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A Socio-Technical Analysis of Patient Accessible Electronic Health Records

Maria HÄGGLUND[a,1] and Isabella SCANDURRA[b]
[a] *Health Informatics Centre, Karolinska Institutet, Stockholm, Sweden*
[b] *Informatics, School of Business, Örebro University, Örebro, Sweden*

Abstract. In Sweden, and internationally, there is a movement towards increased transparency in healthcare including giving patients online access to their electronic health records (EHR). The purpose of this paper is to analyze the Swedish patient accessible EHR (PAEHR) service using a socio-technical framework, to increase the understanding of factors that influence the design, implementation, adoption and use of the service. Using the Sitting and Singh socio-technical framework as a basis for analyzing the Swedish PAEHR system and its context indicated that there are many stakeholders engaged in these types of services, with different driving forces and incentives that may influence the adoption and usefulness of PAEHR services. The analysis was useful in highlighting important areas that need to be further explored in evaluations of PAEHR services, and can act as a guide when planning evaluations of any PAEHR service.

Keywords. EHR, Electronic Health Record. PAEHR, socio-technical analysis

1. 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]. 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 [2]. However, implementing these eHealth services are controversial for the healthcare professionals [3] and it is challenging to realize on a national scale [4]. 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 [5][6], legal constraints [7] and low uptake of other online resources for patients.

As described by Baxter and Sommerville the problems that arise in procuring, developing and operating complex IT systems are not just technical, engineering problems [8]. These systems are developed and operated by people, working in organizations, and these people and organizations inevitably have different, often conflicting, views on what the system should do and how it should inter-operate with other systems. The IT system is therefore part of a broader 'socio-technical' system, and we are convinced that we have to approach the design and evaluation of PAEHR

[1] Maria Hägglund, Karolinska Institutet/LIME, Tomtebodavägen 18A, 17177 Stockholm, Sweden. Email: maria.hagglund@ki.se

services from this broader socio-technical perspective if we are to improve their quality and effectiveness. Baxter and Rooksby argue that socio-technical approaches are especially appropriate in health and social care "because the problems of developing technology for healthcare lie not with the complexity or novelty of the technology itself, but in the complex ways healthcare is practiced and organized" [9]. This is very relevant also in the context of PAEHRs, where relational, legal and organizational challenges have been identified [10].

The purpose of this paper is to analyze the Swedish PAEHR service *Journalen* using a socio-technical framework, to increase the understanding of factors that influence the design, implementation, adoption and use of the service. The results will be used as input into the planning of future evaluations and improvements of PAEHR services.

2. Methods

In this study we will utilize the Socio-Technical framework proposed by Settig & Singh [11] to structure the analysis of the Swedish PAEHR service. The model provides a multi-dimensional framework within which any health information technology innovation, intervention, application or device implemented within a complex adaptive healthcare system can be studied. The framework identifies 8 dimensions of socio-technical systems in healthcare that needs to be considered in both development and evaluation (table 1).

Table 1. Dimensions in the sociotechnical framework [11]

Dimension	Description
Hardware and software	Focuses on only on the hardware and infrastructure required to run the applications
Clinical content	An important success factor in any eHealth application is that the clinical content in the application is sufficient and relevant for the clinical situation. This dimension in the framework includes everything on the data-information-knowledge continuum that is stored in the system.
Human-computer interface	The usability of the system. The International Standard Organisation (ISO) defines usability as a process-oriented standard which states that a piece of software is usable when it allows the user to perform tasks effectively, efficiently and with satisfaction in a specified context of use [12]
People	Represents the humans involved in all aspects of the implementation and use of the eHealth application, and how they experience the use.
Workflows and communication	Focusing on collaboration and communication between different users, and assessing how well the eHealth application supports the current clinical workflow.
Internal organizational policies, procedures, and culture	Acknowledges how the organization's internal structures affect every other dimension in the socio-technical model. Therefore it is important to also include any internal IT-policy documents and managerial procedures that may influence the implementation and usage of eHealth.
External rules, regulations & pressures	External forces that facilitate or place constraints on the design, development, implementation, use and evaluation of eHealth in the respective clinical settings.
System measurement and monitoring	The importance of monitoring and measuring the impact of eHealth is stressed. This is in line with the third part of the WHO ITU eHealth strategy toolbox which also underlines the importance of monitoring and evaluation [13].

The framework breaks down components of the technology to enable researchers to identify specific problems with implementation. It also includes monitoring processes and government structures that need to be in place for the system to achieve its goals [11]. The interrelatedness of the components makes the framework ideal when eHealth technologies and users are at the core of the investigation. The results presented in this paper are based on a retrospective analysis of the design, implementation and evaluation of PAEHR in Sweden. The authors have been following this work over the past 7 years, and have had opportunity to observe the debate and decision making processes. These experiences, combined with publicly available resources regarding the current usage of the national e-services [14] and current scientific publications on the Swedish PAEHR constitutes the data source for our analysis.

3. Results

The socio-technical framework was used to structure the results of previous work done to identify challenges of implementing the Swedish PAEHR [10]. Today (June 2017), 19 of the 21 Swedish counties as well as one large private care provider have given patients access to EHR data through Journalen. The PAEHR is accessed through a national patient portal (1177.se) and contains clinical and administrative content from many different EHR systems (table 2 – clinical content). Currently around 3,9 million citizens have set up accounts in 1177.se (about 39% of the Swedish population) and of those approximately 1 million use the PAEHR.

3.1. Analysis using the socio-technical framework

We applied the socio-technical framework to the Swedish PAEHR service in order to identify and categorize challenges and opportunities of implementing the service that can guide future evaluations as well as improvement work.

Table 2. Analysis of the Swedish PAEHR according to the socio-technical framework.

Dimension	Lessons learned from the Swedish PAEHR
Hardware and software	A national Health Information Exchange (HIE) platform is in place enabling not only the PAEHR to access information from all EHR systems in use in Sweden, but also other eHealth services, such as a national patient overview for healthcare professionals. Establishing this infrastructure has taken time, and one of the hurdles to overcome in the implementation process was to get all EHR systems connected to the HIE platform and publishing the right information [10].
Clinical content	The Swedish PAEHR 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. Different care providers however choose to make different information accessible to their patients [15], causing a fragmented view that does not contribute to equity.
Human-computer interface	Some issues regarding usability and human computer interaction have been identified, but few usability studies have been published. It is e.g. difficult for the user (patient/citizen) to get an overview of what content they can expect to be accessible from their care providers. All functionality is visible, 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 [16].

People	Although patients or citizens are the main user group, many other stakeholders are affected by the implementation of PAEHR, and the service remains a much debated topic. Although the research indicates that patients' experience mainly benefits [17][18], fears among healthcare professionals remain high [3][19]. Hypotheses as to why this is so intimidating are many, but it is clear that the research on different stakeholders' experiences and perceptions need to be followed by more indepth studies of actual impact.
Workflows and communication	An expected benefit of PAEHR is to increase patient participation in healthcare. Having access to one's own data is an important first step, but participation requires a dialogue and collaboration between patients and healthcare professionals. 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 on giving patients access to information, not to support a two-way information exchange. Basic health declaration forms have designed, and functionality for patients to comment on notes in the health record is available – but neither are implemented or used outside Uppsala. In order to support patient participation and communication more interactive ways to exchange information would be required, including integration of data from personal health apps or self-trackers, yet there are few studies of how the PAEHR influence workflow and communication.
External rules, regulations & pressures	The Swedish eHealth strategy highlights the importance of giving citizens access to their health information, putting pressure on the local care providers to introduce the PAEHR service. This standpoint has developed over time, and the first attempt to give patients online access to their EHR was shut down for legal reasons and not until a change in legislation was made in 2008 the PAEHR could be launched [20]. One of the major challenges in the implementation process has been to reach national consistency in the guiding rules for PAEHR. A National Regulatory Framework (NRF) was developed, however, the first version of the NRF contained electable paragraphs that were interpreted and applied differently [16], [21]. 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, ensuring the citizens the same opportunities to access their data [16].
Internal organizational policies, procedures, and culture	Sweden has a decentralized healthcare system and 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 can be completely missing (when care providers are not connected) or partly missing (when care providers give limited access).
System measurement and monitoring	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-consortium, 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.

4. Discussion and Conclusion

The results of this study confirm that introducing a national PAEHR service is a complex socio-technical challenge. The analysis also highlight that there is a lack of research in certain areas, e.g. concerning the infrastructure and the usability of the PAEHR as well as how workflow and communication are affected. Using the Sitting and Singh socio-technical framework [11] as a basis for analyzing the Swedish PAEHR system and its context indicated that there are many stakeholders engaged in these types of services, with different driving forces and incentives that may influence the adoption and usefulness of PAEHR services. The analysis will inform further evaluation studies within the PACESS research project [10], as well as act as a guide when planning evaluations of any PAEHR service.

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