

## Analysis of the Updated Swedish Regulatory Framework of the Patient Accessible Electronic Health Record in Relation to Usage Experience

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### Abstract

*In Sweden, all citizens can (in 2017) access their health data online from all county councils using one national eHealth service. However, depending on where the patient lives, different information is provided as care providers have assessed differently how to apply the National Regulatory Framework (NRF). The NRF recently was updated and this paper analyses version 2.0 should now serve as the guideline for all county councils. Potential improvements are analyzed in relation to patient experiences of using the service, and the rationale for each change in the NRF is discussed. Two real case quotations are used to illustrate potential implications for the patient when the new version is placed into operation. Results indicate that this NRF allows for opportunities to create a national eHealth service that better supports patient-centered care and improves health information outcome.*

### Keywords:

Patient Portals; Electronic Health Records; Health Information Exchange

### Introduction

The number of eHealth services for patients is rapidly increasing, as many countries are launching these services as a means to manage an ageing population, to increase efficiency in healthcare, and to empower patients. Although aiming to improve patient outcomes and satisfaction [1], the adoption of these services has often not been as successful as anticipated by politicians and vendors [2, 3]. Many healthcare professionals are concerned about how, e.g., the information will be understood by patients when reading without any medical support [4]. Patients, on the other hand, often strive to manage their own health and illnesses and want their electronic health record (EHR) [1, 5, 6]. In short, deployment of such a service is controversial for healthcare professionals and the establishment of an asset of rules regulating how the eHealth service should be used has been much discussed in Sweden, since the first region-wide deployment of the eHealth service enabling patients' access to their EHR in 2012 [7]. Sweden has recently (in 2017) extended the Patient Accessible Electronic Health Record (PAEHR) service to cover all county councils and to include its 10 million citizens.

Also, internationally, similar services have been provided to large groups of patients, such as in the UK, the US, and Norway [2, 6, 8, 9]. The strive towards providing PAEHRs has been limited in part by professional resistance and concerns about security and privacy [10], legal constraints [11] and the

need for interoperable solutions [12]. Little has been studied regarding implementation of policies for PAEHR services [2], although policies form the basis for such services, and their use is ultimately dependent on how they are implemented.

Sweden has a decentralized healthcare system, and a National Regulatory Framework (NRF) was developed to support the deployment of the PAEHR in the 21 county councils. From the point of view of the patient, the first version of the NRF was less successful as it contained electable paragraphs that were applied differently across counties [13]. This resulted in a national eHealth service that displayed health data differently depending on where, when and why a patient sought treatment [13].

This paper analyses the recently updated version (October 15, 2016) of the NRF in relation to the previous one, and the rationale for each change is discussed. The analysis was performed in the light of a service still considered controversial, county councils that act autonomously, and a national development and deployment that are ongoing. As many countries are facing an introduction to eHealth services providing health information to patients, not only the NRF, lessons learned from Sweden may be of interest to policy makers and developers in order to improve deployment and use of PAEHRs and similar eHealth services elsewhere.

### Current status of the national PAEHR 'Journalen'

The PAEHR is currently (April 2017) accessible by the citizens of 18 out of 21 healthcare regions or county councils. They access it via a national patient portal [www.1177.se](http://www.1177.se), which contains several services and functionalities. Sweden has approximately 10 million inhabitants, where 37.9 % have created their own account for the 1177.se portal in order to reach these services. Statistics of the month of January 2017 show almost 2 million logins. Each user has, per year, logged in 10.7 sessions (~ services) of 1177.se. The PAEHR currently has over 1 million users. The numbers are increasing, as the PAEHR accounts for 10000-13000 users per day [14].

### Methods

Based on the hypothesis that the new version better supports patient-centered care, this study qualitatively analyzed the first (v.1.0) and the second version (v.2.0) of the NRF, and the functionality of the PAEHR. Data collection regarding the NRF was performed via Inera.se website, the owner of Swedish eHealth services [14], whereas data collection of the PAEHR version 2.6.2 was through 1177.se, the national portal

of all public eHealth services in Sweden. The analysis started off with retrospective reviews (managed by IS) based on experiences and knowledge of the other authors (MP, BE, LL). Subsequently, key concepts of the NRFs were thematically analyzed [15] with regard to the following patient-centered care: children; relatives; information handling; harm; and secrecy. Focus was on eliciting the rationale of the changes in the NRF.

All the authors (BE, LL, MP) have extensive experience with the PAEHR and the NRF. They developed the service in Uppsala County Council (UCC), the first region to deploy the eHealth service regionally, as well as its preceding pilots since 1997 [16]. They also designed the framework of rules valid for UCC, and acted as consultants for the creation of the first national framework [17]. The analysis of the current PAEHR and the NRF 2.0 (in operation since October 2016) was, therefore, based on user data as well as experiences regarding usage during the deployment of the service and NRF v.1.0 [7, 13, 14, 16].

This analysis is limited to the NRF; thus, the analysis of which type of information is displayed in the respective county is not presented here, although sets of information shown still differ between various counties which affects the usage. Decisions from the 18 connected regions were compiled by Inera AB and can be found on their web site [14], whether displaying or not displaying the following sets of information: medical notes; diagnoses; forms; log report; prescriptions; maternity care; lab results; referrals; blocked parts of the record; growth curves; cave and medical alerts; vaccinations; care contacts; and psychiatry notes.

## Results

### National Regulatory Framework Version 1.0

The previous NRF (v1.0) was established by the National Board of Health and Welfare in 2014 after referral to all county councils and stakeholders in Sweden. It was based on the asset of rules developed by UCC to support its deployment of PAEHR, which at the time had been used by over 115 000 users [13]. Thus, the regulation developed for UCC was adopted by the national development of the service, with the aim to create the basis for the NRF. For example, it stated with ‘Healthcare providers allowing direct access to an individual’s patient data will also be responsible for the existence of an assessment system of the parts that require special protection in relation to the individual and shall not be disclosed by direct access’ [13]. That statement, among others, opened up discussions within and between the other counties. Such information entities are per se delicate, and by tradition and culture handled differently by various care providers. Due to the self-governance of the county councils, the NRF 1.0 resulted in a set of both mandatory paragraphs and paragraphs where some content was optional, and where each health authority made decisions for their regional development of the service.

#### Mandatory paragraphs

1. The individual must be identified by secure login.
2. The individual should be informed about where to turn for help to understand what is written in the EHR, as well as to which extent information in the EHR is *not* presented in the PAEHR.
3. Adults from 18 years should have direct access to their own PAEHR.

4. Guardians have access to their child’s information until the child turns 13 years.
5. Adults shall be able to appoint other adults as being their representatives and give them direct access to the proper PAEHR.
6. Children up to 17 years shall not have direct access to their own health data.
7. Individuals shall be able to seal their PAEHR and shall thereafter not have direct access to their health data.
8. Individuals must be able to read the access log, and thereby, obtain information on healthcare professionals who have opened their EHR and representatives who have opened their PAEHR.

#### Electable paragraphs

Application of the **electable paragraphs** was decided by each health authority and, consequently, the content of the PAEHR currently varies between the county councils.

9. The individual should opt for the EHR to be available for direct access, regardless if signed/authenticated – or to be given direct access only if it is signed /authenticated.
10. The individual should opt for the EHR to be immediately available for direct access – or to be given direct access with the delay of 14 days.
11. Medical notes categorized by keyword “Early hypothesis” should not be accessible to the individual by direct access.
12. Medical notes categorized by keyword “Exposure to violence in close relationships” should not be accessible to the individual by direct access.
13. Health data not available for direct access: from care units where the health authority, through a policy decision, has determined that manual audit should precede extradition.
14. Health data not available for direct access: from care professions who the health authority, through a policy decision, has determined that manual audit should precede extradition
15. The individual must receive direct access to all information in the EHR that is electronically available (with exceptions given above) [14]

Proposed rules 11 to 15 could be either accepted or rejected by the various county councils.

### National Regulatory Framework Version 2.0

Although connected regions accepted the use of the NRF v 1.0 and submitted their decisions regarding the electable paragraphs, there was a debate on how to apply certain functionality with respect to the optional rules of the NRF. As stated in the analysis of NRF v. 1.0 [13], there was a need to revise the NRF to provide less electable paragraphs, and to require an adherence to the next NRF by all county councils.

On 22 September 2016, the Board of Inera took the decision on a new framework for the PAEHR that all counties and regions should be able to endorse. The new framework has been developed together with the Swedish Association of Local Authorities and Regions (SALAR) and replaces the previous regulations [14]. Based on the goals of the National Action Plan of eHealth [18] and subsequent updates, “all residents from 16 years should by 2020 have access to all information

documented in county-funded health and dental care through the PAEHR 'Journalen'. Using PAEHR, every individual can reach all information about themselves and actively participate in the healthcare. Care providers take responsibility for the information related to their organizational business, but the individual should have full access to it; anywhere, anyhow and anytime" [14].

The next step is to establish this NRF at the political level of management in counties and regions to underpin the continued development and implementation of the PAEHR.

#### **Principles regarding information to be made available:**

1a. All digital health records, in the county-funded health and dental care, which may be disclosed to the individual, shall be made available through direct access.

2a. The information shall be made available as soon as it is inserted in the EHR.

3a. The individual shall be able to choose what information he/she wants to see, and whether a selected individual should be invited to read information and to what extent.

4a. Guardians have access to their child's information until the child turns 13 years.

5a. Depending on the situation of the child, in individual cases, it shall be possible to extend or shorten the access of a guardian, as well as to advance the child's own access to his/her information.

The five Available-principles (1a-5a) apply throughout county-funded health and dental care. Individuals are referred to as people from 16 years and all digital medical records are referred to as information supported by Inera's service platform, also historically.

#### **Principles regarding information not to be made available**

In exceptional cases and with regard to the law of Public Access and Secrecy, information can be hidden from direct access of an individual. The four principles of exception (1e-4e) concern:

1e. Details of a respondent (third person) in a record entry.

2e. Details of the patient, if it is of particular importance with regard to the purpose of ongoing care and treatment that the information shall not be disclosed to the patient.\*

3e. If information may harm a person in exposure to violence.

4e. If information is subject to investigation secrecy at the request of the Police or prosecutors.

\*This provision shall apply only in exceptional cases and applies only to patients undergoing care and treatment. A patient with a completed treatment cannot be denied access to the PAEHR.

### **Analysis and Discussion: Rationale for Change and Implications for the Patient**

Compared to the NRF v. 1.0, the second version is based on the national and European action plan of eHealth [18, 19] and, thus, the aim is to deliver more general principles; whereas the first version aimed to support practical implementation of the PAEHR in the Swedish regions based on experiences of the first county to deploy the service. Therefore, the paragraphs were quite hands-on and on a detailed level.


### **Goal-oriented principles**

The major change in the NRF is that it clearly marks that all digital health information shall be made available for direct access of the patient.

Moreover, the first version of the NRF resulted in 21 different interpretations, as each region is autonomous and had the opportunity to select among the electable paragraphs which rules should apply in their region. In the second version, 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, and to incorporate the new goals. One is to include dental care, and another is to show all information that may be disclosed to the individual, via the Inera service platform, using standardized service contracts. The service contracts support municipality data as well as historical data.

### **Unified principles replace mandatory and electable rules**

The 15 paragraphs of version 1.0 are unified into five principles regarding information to be made available, and four exceptions when information should not be exposed to the patient directly (figure 1).



Unifying of the rules to improve alignment of the regions regarding:	15 paragraphs (1-8 mandatory, 9-15 electable)	9 principles (5 info available, 4 exceptions)
Children	3, 4, 6	4a, 5a
Agent reads PAEHR	5	3a
How PAEHR is handled	1 tech, 2 info, 13, 14	1a, 2a, 3a
How EHR is handled	8	
.. All info to patient	.. rule out 9,10,11,15	.. 1a, 2a
Potential harm	7 seal, 12	2e, 3e
.. Harm of patient	.. rule out 13, 14	2e, 3e
Law of secrecy		1e, 4e

Figure 1- 9 Principles of v.2.0 replace 15 paragraphs of v.1.0

In a wide interpretation of the rules it is possible to group the paragraphs of NRF 1.0 and the principles of NRF 2.0. The ones that explicitly handle children and adults (from 16 years) are now described in 4a and 5a. 3a states that individuals should choose what to read and who should be able to read the information. Mandatory paragraphs of v.1.0 regarded technical requirements and information about the service, such as what type of data was not available for direct access, as well as logs of who accessed the EHR or the PAEHR. They are now replaced by the 1a, 2a and 3a principles, which also rule out the electable paragraphs 9, 10, 11 and 15. In the same way, the exceptions 2e and 3e that address potential harm to the patient in different circumstances, rule out electable paragraphs 13 and 14. The mandatory paragraph number 7 addresses the action of sealing the PAEHR, which has no direct equivalent in the new NRF. Alike the old paragraphs 1 (secure log in) and 2 (information and help), paragraph 7 is now handled as a functional requirement. Electable paragraph 12 is replaced with exception 3e. A more clear connection to the law of secrecy is made by adding the exceptions 1e and 4e.

### **Rationale for Change**

The new principles aim to support an alignment and a joint adherence of all county councils and regions in Sweden. Version 2.0 states, in short, that health information should be made available directly regardless of what the healthcare authority previously had decided, as long as the information with regard to the law of secrecy does not risk harming the patient or other persons. Individual rules may apply to children and their guardians.

**Principle 1a:** The rules for using the service should take into account the patient's demands of the greatest possible access to data. The NRF should not contain options that lead to different accessibility in different parts of the country.

Provision regarding the patients' direct access can be found in Chapter 5, §5 of the Patient Data Act (PDA) [20]: a healthcare provider may allow an individual direct access to data on the individual himself, as may be disclosed to him or her, and treated for purposes specified in Chapter 2, §4 in the PDA. The government justified the provision on direct access as follows: "Giving patients direct access to their medical health data contributes to their ability to a better way to actively participate in their care" (Prop. 2007/08: 126 p. 158). Further, disclosure on different terms gives rise to unequal healthcare and should be avoided.

**Principle 2a:** In general, the opinion of patients and their representatives has been to show all information immediately, while medical professions have argued that patients should be allowed to have direct access only after a 14 days window [4, 7], as the example of the electable paragraph 10. Principle 2a also refers to electable rule 9: whether the patient should be able to read only signed notes, or get access also to unsigned notes. This issue was settled by the Supreme Administrative Court (HDF 2013 ref. 33). For a public caregiver, record entries are always public documents. This means that such notes are considered established and public before "the ink dries". It is irrelevant according to the court if they are signed or not.

**Principle 3a:** A person acknowledged by the patient, e.g. a relative or an agent, has the right to take part of the patient's health records through direct access. The Agent functionality in the PAEHR has been tested by the Administrative Court (judgment 2016-06-10, Case No. 5402-15). The court considers the operation legal in accordance with the individual consent under Chapter 2, 3§ PDA; the conditions are the same for the agents as for the individual. The judgment has been appealed.

**Principle 4a, 5a:** A big change is that the age of majority for accessing health data is now set to 16 years, compared to the previous 18 years. This decision was preceded by discussions with representatives of children, pediatricians and SALAR based on an increasing pressure to lower the majority age for health data, with respect to children's rights not to be excluded. Previously, it was not possible for a 16 years old person to get an e-Identification, as the age of majority in general is 18, and that age seemed reasonable to keep. Now, Sweden follows the example of Norway [6] of trying out the new age of 16 years for accessing health data (prop. 2007/08:126 s. 153). Currently, there is no law that supports this decision as the Parental Code refers to a "degree of maturity", which does not apply for a technical system. However, both the Data Inspection Board and the European Data Protection Regulation (art 8.1) acknowledge that at the age of 16, children can prevail over questions of confidentiality and consent to the processing of personal data.

The guardians lose the possibility to read their child's health information when the child turns 13 years, unless there are individual needs (see 4a, 5a).

**Exceptions 1e-4e:** The starting point, under current law, is that the patient has the right to take part in all care documentation. In exceptional cases, information can be hidden from direct access of an individual. Compared to NRF v. 1.0, this does not regard information from specific organizations, care facilities or professional groups. The exception addresses confidentiality in relation to the patient pursuant to Chapter 25, §§ 6 and 7 of the law of Public Access and Secrecy.

### **The NRF v 2.0 in relation to patients' own stories**

Introducing PAEHR in Sweden has been a success from the patients' perspective. The PAEHR allows for users to send feedback via email, and the mailbox receives 10 emails a day. Also, the patient portal 1177.se receives feedback from patients and, approximately, 400 phone calls a day, where some are in regards the PAEHR. A brief overview of the feedback content revealed that patients most often had difficulties in understanding the different interpretations of the NRF and the different filtering of the care providers, as a result of that some information is displayed from certain regions while the same information is not displayed from other regions. The most frequent question was the fact that patients want direct access to all information. One user quote illustrated that the PAEHR is not only appreciated by the patients, but also a benefit for the patient in terms of improved health information outcome:

"I have used the eService "Journalen" a few times now, and thanks to the ability to continuously follow up clinic visits, with notes nobody can dispute, after two years, I finally received the referral I was promised already in 2014 and I have taken the tests for the disease that doctors speculated on. I think your service can save healthcare in this country. You deserve a medal and hero status!".

Here the patient benefits from principles 1a, 2a and 3a from NRF v. 2.0, as well as the provision stating that "all digital medical records are referred to as information supported by Inera's service platform, also historically".

Another written remark from a patient illustrated the need of the 4a and 5a principles:

"Hi Journalen! => I am writing from two completely different angles, firstly as myself as a patient. When will more regions be connected to the different parts of the PAEHR? It is amazingly annoying to wait for important test results, to log in, and to see that my region (Skåne) does not report test results. Furthermore, I am a geek (and many with me), and would have had a benefit of arranging the values in, for example in a graph! It is a pity that not everyone uses the great technology that is available. AND: I am the mother of a son who will turn 14 and have a lot of chronic diseases I need to relate to. In the past, I could, before a doctor's appointment log in and read, check the values from last month, remind myself of which preparation he received in his last vaccination etc. From the day he turned 13 there is not this possibility anymore. WHY? Above all: Why is there no agent system for one's own children? My dad can share his medical records – but the one of my son, I cannot have access to? How did you think? I was answered by your support that he can order his records on paper – but that is not at all what we want. This is the WORST I have ever been through, and besides, I think that 13 is a very low age limit. Now it sounded like I am not satisfied with your product, but I am, as a whole. Thanks for letting me leave my comments."

One of the most common complaints of patients is that the latest information cannot be read when the provider has chosen to show only information that is signed or authenticated. Experience shows that positive effects related to direct access outweigh the negative effects [7].

Data analysis of the UCC implementation presented that a majority of patients (98%) chose immediate access to health record information. A window of two weeks is experienced as too long for patients who want to be involved in their care [7]. This is in line with the Swedish eHealth Strategy [18] and the European eHealth Action Plan [19] promoting personalized service and interactive eServices to exercise participation and self-determination on their own terms.

If this transformation of healthcare is going to take place, there is a need to consider development and deployment from a real patient-centered perspective. Although the NRF and the PAEHR now follow the strategy objectives, there is still much work to do to reach a service addressing patient needs to follow his/her care and treatment.

## Conclusion

To date, care providers have assessed differently how to apply the NRF v.1.0. The framework of v.2.0 shows potential as it indicates a clear direction towards all information to be made available to the patient. It is more equitable for all patients to get access to and share all their health information regardless of where they live or receive care. The exemption is valid only in specific cases, and will apply only during ongoing care, which means that limits are neither static nor valid forever.

All county councils have endorsed the new framework, and regional decisions to adopt the framework are expected in the near future. The county councils now have a few years to work to get all pieces in place by 2020. However, the increasing usage reveals that citizens probably do not want to wait until 2020 to get involved, and the authors anticipate that the work needs to be intensified, once the ball is set rolling.

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