice service reached through the national phone number 1177,
2. *1177.se on the web* - without authentication the public can access and search among information about illnesses, symptoms and treatments, as well as information about healthcare in the region. The virtual portal is national, but each region or county council in Sweden can adapt the information to its inhabitants.. As a user, it is also possible to choose which region you would like to view and change between regions..
3. *1177.se personal e-services* – after authentication (using a nationally approved BankID) you have access to personalized e-services where you can e.g. add your primary care centres or hospital units, and send secure messages to them. Depending on what e-services the care providers of your region offer, you may also e.g. request, reschedule or cancel appointments, renew prescriptions and access documents such as sick-leave.

Sweden has approximately 10 million inhabitants whereof 34.1 % (N=3 354 806) have created their own account for the 1177.se portal to use the personal e-services [13]. In September 2016, 1 427 576 log-ins were made to the personal e-services, and as an example 26 943 appointments were booked online [13].

Figure 1 shows an example of the different eHealth services a user can access via 1177.se (in this case the first author's own view when logged in). It is also possible to act as a proxy for children under 13 years, so parents can manage their children's appointments and contacts with healthcare.

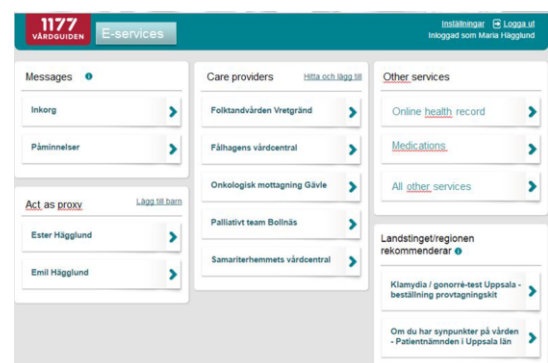


Figure 1– An example of a citizen view of the patient portal 1177.se after valid authentication (partially translated).

PAEHR in Sweden – retrospect and current challenges

Sweden has a decentralized healthcare system allowing for regional decisions.

For some time, both Journalen and Vårdhändelser (the alternative PAEHR service developed within My Care Pathways) were accessible to patients through 1177.se.

However, connecting to the respective e-service as an information provider was a costly process, and most care providers chose to publish their information to *either* Journalen or Vårdhändelser. This caused a fragmented view for patients; if you visited care providers that used the different services, some of your information would be visible through Journalen, and some through Vårdhändelser. Finally, all county councils agreed that Journalen is the national PAEHR service, to create one common view for the patients. Journalen has also been migrated from its UCC platform to the National HIE platform which also increased the incentives for the other, self-governing, care providers to connect their EHR systems.

Today (December 2016), 17 of the 21 Swedish counties have given access to EHR data through Journalen, and the service is expected to be truly national in the near future. Figure 2 gives an overview of the Swedish counties that have currently implemented and provide access to this service (in blue).

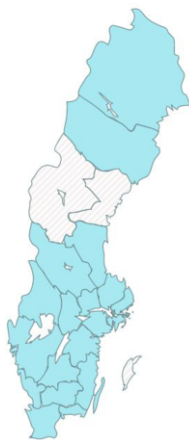


Figure 2– Implementation of PAEHR in Sweden, Dec. 2016.

The maturity of the implementation varies among the counties, e.g. Stockholm County Council, one of regions with most inhabitants in Sweden, have begun pilot testing during late 2016 and will implement the service throughout the county during 2017, whereas UCC has had Journalen in place for more than 5 years.

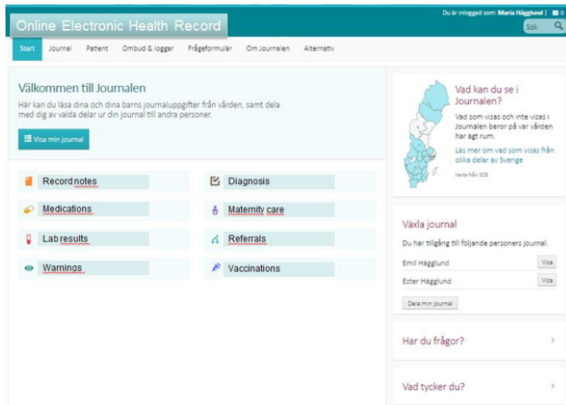


Figure 3– Example of PAEHR view (partially translated – Journalen is currently only available in Swedish).

Currently, when a patient is logged into 1177.se, and chooses to access the PAEHR the user finds the service shown in Figure 3. Journalen can contain notes from the EHRs (from all healthcare professions and all regions), a list of prescribed medications, lab results, warnings, diagnosis, maternity care records, referrals and vaccinations. In addition, there is a log list showing everyone that has accessed the record. The patient also has the possibility to share their EHR with anyone they choose, e.g. a close relative or an agent, and parents can access their children's records until the age of 13.

Agreeing on a national regulatory framework

One of the major challenges in the implementation process has been to achieve national consistency in the guiding rules for PAEHR. A National Regulatory Framework (NRF) was developed to support the deployment of the PAEHR in the 21 regions. However, from the point of view of the patient, the first version of the NRF was less successful as it contained electable paragraphs that were interpreted and applied differently in the counties [23], [24].

The PAEHR is one of the most important services for the patients and consequently the NRF needed an update [23]. In the recently launched second version of the NRF, the goals of the European and national eHealth strategies are used to create a number of principles, thereby giving the citizens the same opportunities regardless of where you live, where and when you seek care. Further, it should be possible for the regions to update their solutions to adhere to version 2.0 by 2020 [24].

Fragmented views of healthcare data

Despite the national HIE platform and the intention to provide patients with a complete overview of their health related data, the view remains fragmented depending on where, when and why a patient seeks treatment [23], [24]. There are important differences in how much information each care provider gives access to. Figure 4 provides an example of what information types some of the counties have chosen to provide (not including all information types and counties). For a complete list, please visit Inera's web site [25].

	Blekinge	Dalarna	Jönköping	Kalmar	Kronoberg	Norrboten	Skåne	Södermanland	Uppsala
Notes	Green	Green	Green	Green	Green	Green	Green	Green	Green
Diagnosis	Green	Green	Green	Green	Green	Green	Green	Green	Green
Log reports	Green	Green	Green	Green	Green	Green	Green	Green	Green
Medications	Green	Green	Green	Green	Green	Green	Green	Green	Green
Lab results	Green	Green	Green	Green	Green	Green	Green	Green	Green
Referrals	Green	Green	Green	Green	Green	Green	Green	Green	Green
Warnings	Green	Green	Green	Green	Green	Green	Green	Green	Green
Vaccinations	Green	Green	Green	Green	Green	Green	Green	Green	Green

Figure 4– Examples of information provision from 9 of the 17 Swedish counties connected to Journalen, Dec 2016.

Local initiatives

Despite the national eHealth strategy, development and implementation of PAEHR in Sweden is based on local initiatives. Research and development projects, although funded by European and national funds, have been run in different regions in Sweden and decisions on a national level have only been made when absolutely necessary. Whether a top-down or a bottom-up approach to national eHealth implementation is best can be debated, but we will here describe some challenges observed in the implementation.

Different PAEHR services; different local initiatives running in parallel resulted in different solutions for accessing your health-related data. This would not have been a problem if all healthcare providers made their data accessible through both e-services, but due to cost and maintenance issues this was not feasible.

Poor coverage; although the national HIE platform aims to make all health-related data accessible, there are still many health information systems that are not connected to the platform. This can be due to technical issues, but also costs related to the connection can play a part – especially for smaller private care providers. Over time, hopefully this issue will become less of a problem as more and more care providers connect to the national platform.

Inequitable information provision; the different interpretations of the NRF causes uneven information access depending on which care providers you have visited. A patient that moves between care providers and/or counties, which is quite common, risk misunderstandings or frustration as information from parts of their care process is completely missing (when care providers are not connected) or partly missing (when care providers give limited access).

Overview of information; it is difficult for the user to get an overview of what content they can expect to be accessible from their care providers. All functionality is available, regardless of whether there is any information available or not, and if you have your lab results from one care provider but not from another it might be confusing. This causes many support errands from users asking where their information is [24].

Resistance from healthcare professionals

Patients' online access to their health records is a much debated topic. Although the research done regarding these types of services indicates that patients' experience mainly benefits [11], the fears among healthcare professionals remain high [5]. Hypotheses as to why this is so intimidating are many, but a prominent one stresses the power balance between patients and healthcare professionals as an explanation to the reluctance to share information with patients. Another angle is the paternalistic structures of traditional healthcare. Empowerment has been acknowledged as an alternative to compliance in order to guide the provider-patient relationship [26]. In the more traditional compliance-oriented approach to healthcare, patients are seen as the recipients of medical decisions and prescriptions, whereas the empowerment-oriented approach views patients as being responsible for their actions and their consequences. These perspectives clashed in a recent debate regarding a patient finding out about her cancer through the PAEHR [27]. Many voices were raised to condemn the PAEHR, arguing that it put patients at risk and that certain information needs to be blocked to protect patients. Others defended the right to decide for oneself if and when to read the PAEHR, and claimed that patients can handle these choices.

Long-term assessments are not prioritized

Evaluations of the effects of PAEHR have so far been project based and there's a lack of long-term evaluation planned. Within the DOME-constortium, researchers from different disciplines collaborate to research the impact of PAEHR, but financial support is scarce. Project-based assessments do not cover long-term effects and there are many questions that remain to be answered. Is the PAEHR a means to empower all patients or is it a tool appropriate for those who are already empowered? How can we address the needs of different patients, with different levels of health and digital literacy to navigate the online healthcare world? And what is the role of healthcare professionals in this process?

Limited support for patient participation and communication

One of the expected benefits of PAEHR is to increase patient participation in healthcare. Having access to ones own data is an important first step, but participation requires more. A

dialogue and collaboration between patients and healthcare professionals is required, and PAEHR does not automatically create this – in Sweden, the implementation has rather been performed under the premises that this is a tool for patients, so healthcare professionals will not need to change their way of working.

Focus in the PAEHR is also very much on giving patients access to information, not to support a two-way information exchange. Basic forms have been implemented in Uppsala that enables patients to fill out questionnaires that healthcare ask for, and a functionality for patients to comment on notes in the health record is also available – but not implemented or used outside Uppsala. In order to support patient participation and communication more interactive ways to exchange information would be required. In addition, integration of data from personal health apps or self-trackers could also be useful.

Discussion

Sweden has a decentralized healthcare system and the county councils and regions have great autonomy. Despite the national eHealth strategy, development and implementation of PAEHR in Sweden is based on local initiatives. Research and development projects, although funded by European and national funds, have been run in different regions in Sweden and decisions on a national level have only been made when absolutely necessary. Whether a top-down or a bottom-up approach to national eHealth implementation is best can be debated, but we have described some challenges that have been observed in the Swedish implementation; agreeing on a national regulatory framework, fragmented views of healthcare data, resistance from healthcare professionals, limited support for patient participation, and lack of longterm evaluations.

Healthcare professionals' resistance to PAEHR is also well-known from international literature [10]. When PAEHR is implemented, actual experiences are however mainly positive, especially patients experiences. In Sweden, despite the decentralized healthcare, decisions to implement PAEHR have mainly been politically driven, and resistance from healthcare professionals have often been strong. Health and digital literacy are often listed as risks, as are concerns that information in the PAEHR will cause worry for the patient. However, we argue that patients need to be allowed to make the decision of whether or not they want to use the PAEHR themselves, that actual patient experiences is an essential part of evaluating PAEHR's.

In order to harness the powers of eHealth, we need a better understanding of how roles, relationships and organizational structures are affected on micro, meso, and macro levels through the introduction of such eHealth services. In the recently funded research project **PACCESS**, the main objective is therefore to explore the impact of information access and innovative eHealth on patients and healthcare. 2 work packages are planned; (1) long-term evaluation of PAEHR in Sweden, and (2) co-creation of innovative e-services that empower citizens. Throughout the project we will establish a theoretical framework to explain how implementation of eHealth services impact different patient groups and healthcare on different levels of the health system. Furthermore, patient-centered quality indicators will be created to facilitate joint assessment of deployment and use of PAEHRs.

Conclusion

The Swedish path to a nationally available PAEHR has been long and challenging, and still we're not quite there yet. Challenges that remain have to do with local differences in the implementation that lead to fragmentation and unequal access to information. Initiatives have been taken to reconcile some of the problems, e.g. an updated national regulatory framework for PAEHR, but further efforts are needed to evaluate the implementation from a patient perspective.

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