

Minor and Parental Access to Electronic Health Records: Differences Across Four Countries

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Abstract. An increasing number of countries are implementing patient access to electronic health records (EHR). However, EHR access for parents, children and adolescents presents ethical challenges of data integrity, and regulations vary across providers, regions, and countries. In the present study, we compare EHR access policy for parents, children and adolescents in four countries. Documentation from three areas: upper age limit of minors for which parents have access; age at which minors obtain access; and possibilities of access restriction and extension was collected from Sweden, Norway, Finland, and Estonia. Results showed that while all systems provided parents with automatic proxy access, age limits for its expiry differed. Furthermore, a lower minimum age than 18 for adolescent access was present in two of four countries. Differences between countries and potential implications for adolescents are discussed. We conclude that experiences of various approaches should be explored to promote the development of EHR regulations for parents, children and adolescents that increases safety, quality, and equality of care.

Keywords. Adolescents; Children, Parents; Patient accessible electronic health records; International comparison

1. Introduction

Implementation of patient accessible electronic health records (PAEHR) is ongoing globally, with around 20 countries developing online systems [1]. PAEHR systems enable access for patients to health information such as notes, medication, lab results etc. However, there is considerable variety in appearance and functionality of services used to provide patients with continuous health data access. In response to this rapid development, legal frameworks are continuously being adapted to improve use and ensure privacy of such PAEHR systems.

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A key issue for implementing PAEHR is the area of parents, children, and adolescents. Though parents report benefits from having access to their child's EHR [2], issues around information privacy may arise as the child becomes an adolescent. As such, the adoption of EHR access in a pediatric population has raised ethical and legal challenges and been subject to much dispute [3]–[5]. Among concerns expressed by healthcare professionals (HCPs) regarding PAEHRs, it is anticipated that adolescents may have poor understanding of their clinical information which can lead to harm. In contrast, surveyed adolescents express a desire for access to their EHR [6] and a cross-sectional survey has revealed high satisfaction and adequate comprehension among adolescents [7]. Still, the transition from parental access to self-access requires careful consideration, as adolescents' acceptability of parental EHR access may be contingent on the relationship with the parent [8]. Furthermore, two US studies found adolescents to be less likely to share information with HCPs if unsure about confidentiality [9], [10].

There is not yet consensus about when to retract parental access and provide individuals with self-access, leaving a variability in policies across countries [1]. Some have adopted a case-by-case approach, often relying on subjective judgments about adolescents' maturity. To increase equality and furthermore, allow for exceptions, a need for shared principles has been suggested, rather than determined standards [1]. Development of such principles should be informed by current PAEHR policies. Therefore, the aim of the study is to compare national PAEHR regulations and services for parental access and adolescent self-access to EHR in four countries. We focus on three areas: upper age limit of minors for which parents have access, age at which minors obtain access, and possibilities of access restriction and extension.

2. Methods

The study was carried out within the NORDeHEALTH research project [11]. In project meetings, workshops were planned for designing a socio-technical comparison of PAEHR implementation in Sweden, Norway, Finland, and Estonia. The selected countries are part of the project and target of this study due to being forerunners in PAEHR implementation. A socio-technical analysis was carried out, informed by a framework by Sittig and Singh [12] especially tailored to health systems. For each dimension proposed in the framework a number of questions were developed to cover socio-technical situations regarding development, implementation and use of patient portals. Analysis categories related to the eight framework dimensions *Hardware & software computing infrastructure*; *Clinical content*; *Human computer interface*; *People*; *Workflow & communication*; *Internal organizational features*; *External rules, regulations & pressures*; and *System measurement & monitoring*, and the added dimension *Features & functions* were continuously refined during several workshops between 3/2021 to 5/2021 with between one to four topic experts from each of the countries mentioned above. This process resulted in a data collection form with questions to be answered by the respective topic experts in relation to their own country's PAEHR system(s). This paper focuses on a subset of questions from the dimension *External rules, regulations & pressures*, that were of special interest regarding parental and adolescent access to records, namely: 'At which age do minors obtain access to their own PAEHR?'; 'Do parents have the right to access their children's PAEHR?'; 'Is any potentially sensitive health information exempted from parental access?'; 'Can minors apply for restrictions in parental access?'; 'Can parents apply for prolonged access to the child's

EHR beyond the default?'; and 'Can minors apply for earlier access to their EHR before the default set-up?'

The original data collection was finished in November 2021 and a complementary, smaller, data collection was carried out during a workshop in December 2021 to elaborate on questions related to parental and adolescent access to records online in particular. The same topic experts in each country were surveyed and were contacted via e-mail when additional clarification was required. Analysis was performed by the primary author by comparing the answers to these questions across the four countries.

3. Results

All national systems in the four countries provided parents with automatic access to their child's EHR at birth. Figure 1 visualizes the patterns for parental EHR access and child/adolescent self-access in the four studied countries.

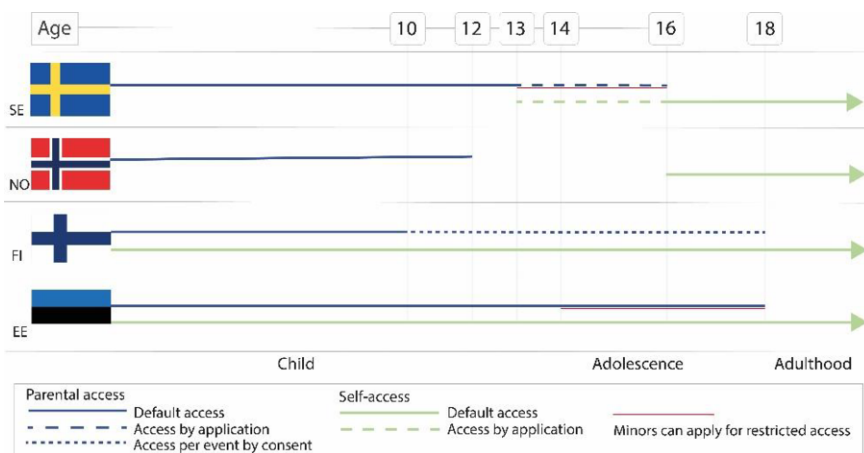


Figure 1. Parental and child/adolescent access to EHRs in Sweden, Norway, Finland and Estonia.

Age limits for parental loss of access were lower in Sweden (age 13) and Norway (age 12), than in Finland and Estonia (age 18). In Finland, parental access for minors above the age of 10 was not the default, though access was subject to the minor's capability to decide for their own care and their consent in the following way: for each care event and prescription, an HCP had to select one of four options: (1) the minor does not have decision-making capacity, and the event note is made accessible for parents; (2) the minor has decision-making capacity and consents to making the event note accessible for parents; (3) the minor has decision-making capacity and does not consent to making the event note accessible for parents; (4) the minor's decision-making capacity is unknown, and the event note is not made accessible for parents.

The age of obtaining EHR self-access was the same in Sweden and Norway (age 16) while by contrast in Finland and Estonia, there was no lower age for when the minor obtained access to their EHR. Instead, children and adolescents could access their own records when they had acquired an electronic ID. Sweden and Norway also required an electronic ID to access the national PAEHR, for which one must be 8 (Sweden) and 16 years old (Norway). None of the studied countries exempted any potentially sensitive health information by default from parent access. In all countries except for Norway,

adolescents were able to apply for restrictions in parental access to their EHR. In Estonia, the lower age limit for this was 14.

In Sweden and Norway, where parents' access to their child's record is by default ended as the child turns 16, there is a possibility for parents to apply for a prolonged access. Of the two, only parents in Sweden had the opportunity to apply for access after the child had turned 13 years old. Because the procedure relying on adolescents' capability to decide for their own care and their consent applies until the age 18 in Finland, there is no separate procedure for prolonging parental access. Similarly, the ability to apply for earlier access was only applicable for Sweden and Norway where there were lower age limits. Of these, only adolescents in Sweden could apply for self-access to their EHR prior to the age of 16, at which point they gained automatic access.

4. Discussion

Our findings show that the national eHealth services in Sweden and Norway held similarities in regards to regulations on parental access and self-access for minors, whereas Finland and Estonia had a somewhat different approach. Sweden and Norway used a default blocked access approach as soon as the child reached the age of 16, while Finland and Estonia enabled parent access until the child turned 18.

Finland held the lowest age limit (age 10) for parental loss of default access. Parental access for minors older than 10 in Finland was decided on event-basis, which prevents some of the risks in the approach of default shared access of parents and adolescents used in Estonia. One may argue that not all children aged between 10-14 can fully understand the information in their EHR and independently make informed decisions around their health, however, it is worth emphasizing that at least some researchers argue that children are capable of full informed consent from the age of 12 [13]. The ability to protect the privacy of adolescents is important as situations that may threaten the minor's wellbeing are numerous and hard to foresee. For example, adolescents may not want to reveal information pertaining to sexual activity, disclosure of alcohol or drug abuse, or stigmatized illnesses such as anxiety or depression. While shared access by event increases privacy, issues may still arise in cases when part of a visit concerns confidential information [5]. Furthermore, the regulations in Finland largely depend on subjective judgment of the professional treating the adolescent.

The more restrictive regulations in Sweden and Norway lead to other challenges: namely, a "gap" between the ages of 13-16 (from age 12 in Norway) where neither parent nor child can access the records. The age 13-limit is in fact not legislated but was set in 2012, and established in the national regulatory framework of the PAEHR in collaboration with the Swedish Association of Local Authorities and Regions (SALAR) [14], and thereafter Norway made similar decisions. This lack of access has been subject to criticism in Sweden [15], where parents ask for access to "non-sensitive" information. Though it is possible for parents and adolescents in Sweden to apply for access outside of regulations, the procedure requires knowledge, time, and effort.

Lastly, while none of the countries studied here had by regulation exempted any sensitive information in the child's EHR from parental access, implementation may vary in regards to setting and region. For example, access to records from psychiatry have been topic of considerable debate for both adult and youth psychiatry [16]. As of 2021, one of Sweden's 21 regions has decided to exempt child and adolescent psychiatry notes from availability in the national EHR service.

It should be noted that implementation of these services is ongoing and while all functionalities mentioned in this paper are available in each country, they may not yet have been implemented across all regional settings.

5. Conclusions

The complexity of PAEHRs in the context of the pediatric population is evident from its policy diversity across countries. This may be the first attempt to compare detailed PAEHR regulations of parental access and adolescent self-access to EHR. Findings gained from the four countries can be of assistance to future work with a greater focus on improving our understanding of how these approaches are experienced by stakeholders, primarily parents and young patients. Shared insights from a diversity of approaches necessitate concurrent safety monitoring. This will be indispensable to improve safety and equality of care in this emergent field.

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