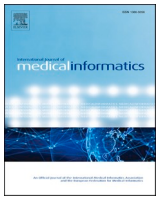
International Journal of Medical Informatics 187 (2024) 105465

Contents lists available at ScienceDirect

International Journal of Medical Informatics

journal homepage: www.elsevier.com/locate/ijmedinf



Minors' and guardian access to and use of a national patient portal: A retrospective comparative case study of Sweden and Finland

Josefin Hagström [a,b,*], Maria Hägglund [a,b], Mari Holmroos [c], Päivi Lähteenmäki [d,e], Iiris Hörhammer [f]

[a] Participatory eHealth and Health Data Research Group, Department of Women's and Children's Health, Uppsala University, Dag Hammarskjölds väg 14B, 752 37 Uppsala, Sweden
[b] MedTech Science & Innovation Centre, Uppsala University Hospital, 751 85 Uppsala, Sweden
[c] Kela, Nordenskiöldinkatu 12, 00250 Helsinki, Finland
[d] Department of Women's and Children's Health, Karolinska Institute, 171 77 Stockholm, Sweden
[e] Department of Pediatrics and Adolescent Medicine, Turku University, and Turku University Hospital, Kiinamyllynkatu 4-8, 20521 Turku, Finland
[f] Department of Computer Science, Aalto University, Konemiehentie 2, 02150 Espoo, Finland

ARTICLE INFO

Keywords:
Adolescent health
Patient Accessible Electronic Health Record (PAEHR)
Patient portal
Case study
Usage
International comparison

ABSTRACT

Background: Approaches to implementing online record access (ORA) via patient portals for minors and guardians vary internationally, as more countries continue to develop patient-accessible electronic health records (PAEHR) systems. Evidence of ORA usage and country-specific practices to allow or block minors' and guardians' access to minors' records during adolescence (i.e. *access control practices*) may provide a broader understanding of possible approaches and their implications for minors' confidentiality and guardian support.
Aim: To describe and compare minors' and guardian proxy users' PAEHR usage in Sweden and Finland. Furthermore, to investigate the use of country-specific access control practices.
Methods: A retrospective, observational case study was conducted. Data were collected from PAEHR administration services in Sweden and Finland and proportional use was calculated based on population statistics. Descriptive statistics were used to analyze the results.
Results: In both Sweden and Finland, the proportion of adolescents accessing their PAEHR increased from younger to older age-groups reaching the proportion of 59.9 % in Sweden and 84.8 % in Finland in the age-group of 17-year-olds. The PAEHR access gap during early adolescence in Sweden may explain the lower proportion of users among those who enter adulthood. Around half of guardians in Finland accessed their minor children's records in 2022 (46.1 %), while Swedish guardian use was the highest in 2022 for newborn children (41.8 %), and decreased thereafter. Few, mainly guardians, applied for extended access in Sweden. In Finland, where a case-by-case approach to access control relies on healthcare professionals' (HCPs) consideration of a minor's maturity, 95.8 % of minors chose to disclose prescription information to their guardians.
Conclusion: While age-based access control practices can hamper ORA for minors and guardians, case-by-case approach requires HCP resources and careful guidance to ensure equality between patients. Guardians primarily access minors' records during early childhood and adolescents show willingness to share their PAEHR with parents.

1. Introduction

A growing number of countries and healthcare providers are implementing patient-accessible electronic health records (PAEHRs), as information transparency has become a more prominent legal issue [1] and several patient benefits are demonstrated [2]. A key challenge is providing access to pediatric electronic health records (EHRs), since most patient portals are not designed for use with children. Parents or

Abbreviations: EHR, electronic health record; HCP, healthcare professional; ORA, online record access; PAEHR, patient-accessible electronic health record.

* Corresponding author at: Dag Hammarskjölds väg 14B, 752 37 Uppsala, Sweden.
E-mail addresses: josefin.hagstrom@uu.se (J. Hagström), maria.hagglund@uu.se (M. Hägglund), mari.holmroos@kela.fi (M. Holmroos), paivi.maria.lahteenmaki@tyks.fi (P. Lähteenmäki), iiris.horhammer@aalto.fi (I. Hörhammer).

https://doi.org/10.1016/j.ijmedinf.2024.105465
Received 9 February 2024; Received in revised form 21 March 2024; Accepted 22 April 2024
Available online 25 April 2024

guardians (herein used interchangeably) are responsible for minors' care, requiring consideration of shared 'proxy' access to the minors' EHRs with guardians. However, adolescent minors may be deterred from seeking healthcare if worried about confidentiality for sensitive matters (e.g. sexual health or substance abuse). A simple solution is to prevent online record access (ORA) for minors and guardians by default, as a safety measure. Due to a lack of policymaker guidance, pediatric ORA varies globally [3]; some countries use a case-by case approach while others apply 'default' set access ages. The authors have previously compared the different approaches adopted by Sweden, Norway, Finland, and Estonia [4], in dealing with minors' and guardians' ORA. In this paper, we refer to the practices of allowing or blocking guardian proxy access during adolescence as *access control practices*.

Studies suggest benefits from ORA for adolescent minors [2], e.g. enhanced recall [5–7], increased empowerment [6–8], and support of transition into adult patienthood [5]. However, adolescents report low knowledge about the functions of PAEHRs [9,10] and low usage [11–13]. In the United States, self-logins increased steadily between 10–17 years old and adolescents' and guardians' usage increased annually between 2008 and 2014 [12]. Another US study covering one academic healthcare center [14] found that 5.9 % of parents opted to enroll in proxy access during adolescence (12–17 years).

Providing a deeper understanding of guardians' and minors' use as well as of access control practices is necessary to improve policies and patient portals. Only a few US studies have examined minors' and guardians' PAEHR usage and study settings have been limited to one or several medical centers [12,14,15]. Furthermore, observing national PAEHR systems with an opt-out approach (where users are provided access by default) may provide a more accurate reflection of interest in using PAEHRs than local systems with opt-in approaches, often used in the United States [14,16]. Though national PAEHR systems in the Nordic countries have been in place for more than a decade, no study has examined minors' and guardians' use. The potential of the Nordic research community in improving adolescent health [17] was recently highlighted, citing the region's statutory measures to improve public health, data availability, and strong value of equality in health. This study aimed to describe minors' and guardians' PAEHR usage in Sweden and Finland, and investigate the use of access control practices. The research questions are:

RQ1: What proportion of minors at different ages in Sweden and Finland access their health records online, and how has access changed over time?
RQ2: What proportion of guardians access their minors' health records online in Sweden and Finland, and how has access changed over time and with the age of the minor?
RQ3: How are country-specific access control practices used?

2. Methods

A retrospective, observational case study [18] was conducted to explore minors' and guardians' usage of national PAEHRs in two countries where different approaches have been adopted in regards to minors' and guardians' ORA.

2.1. Setting

In 2022, Sweden's population was 10,549,347 people (minors aged 10–17: 997,263) and Finland's population was 5,563,970 (minors 10–17: 598,075) [19,20]. Swedish citizens with an electronic ID have access to the national PAEHR service *Journalen*, available on a web platform managed by Inera AB, a company owned by Sweden's regions and municipalities. Finland's national PAEHR service is *My Kanta* [21], provided by the Finnish social security institution Kela. PAEHR content is similar, including for example clinical notes, test results, medications, vaccinations, and diagnoses, yet information availability in Sweden differs according to region and health care providers who have agreed to give access.

In Sweden, the access control practice is based on default access age limits set by Inera AB in 2017 [22]: guardian users have access to their child's EHR from birth until the age of 13, and minors gain their own access at age 16. The access gap between age 13–15 has been criticized by parents of children with serious illnesses [23,24]. Minors and guardians can apply for extended access under special circumstances (such as chronic illness), by filling in a specific paper form followed by a maturity assessment and approval by the healthcare provider. Before 2017, minors had no access while guardians had access until the minor turned 13 years old. Not all regions had implemented PAEHRs before 2018, so this study includes data from 2018 and onwards.

Finland has no lower access age [4], thus minors can access their own records as soon as they have acquired an electronic ID. During the time period of this study, Finland was transitioning to a new practice regarding guardian access. Until October 2020, all guardians had default access to their child's records until the child's age of 10. As of October 2020, healthcare organizations have had the opportunity to implement the new practice where granting (or blocking) of guardian access to minors (ages 0–18) records follows a record-specific procedure. For each care event or prescription, the healthcare professional (HCP) is to assess the minor's decision-making capacity, and, in cases where the minor is mature enough, inquire their consent to grant parental access. The HCP then selects one of four options in the EHR system:

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 procedure is based on Finnish patient law regulating minors' rights to decide about their care (when assessed mature enough to do so by the HCP) and is mandatory for healthcare providers to implement. The proportion of public primary and secondary healthcare organizations that had implemented this practice rose from 2.5 % to 64.8 % during the study period (January 2021-December 2022). That is, a rather substantial part of organizations still remained in the old practice where guardians have access from birth until the minors turn 10, at which point they lose access.

2.2. Data collection

Use statistics were collected for *Journalen* from Inera AB by two Sweden-based authors (JH and M Hägglund) and for *My Kanta* from Kela by two Finland-based authors (IH and M Holmroos) (see Table 1). Because extension applications were administered independently by Sweden's 21 regions, there was no national statistic. All regions were

Table 1
Data received for Sweden and Finland.

	Sweden	Time span	Finland	Time span
Minors' logins (unique users)	Yes	2018–2022	Yes	2021–2022
Guardians' proxy access to minors' records	Yes[a]	2018–2022	Yes[b]	2021–2022
Use of access control practices	Yes	2018-2022[c]	Yes[d]	2021–2022

[a] Unique guardian users who have proxy-accessed their dependents' records.
[b] Number of minors on behalf of whom a guardian has proxy-accessed their records.
[c] Only 2020–2022 for Uppsala and 2021–2022 for Södermanland.
[d] Only regarding medication prescription events.

thus contacted, whereof five provided the data (Uppsala, Halland, Södermanland, Örebro, and Västernorrland). Guardian access and prescription-specific granting of guardian access were not available by minor's age group in Finland.

Ethical approval was granted by the Regional Ethical Review Board, in Uppsala, Sweden (EPN 2023-02939-01 and amendment 2023-05735-02). No ethical approval was required in Finland to retrieve data from Kela.

2.3. Data analysis

The data were provided as aggregated statistics of unique users. To calculate proportions of users and non-users among minors and guardians, the number of unique adolescent and guardian users was divided by total number of guardians and minors for each respective year in Sweden [19] and Finland [20]. To study the use of access control practices, for Sweden, we report the numbers of applications for extended guardian and earlier minor access in the five regions, and, for Finland, the proportions of different options recorded by HCP regarding minor's decision-making capacity. Figures were created using R [25], IBM SPSS Statistics version 28.0, and Datawrapper (Datawrapper GmbH).

3. Results

3.1. Minors' logins

In Sweden, an increasing proportion of minors accessed their records between 2018–2022 with age during adolescence. In the most recent year observed (2022), a majority of minors (50.5 %) logged in during their first year of default access (age 16). A somewhat larger proportion of Finnish peers accessed their records during the same year (61.0 %), and the increase by age 17 was almost 15 % higher (23.8 % compared to 9.4 % in Sweden). In 2022, the highest proportion of minors logging in occurred at 17 years old in both Sweden (59.9 %) and Finland (84.8 %). Minors' logins increased annually between the ages of 13–17 in both Sweden and Finland (see Fig. 1), with one exception: minors' logins to the Finnish PAEHR was higher in 2021 than 2022 for ages 16 and 17.

Because ORA in Sweden was only possible by application prior to age 16, proportions of minors between 13–15 years old accessing their PAEHR were very small (0.0 % for all ages and years). In Finland in 2022, 9.9 % of 13-year-olds and 35.8 % of 15-year-olds accessed their PAEHR. Small proportions of minors below age 13 accessed the records; age 10 (0.6 %), 11 (1.3 %), and 12 (5.9 %), while use prior to age 10 ranged between 0.0–0.1 % (see Appendix 1).

3.2. Guardians accessing minors' records

In Sweden, there was an increasing trend in guardian proxy access over time (see Fig. 2). The one exception to this trend was the year of 2021, when guardian use for ages 6–12 was higher than in 2022. For all years, the highest use was recorded for newborn children (41.8 % in 2022), followed by a decrease in use with the age of the minor until loss of access when the child turned 13 (19.4 % for age 12 in 2022). Proportions of guardians of minors aged 13–15 years old accessing the Swedish PAEHR were very small (less than 1 % per age and year).

Higher guardian use was observed in Finland, as around half of minors' records were accessed by a guardian between 2021 and 2022, with a larger proportion in 2021 (53.5 %), compared to 2022 (46.1 %) (see Appendix 1).

3.3. Access control practice use

In Sweden, applications for extended guardian access have been more common than minors' earlier access (Fig. 3). Among the five regions observed, three had almost no cases of applications for minor access. There was also interregional variety, where two regions demonstrated notably higher numbers of minors' applications. The highest number of total applications in 2022 was found in the region with the smallest population size (Västernorrland).

In Finland, in both 2021 and 2022, the most selected maturity assessment option was *Minor does not have decision-making capacity, and the event note is made accessible for parents* (2021: 45.3 %, 2022: 54.9 %), see Fig. 4. The least selected option was *Minor has decision-making*

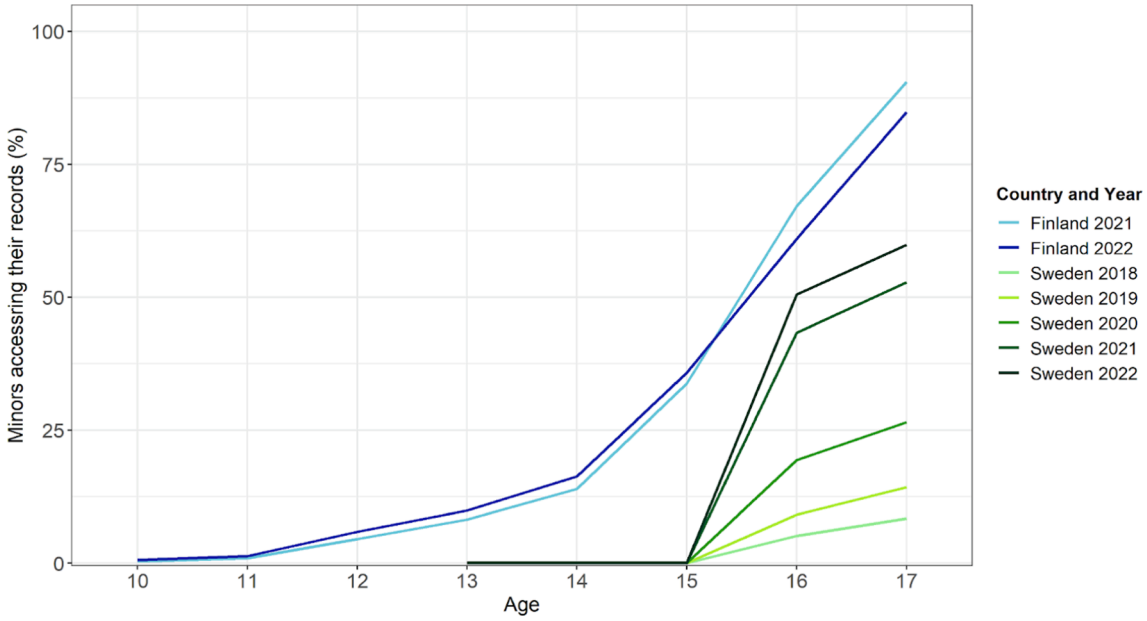


Fig. 1. Proportions of minors (10–17 years old) logging into the PAEHR in Sweden (years 2018–2022) and in Finland (years 2021–2022). Footnote: In Finland, Covid-19 vaccination certificates were provided via *My Kanta*. In 2021, *My Kanta* usage peaked in all age-groups when, as of June the certificates were used for traveling purposes and as of October to support regional restrictions (e.g. granting entry to events). Restrictions were removed in 2022. Also, vaccination certificates (and test results in some regions) were made available externally from the Swedish PAEHR in some Swedish regions, contrarily from Finland, where vaccinations and certificates were shown in the PAEHR.

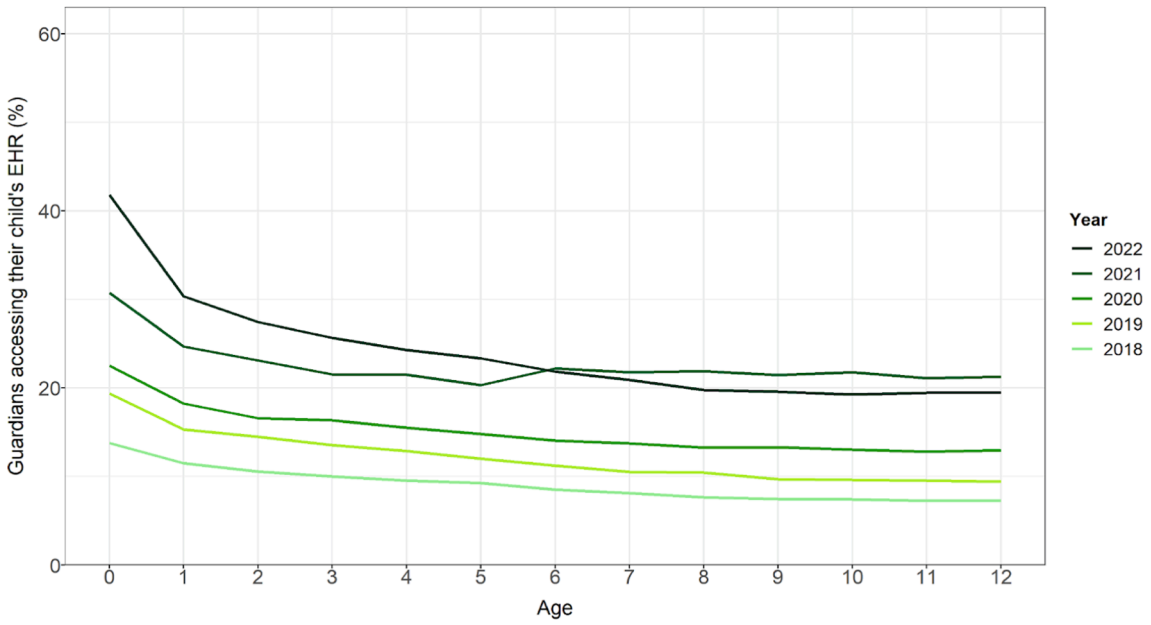


Fig. 2. Proportions of guardians accessing their minors' records in the Swedish PAEHR *Journalen* between 2018 and 2022, categorized by year and minor's age. Footnote: In Sweden, Covid-19 vaccinations are only given to children over 12 years in Sweden. However, all age groups were tested and results were made available in the PAEHR in most regions.

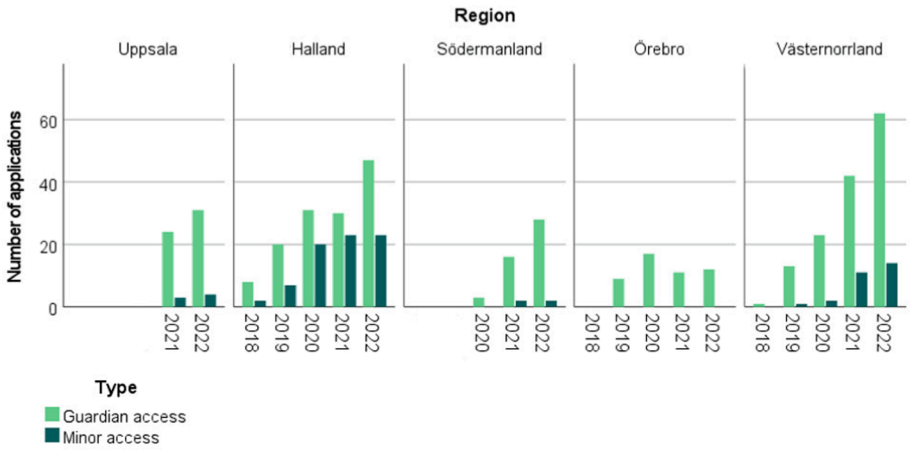


Fig. 3. Number of applications for extended access for minors and guardians to the Swedish PAEHR *Journalen* in five regions in Sweden, between 2018–2022. Regions are ordered in population size, Uppsala the biggest and Västernorrland the smallest. Data were not available for all years in two regions (Södermanland and Uppsala), and only years where data has been provided are included.

capacity and does not consent to making the event note accessible for parents (2021: 2.1 %, 2022: 1.0 %). In 2022, in 95.8 % (152,501/159,189) of the assessments made, minors assessed to have decision-making capacity allowed information disclosure to their guardians (see Appendix 2).

3.4. Summary

The key findings and implications can be found in Table 2.

4. Discussion

4.1. Key findings

The study aim was to describe minors' and guardians' PAEHR usage in Sweden and Finland between 2018 and 2022.

4.1.1. RQ1

In Sweden, where minors between aged 13–15 can only access their records if an application for early access is approved, very few minors or guardians accessed the records during this age span. In Finland, the highest increase in minors' PAEHR use occurred between the ages of 14 and 15. Somewhat larger proportion of minors aged 16 accessed their records in Finland and this difference grew even larger until adulthood.

4.1.2. RQ2

Among guardians in Sweden, usage peaked after birth and decreased with the minor's age. Guardian proxy access was higher in Finland than in Sweden for the years available for comparison. Guardians' logins in Sweden increased between 2018 and 2022, though in both Sweden and Finland, guardian proxy access was to some extent higher in 2021 than in 2022.

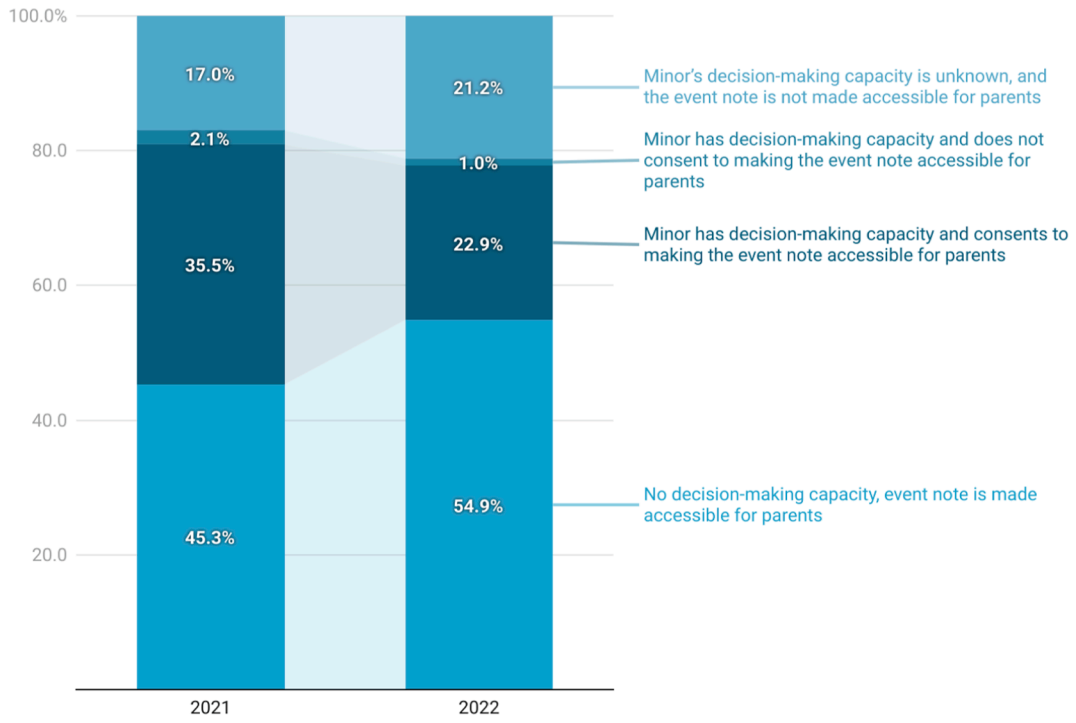


Fig. 4. Selection of maturity assessment options regarding prescription information events of minors aged between 0–17, as selected by HCPs documenting in the Finnish PAEHR *My Kanta* in 2021 and 2022.

Table 2
Key findings and implications.

Key findings	Implications
RQ1	*What proportion of minors at different ages in Sweden and Finland access their health records online, and how has access changed over time?*
• Low use in Sweden during age 13-15 • Increasing use in Finland from age 10 • Larger proportions of minors aged 16-17 accessed their records in Finland than in Sweden.	• Early access may lead to higher use among minors
RQ2	*What proportion of guardians access minors' health records online in Sweden and Finland, and how has access changed over time and with the age of the minor?*
• Usage in Sweden peaked after birth and decreased with the minor's age • Higher in Finland than in Sweden • Increased in Sweden between 2018-2022, though in both Sweden and Finland, guardian proxy access was to some extent higher in 2021 than in 2022.	• Guardian proxy PAEHR use is highest during early childhood
RQ3	*How are country-specific access control practices used?*
• In Sweden, applications for extended access between ages 13 and 15 were few and mainly concerned guardians • In Finland, minors were most frequently assessed to have no decision-making capacity. Furthermore, minors rarely chose to conceal information from their parents • Differences in practice between healthcare providers were indicated	• Guardians' need to access adolescent minors' EHR must be considered • Evaluation of HCP burden and variety in practice related to access control practice is essential

4.1.3. RQ3

In regards to the Swedish access control practice, extension applications were few and mainly concerned guardians. In Finland, a new access control practice with record-specific HCP consideration of a minor's maturity was implemented in many healthcare organizations during the study. Minors were most frequently assessed to have no decision-making capacity and guardians were therefore allowed access to a record. Minors who were assessed mature enough to decide on their care very rarely chose to conceal information from their parents.

4.2. Comparison with prior work

The results suggest that minors' PAEHR use and guardians' proxy access has increased annually in Sweden since 2018. A likely explanation for the increase since 2020 pertains to the Covid-19 pandemic, which has been mentioned by other researchers [26]. The pandemic may also explain why the year 2021 deviated from the increasing pattern for some of the age-groups, with higher access than in 2022. During this time, guardians may have been motivated to access Covid-19 test results and immunization records. Still, the Swedish data suggests that the proportions of minors and guardians accessing the PAEHR were increasing also prior to the pandemic. Possibly, more young people are being made aware of the possibility to access their records online, and have the capability of doing so.

The proportion of minors logging into PAEHRs increased with age during adolescence in both countries. While this finding aligns with work conducted in the United States [12,15], percentages are not easily compared given that US studies used opt-in systems. Previous researchers have hypothesized that adolescents become more involved in their care as they mature [12]. Similarly to Finland, notable adolescent use of their PAEHR already by the age of 15 has been previously reported in US studies [12,15]. Another finding was that a somewhat larger proportion of minors aged 16 accessed their records in Finland than Sweden and this difference grew even larger until adulthood. There are several possible reasons for this. First, earlier access during adolescence may encourage autonomous care engagement, enabling a smoother transition into independent PAEHR use. In a study [15] where parents had to request access after age 12, nearly 60 % of adolescents became the primary users of their own records by age 15. In a study by

Steitz et al. [12] where guardians' access was unrestricted, observed long-term usage of records of minors from 0 to 18 years, where for patients aged 13–18, 16.5 % of logins were self-logins while guardians' logins composed 83.2 %. Secondly, HCPs in Finland routinely inform families about ORA via *My Kanta* after each visit. This may also explain higher use among guardians.

Furthermore, Swedish data showed that guardians' use peaked after birth and decreased with the age of the child, which is aligned with earlier research [12,15,27]. While guardians are avid patient portal users in accessing their minors' EHR, particularly during early years of childhood [12,14,16,28], guardians of minors with serious illness report benefits of proxy access into adolescence [5,29]. This may be related to the higher frequency of preventive check-ups in the pre-school period. While the data were limited because the Finnish data on guardian use did not include minors' ages, the use of access control practices provided some insights. First, most minors in Finland assessed to hold decision-making capacity allowed their guardians to view prescription information. Secondly, the majority of applications for extended access in Sweden concerned guardians, underlining the importance of allowing parental involvement (with permission from the minor). As this possibility is intended for cases of adolescent minors with serious illness, these patients may rely on their parents for care management [30,31].

In Finland, most of HCPs' maturity assessments of minors aged 0–17 years old resulted in guardian access due to the minor lacking decision-making capacity. However, the available data did not include minors' ages, preventing investigation of age-based assessments. A notable proportion of assessments (about a fifth) resulted in an unknown minor's decision-making capacity, denying guardians' access. Importantly, this option was the default selection until 2024, from which point option 1 (no decision-making capacity and parental access) can be selected as the default for children under 12 years of age [32]. The default option may have been common due to a lack of time to conduct an assessment, given that documentation burden is a known source of HCP job dissatisfaction [33,34]. Additional research is required to explore HCPs' assessments, and in what circumstances a minor's decision-making capacity is marked as unknown. Moreover, extension applications in Sweden were few and the number differed across regions. The variety may be due to differing knowledge or routines among HCPs. Similarly, there may be differences in practices of Finnish HCPs in maturity assessments. The laborious process of recording assessments may also lead to missing information on minors' decision-making capacity causing problems of access to patients and their guardians. Different access control practices provide different advantages and disadvantages. While set default ages as those used in Sweden can be onerous and cause problems for parents of ill children, they ease the work of HCPs. Conversely, a case-by-case approach allows tailoring to minor patients' and guardians' personal situation, though it may be demanding and include a risk of inequality of confidentiality. High usability information systems and careful guidance for HCPs may allow case-by-case practices that better meet minors' and guardians' ORA needs without overly burdening HCPs or risking equality between patients.

4.3. Limitations

This study had several limitations. The data available to researchers was limited, due to difficulties in gaining access to information around guardians' and minors' PAEHR use such as a lack of time among contact persons to provide the data requested by the authors, or technical restraints of the system to retrieve the information. Due to the lack of detail in the Finnish data, the development of guardian access by minor's age could only be studied for Sweden. To facilitate efforts to benchmark and compare adoption of informatics systems such as PAEHRs, enabling retrieval of similar data is crucial, similarly to clinical quality registries. Furthermore, some guardians may access records using their children's accounts [35], especially for younger adolescents who are more open to guardian access [36]. Also, this study did not examine applications for blocked access in Sweden, and minors in Finland chose to forbid information disclosure to a prescription note in four percent of cases. Considering that other types of information, e.g. notes on mental or behavioral health, may be more sensitive, the frequency of hiding such information from guardians could be higher. Subsequently, minors' desire for information concealment requires further investigation. Lastly, despite the identified differences between Sweden and Finland, the countries may from an international perspective be relatively similar in regards to PAEHR adoption and healthcare for minors, and even greater differences to other countries can be assumed. These differences need to be considered when assessing PAEHR potential globally.

4.4. Conclusion

There is potential for PAEHR to involve young people in their health at an early age. This study confirmed findings that adolescents and parents are accessing PAEHRs at an increasing rate. Future research is needed to examine minors' desire to conceal information from parents, and access of parents to adolescents' accounts.

CRediT authorship contribution statement

Josefin Hagström: Writing – review & editing, Writing – original draft, Visualization, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Maria Hägglund:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Mari Holmroos:** Writing – review & editing, Data curation. **Päivi Lähteenmäki:** Writing – review & editing, Formal analysis. **Iiris Hörhammer:** Conceptualization, Data curation, Formal analysis, Methodology, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

We would like to thank Inera AB, Kela, and the Swedish regions who provided data for the study.

This work was supported by NordForsk through the funding to Nordic eHealth for Patients: Benchmarking and Developing for the Future, NORDeHEALTH, (Project #100477), the Swedish Research Council for Health, Working Life and Welfare (FORTE) through the funding to Beyond Implementation of eHealth (Project #2020-01229).

Summary table

What was already known on the topic:

- Guardians' proxy access to PAEHRs peaks for newborns and decreases through childhood, while minors' use increases during adolescence.
- Need for confidentiality require patient portals to consider restrictions of guardian proxy access to adolescent minors' records.

What this study added to our knowledge:

- The comparative case study approach can provide insights on the different approaches to proving access to minors' health records online across countries.
- The Covid-19 pandemic appears to have increased pediatric ORA particularly in 2021, eliciting deviations to an otherwise increasing trend.

- Use of access control practices indicates differences in conduct with likely implications to HCP burden, and to how well minors' and guardians' ORA needs are met.

Appendices A and B. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ijmedinf.2024.105465.

References

[1] C.M. DesRoches, Healthcare in the new age of transparency, Semin. Dial. 33 (2020) 533–538, https://doi.org/10.1111/sdi.12934.

[2] J. Hagström, C. Blease, B. Haage, I. Scandurra, S. Hansson, M. Hägglund, Views, use, and experiences of web-based access to pediatric electronic health records for children, adolescents, and parents: scoping review, J. Med. Internet Res. 24 (2022) e40328.

[3] A. Essén, I. Scandurra, R. Gerrits, G. Humphrey, M.A. Johansen, P. Kierkegaard, J. Koskinen, S.T. Liaw, S. Odeh, P. Ross, J.S. Ancker, Patient access to electronic health records: Differences across ten countries, Health Policy Technol. 7 (2018) 44–56, https://doi.org/10.1016/j.hlpt.2017.11.003.

[4] J. Hagström, I. Scandurra, J. Moll, C. Blease, B. Haage, I. Hörhammer, M. Hägglund, Minor and parental access to electronic health records: differences across four countries, Stud. Health Technol. Inform. 294 (2022) 495–499, https://doi.org/10.3233/SHTI220508.

[5] M.K. Hong, L. Wilcox, C. Feustel, K. Wasileski-Masker, T.A. Olson, S.F. Simoneaux, Adolescent and caregiver use of a tethered personal health record system, AMIA Annu. Symp. Proc. AMIA Symp. 2016 (2016) 628–637.

[6] F. Bourgeois, E. Lowe, D. Wachenheim, OpenNotes: sharing visit notes with patients and families, Pediatr. Nurs. 44 (2018) 45–48.

[7] M.M. Kelly, A.S. Thurber, R.J. Coller, A. Khan, S.M. Dean, W. Smith, P.L. T. Hoonakker, Parent perceptions of real-time access to their hospitalized child's medical records using an inpatient portal: a qualitative study, Hosp. Pediatr. 9 (2019) 273, https://doi.org/10.1542/HPEDS.2018-0166.

[8] O. Asan, M.C. Scanlon, B. Crotty, R.J. Holden, K.E. Flynn, Parental perceptions of displayed patient data in a PICU: an example of unintentional empowerment*, Pediatr. Crit. Care Med. 20 (2019) 435–441, https://doi.org/10.1097/PCC.0000000000001895.

[9] D.J. Miklin, S.S. Vangara, A.M. Delamater, K.W. Goodman, Understanding of and barriers to electronic health record patient portal access in a culturally diverse pediatric population, JMIR Med. Inform. 7 (2019) e11570.

[10] L. Beaton, I. Williams, L. Sanci, Exploring adolescent and clinician perspectives on Australia, Aust. J. Prim. Health. 27 (2021) 102–108, https://doi.org/10.1071/PY20169.

[11] N. Calman, H.R. Pfister, R. Lesnewski, D. Hauser, N. Shroff, Electronic access to adolescents' health records: legal, policy, and practice implications, 2014. https://www.aafp.org/fpm/2015/0300/p11.html.

[12] B.D. Steitz, R.M. Cronin, S.E. Davis, E. Yan, G.P. Jackson, Long-term patterns of patient portal use for pediatric patients at an academic medical center, Appl. Clin. Inform. 8 (2017) 779–793, https://doi.org/10.4338/ACI-2017-01-RA-0005.

[13] F.C. Bourgeois, A. Fossa, M. Gerard, M.E. Davis, Y.J. Taylor, C.D. Connor, T. Vaden, A. McWilliams, M.D. Spencer, P. Folcarelli, S.K. Bell, A patient and family reporting system for perceived ambulatory note mistakes: experience at 3 U.S. healthcare centers, J. Am. Med. Inform. Assoc. 26 (2019) 1566–1573, https://doi.org/10.1093/jamia/ocz142.

[14] L.A. Thompson, T. Martinko, P. Budd, R. Mercado, A.M. Schentrup, Meaningful use of a confidential adolescent patient portal, J. Adolesc. Health 58 (2016) 134–140, https://doi.org/10.1016/j.jadohealth.2015.10.015.

[15] P.G. Szilagyi, R. Valderrama, S. Vangala, C. Albertin, D. Okikawa, M. Sloyan, N. Lopez, C.F. Lerner, Pediatric patient portal use in one health system, J. Am. Med. Inform. Assoc. 27 (2020) 444–448, https://doi.org/10.1093/JAMIA/OCZ203.

[16] T. Ketterer, D.W. West, V.P. Sanders, J. Hossain, M.C. Kondo, I. Sharif, Correlates of patient portal enrollment and activation in primary care pediatrics, Acad. Pediatr. 13 (2013) 264–271, https://doi.org/10.1016/j.acap.2013.02.002.

[17] K.-I. Klepp, A. Helleve, A.-S. Fismen, H. Rutter, Improving the health of adolescents: the Nordic countries can help fill the evidence gap, Scand. J. Public Health 50 (2022) 887–891, https://doi.org/10.1177/14034948221124675.

[18] R.K. Yin, Case study research: design and methods, SAGE, London, 2014.

[19] Befolkningsstatistik, Stat. Cent. (2022). https://www.scb.se/hitta-statistik/statistik-efter-amne/befolkning/befolkningens-sammansattning/befolkningsstatistik/ (accessed March 7, 2023).

[20] Befolkningsstruktur, Statistikcentralen. (2023). https://stat.fi/sv/statistik/vaerak (accessed December 5, 2023).

[21] My Kanta Pages, Kanta.Fi. (2022). https://www.kanta.fi/en/my-kanta-pages (accessed November 23, 2022).

[22] Nationella rekommendationer inför publicering av patientjournal via nätet om barnsjukvård, Inera AB, 2017.

[23] Föräldrar blockade från Vilmers vårdkontakter "Besök missas," P4 Malmöhus. (2022). https://sverigesradio.se/artikel/foraldrar-blockade-fran-vilmers-vardkontakter-besok-missas (accessed November 19, 2022).

[24] Fick inte se sin cancersjuke sons journal på nätet – regeringen lovar ändring, Ekot. (2023). https://sverigesradio.se/artikel/fick-inte-se-sin-cancersjuke-sons-journal-pa-natet-regeringen-lovar-andring (accessed September 20, 2022).

[25] R Core Team, R: A language and environment for statistical computing, (2022). https://www.R-project.org/.

[26] M. Hägglund, I. Scandurra, User evaluation of the Swedish patient accessible electronic health record: system usability scale, JMIR Hum. Factors 202183e24927 Httpshumanfactorsjmirorg20213e24927. 8 (2021) e24927. doi: 10.2196/24927.

[27] J. Benjamins, J.-G. Duinkerken, G. den Hamer-Jordaan, R. Canfijn, R. Koster, E. de Vet, A. Haveman-Nies, Implementation of EPR-Youth, a client-accessible and multidisciplinary health record; A Mixed-Methods Process Evaluation 23 (2023) 26. doi: 10.5334/ijic.6905.

[28] E. Torrens, S.M. Walker, Demographic characteristics of Australian health consumers who were early registrants for opt-in personally controlled electronic health records, Health Inf. Manag. J. 46 (2017) 127–133, https://doi.org/10.1177/1833358317699341.

[29] J.L. Carlson, R. Goldstein, T. Buhr, N. Buhr, Teenager, parent, and clinician perspectives on the electronic health record, Pediatrics 145 (2020), https://doi.org/10.1542/peds.2019-0193.

[30] M. Sharko, L. Wilcox, M.K. Hong, J.S. Ancker, Variability in adolescent portal privacy features: how the unique privacy needs of the adolescent patient create a complex decision-making process, J. Am. Med. Inform. Assoc. 25 (2018) 1008–1017, https://doi.org/10.1093/jamia/ocy042.

[31] A. Anoshiravani, G.L. Gaskin, M.R. Groshek, C. Kuelbs, C.A. Longhurst, Special requirements for electronic medical records in adolescent medicine, J. Adolesc. Health 51 (2012) 409–414, https://doi.org/10.1016/j.jadohealth.2012.08.003.

[32] FINLEX ® - Ursprungliga författningar: Lag om behandling av kunduppgifter inom social-… 703/2023, (n.d.). https://www.finlex.fi/sv/laki/alkup/2023/20230703 (accessed January 23, 2024).

[33] M. Stillman, Death by patient portal, JAMA 330 (2023) 223–224, https://doi.org/10.1001/jama.2023.11629.

[34] D.T.Y. Wu, C. Xu, A. Kim, S. Bindhu, K.E. Mah, M.H. Eckman, A scoping review of health information technology in clinician burnout, Appl. Clin. Inform. 12 (2021) 597–620, https://doi.org/10.1055/S-0041-1731399.

[35] W. Ip, S. Yang, J. Parker, A. Powell, J. Xie, K. Morse, R.C. Aikens, J. Lee, M. Gill, S. Vundavalli, Y. Huang, J. Huang, J.H. Chen, J. Hoffman, C. Kuelbs, N. Pageler, Assessment of prevalence of adolescent patient portal account access by guardians, JAMA Netw. Open. 4 (2021) 1–9, https://doi.org/10.1001/jamanetworkopen.2021.24733.

[36] C. Frazer, F. Ratchford, J. Roch, Enabling adolescent electronic access to personal health information, Stud. Health Technol. Inform. 234 (2017) 115–119.