



## Original article

# Security and Privacy of Online Record Access: A Survey of Adolescents' Views and Experiences in Sweden

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## A B S T R A C T

**Purpose:** Ensuring security of online health records and patients' perceptions of security are concerns in adolescent healthcare. Little is known about adolescents' perceptions about healthcare's ability to protect online health records. This article explores adolescents' perspectives on security and privacy of their online health records, potential differences based on gender and health, attitudes to sharing information, and perceptions of what constitutes sensitive information.

**Methods:** This study included a subset of items from a national online patient survey conducted in Sweden (January–February 2022), focusing on respondents aged 15–19 years. Gender and health status differences were calculated using the Kruskal-Wallis test.

**Results:** Of 218 adolescent respondents (77.1% female), a minority had security and privacy concerns. A notable proportion (41.3%) wished to control who could see their records, and those who reported better perceived health were more likely to want to manage access to their electronic health record ( $H = 13.569, p = .009$ ). Most had not experienced unauthorized access to their records (75.2%) and had never shared health information on other online applications (85.8%). More than half (56.0%) perceived some information as sensitive, where mental health was the most common (76.0%). Most felt that reading their notes improved their trust for their healthcare professional (65.6%) and supported better communication with healthcare professionals (66.5%).

## IMPLICATIONS AND CONTRIBUTION

Adolescents perceive patient portals as secure but have more diverse views on privacy. With enabled management of access to their record and independent designation of sensitive information, adolescents' experience of patient portals can be improved.

**Conflicts of interest:** The authors have no conflicts of interest to disclose.

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**Discussion:** In this national survey, adolescents generally reported few concerns about patient portals. Findings emphasize the need for security and privacy protection and to empower adolescents with greater control over access to their health information housed in electronic health record systems.

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Online record access (ORA) refers to healthcare professionals (HCPs) or patients having internet-based access to electronic health records (EHRs), commonly via patient portals. Studies show that providing ORA improves engagement with adult patients [1] and helps patients recall information from healthcare consultations [2]. These benefits have also been observed for adolescent patients, for whom patient-accessible EHRs (PAEHRs) may also play a guiding role in the transition into adulthood [3]. Furthermore, access can make patients more aware of, and interested in, privacy aspects of their records [4] as well as being more knowledgeable and in control of their health information [5].

With the rapid growth of digitalized healthcare, breaches of health records have become increasingly common [6]. EHR breaches can harm patients' trust and willingness to seek care. The importance of security as it relates to confidentiality, data integrity, and availability, needs to be differentiated from the social, philosophical, and technical aspects of privacy related to protecting personal (health) information [7,8]. Both are crucial. For adolescents, there are unique issues that pose social and legal challenges for designers. The main issue is that while many parents feel they require access to their child's health information as part of their parental responsibility [9], adolescents often desire increased autonomy and control as they approach adulthood [10].

The need to ensure the security and privacy of patient portals intended to manage minors' health information is well recognized [11], and recent reviews have identified confidentiality concerns as the main issue for topic experts, including HCPs, information technology experts, researchers, and policymakers [12,13]. HCPs face an ethical dilemma when needing to document information that the adolescent may wish to keep confidential (e.g. asking for contraceptives) while the parent has access to the records [3]. Indeed, young patients are likely to forego healthcare if unsure who will access their information [14]. However, experience of having read EHRs in conjunction with patients' healthcare circumstances may influence opinions about privacy. For example, among adolescents without serious health issues who have not read their records, privacy appears to be the main concern [15]. In contrast, research suggests that among adolescent patient portal users with serious health issues such as cancer or blood disorders [16] and chronic gastrointestinal disease, confidentiality concerns were less likely to be cited as a concern [17].

Perceptions of sensitive information can differ depending on factors such as gender, sexual orientation, health status, and culture [18]. Adolescents aged 12–17 years old have referred to topics such as depression, suicide, substance abuse, and sexually transmitted diseases as sensitive. Still, it is possible that societal changes during recent years have begun to normalize mental health among adolescents in Sweden [19].

In Sweden, parents receive automatic proxy access to their child's records from birth until the child turns 13. The

adolescent gains their own record access at the age of 16 [20]. Thus, adolescents and parents never hold shared access to the minor's records by default after the child is 13 years of age. Parents and adolescents can apply for access when the adolescents are between 13 and 15 years old by submitting a paper application to each healthcare unit of interest. Applications are intended for special circumstances such as chronically ill minors or minors with special care needs. To be approved, HCPs assess needs and risks, as well as the minor's maturity and wishes. Currently, there are no available data on these applications. The record typically includes clinical notes, lab results, diagnoses, but information availability differs across Sweden's 21 regions and connected healthcare providers (who have agreed to give access). No data are concealed from parental view unless the healthcare provider actively chooses to block information access, which can be done in cases where, for example, child abuse is suspected. Access to the PAEHR service requires log-in with an electronic ID downloaded on one's device. While most adult patients in Sweden trust healthcare to protect health data [21], until now adolescents were not consulted. Young users of the Swedish PAEHR are unique in that they have grown up with a PAEHR that has been nationally available for more than a decade. Here, we aimed to explore adolescents' views on security and privacy of their EHRs. A secondary aim was to explore attitudes to sharing information and perceptions about the specific data that constitutes sensitive information. Due to gender-related health differences, we examined the relationship between gender and sensitive information as well as security and privacy ratings. So far, international studies have failed to address adolescent users' experiences of privacy breaches in the health record.

## Methods

### Setting and participants

An online survey was developed within the NORDeHEALTH research project [22], to elicit the opinions and experiences of patient portal users in Sweden. Data collection occurred from January to February 2022 after ethical approval (EPN 2021/05229). Patients accessing the national PAEHR *Journalen* via the web patient portal 1177.se were invited to participate in the survey. Informed consent was provided electronically before the appearance of survey items. No incentives were offered. For this article, survey respondents between 15–19 years old were included and defined as adolescents. Age 15 was chosen as the minimum age for participation since even though adolescents in Sweden gain ORA at age 16, they can apply for earlier access from age 13. Still, due to an ethical-legal requirement of written parental consent for participants younger than 15 years old (The Act concerning the Ethical Review of Research Involving Humans) [23], which would complicate survey distribution,

those aged younger than 15 were excluded. The Sex and Gender Equity in Research guidelines [24] were adopted for reporting this study and are found in Appendix C.

### Survey

An anonymous, open survey of 45 questions (38 close-ended and seven free-text) was created in English and translated into Swedish. Answering close-ended questions was mandatory, while free-text questions were optional. For this study, 11 questions were included (see Figure 1 and Appendix B, Table B1 and B2) based on the study aim: one related to security and privacy (number 30 in the survey), one on impact on trust and communication with HCPs (number 7), five on sharing information (number 31–35), two on sensitive information (number 36–37), and two on demographics (number 20 and 41). Two close-ended questions consisted of statements (using a 5-point Likert scale, ranging from *disagree* to *agree*), eight were regular close-ended questions, and one was an open-ended free-text question. The Checklist for Reporting Results of Internet E-Surveys (CHERRIES) [25] was used to report the study (Appendix D), and the full survey and further details about the data collection procedure are found in a separate publication [26].

### Analysis

This study was a subgroup analysis of a larger survey study, including the age span of 15–19 years (collected as a categorical variable). This study included the participants characteristics of gender and self-reported health. Age was collected as a categorical variable, and this study included the age span 15–19 years. Gender was collected as *man/woman/other* and the five response options for self-reported health ranged from *very bad* to *very good*. Aside from using descriptive statistics for calculating

percentages for different response options, nonparametric tests were conducted, due to the small sample size, to detect group-wise differences. The significance level was set to 95% for all tests. The Kruskal-Wallis test was used to detect possible differences in ratings on security and privacy across gender and health status. IBM SPSS 28 software was used for all analyses, and R was used to produce Figure 2. Free-text answers were analyzed using inductive content analysis. Categories and subcategories developed by the main author (J.H.) were assessed by a coauthor who is a privacy and security expert (R.Å.), and any disagreement was resolved through discussion.

## Results

### Respondents

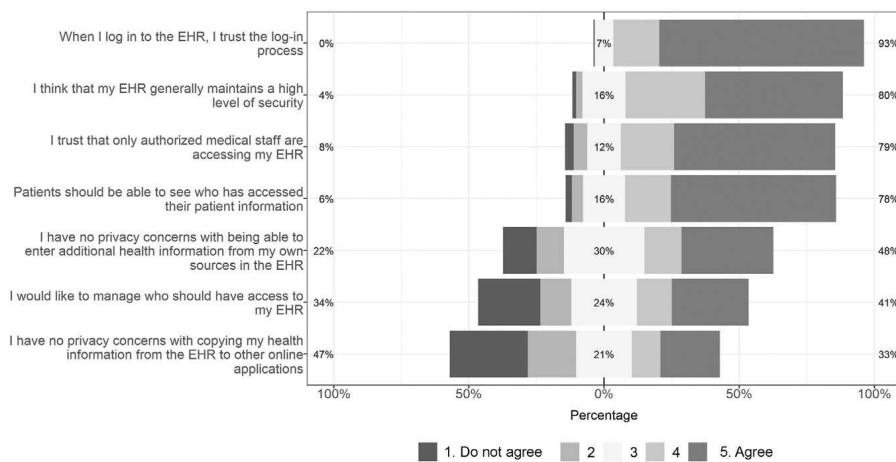
Of 13,008 respondents who completed the survey, 218 were 15–19 years old (1.68%). Of these, 77.1% (168/218) identified as women, 17.9% (39/218) as men, and 5% (11/218) chose *other*. Two respondents were excluded due to being younger than 15 years old. See a previous publication for detailed data on survey completion [26].

### Security and privacy

Most adolescents trusted the log-in process (202/218, 92.7%), perceived the EHR to be secure (175/218, 80.3%), trusted that authorized medical staff were the only other individuals accessing the EHR (173/218, 79.4%), and agreed with that patients should be able to see who had accessed their information (170/218, 78.0%), see Figure 2. A higher proportion of respondents (90/218, 41.3%) desired the ability to manage who should have access to their records than those who did not (75/218, 34%). Almost half (104/218, 47.7%) had no concerns with entering additional

1. What is your opinion on information security and privacy?
  - I. I think that my health record generally maintains a high level of security.
  - II. I trust that only authorized medical staff are accessing my health records.
  - III. Patients should be able to see who has accessed their patient information.
  - IV. When I log in to the health record, I trust the log-in process.
  - V. I have no privacy concerns with being able to enter additional health information from my own sources in the health record, such as exercise data, EKG-data and other health data from private applications.
  - VI. I have no privacy concerns with copying my health information from the health record to other online applications (example: Google Health, Apple Health, Facebook etc.).
  - VII. I would like to manage who should have access to my health record (for example that a certain diagnosis is not accessible to certain groups of staff or relatives).
2. Please indicate how much you disagree or agree with the following statements: Having access to my health record...
  - I. ... helps me trust my health care provider more.
  - II. ... supports better communication between myself and healthcare professionals.
3. How often do you copy and paste information from your health record to another online application (Google Health, Apple Health, Facebook etc.)?
4. Have you experienced that family, friends or another have demanded access to your health record that you did not want to share?
5. If YES: Who demanded access to your health record that you did not want to share?
6. Have you experienced that someone has seen your health record that you did not want to share?
7. If YES: Who accessed your record without your consent?
8. Do you consider some types of health information especially sensitive?
9. If YES: Can you give an example of what type of health information that is most sensitive to you?
10. How is your overall health?
11. Gender

Figure 1. The survey questions used in analysis.



**Figure 2.** Adolescents' views on security and privacy of the EHR.

health information into their EHR (e.g., exercise data, electrocardiogram data, and other health data from private applications). It should be noted that this function is not currently available in the Swedish PAEHR. See detailed results in Appendix A, Table A1.

Kruskal-Wallis tests demonstrated a relationship between desiring the ability to manage who should have access to one's EHR and self-reported health, where those who reported better perceived health were more likely to want to be able to manage who should access their EHR ( $H = 13.569$ ,  $p = .009$ ). No other relationships between self-reported health and security and privacy views were identified, and no differences were found based on gender (see detailed results in Appendix A, Table A2 and A3).

#### Effect on trust and communication

A majority of participants reported that reading their notes improved their trust in their HCP (143/218, 65.6%) and that their PAEHR supported better communication with healthcare (145/218, 66.5%). For both statements, the median response option was 4 (Likert-style scale of 1–5 where one indicated *disagree* and five indicated *agree*) and few participants (29/218, 13.3%) chose option one or 2, that is, disagreed. See detailed results in Appendix A, Table A4.

#### Experience of sharing information and nonconsensual access

A majority of respondents had never copied or pasted from the EHR to share on other online applications (187/218, 85.8%), approximately one 10th of respondents had shared information a few times (24/218, 11.0%) and few (7/218, 3.2%) had done so on five or more occasions.

A majority of adolescents had no experiences of anyone demanding access to their records (184/218, 84.4%). Six percent had experienced demands to share (13/218) and 9.6% did not know (21/218). For those with experience of demands, the source was almost exclusively a family member (11/13, 84.6%), while two cited *other* (2/13, 15.4%), of which one person (50%) wrote the free-text comment, "Ex." While around 7% of respondents (15/218, 6.9%) had experience of someone viewing their records without consent, three out of four (164/218, 75.2%) did not, and 17.9% did not know (39/218). For those with the experience of

unconsented viewing, the source was commonly a family member (6/15, 40.0%) or an HCP (6/15, 40.0%), only one stated a friend (1/15, 6.7%). Two respondents chose *'other'* (2/15, 13.3%), one of whom clarified the source in a free-text comment as "Family member and social services." See detailed results in Appendix A, Table A5.

#### Information perceived as sensitive

More than half of adolescent users (122/218, 56.0%) perceived some health information to be sensitive. A free-text description was provided by 67.2% (82/122), and a content analysis resulted

**Table 1**  
Information perceived as sensitive by gender

Information	Frequency, n (%)			
	Female adolescents (n = 62)	Male adolescents (n = 13)	Other (n = 7)	Total (n = 82)
Mental health	45 (73)	10 (77)	6 (86)	62 (76)
Self-harm and suicidality	5 (8)	0 (0)	0 (0)	5 (6)
Neurodevelopmental disorder diagnoses	2 (3)	2 (15)	1 (14)	5 (6)
Relationship issues	2 (3)	0 (0)	0 (0)	2 (2)
Eating disorders	1 (2)	0 (0)	1 (14)	2 (2)
Depression	1 (2)	0 (0)	0 (0)	1 (1)
Miscellaneous	17 (27)	4 (15)	1 (14)	25 (24)
Weight	9 (15)	0 (0)	0 (0)	9 (11)
Diagnoses	2 (3)	1 (8)	1 (14)	4 (5)
Notes	2 (3)	0 (0)	0 (0)	2 (2)
Gender identity issues	1 (2)	0 (0)	0 (0)	1 (1)
Life-threatening illness	1 (2)	0 (0)	0 (0)	1 (1)
Medications	0 (0)	1 (8)	0 (0)	1 (1)
Care related to crime or abuse	2 (3)	0 (0)	0 (0)	2 (2)
Reproductivity and sexual health	12 (19)	4 (31)	1 (14)	17 (21)
Gynecological care	7 (11)	0 (0)	1 (14)	8 (9)
Unspecified	3 (5)	2 (15)	0 (0)	5 (7)
Sexually transmitted diseases	4 (6)	1 (8)	0 (0)	5 (6)
Pregnancy and fertility	1 (2)	1 (8)	0 (0)	2 (2)
Unspecified	8 (13)	2 (15)	0 (0)	10 (12)
Differs depending on individual	7 (11)	2 (15)	0 (0)	9 (11)
Nonresponse	1 (2)	0 (0)	0 (0)	1 (1)

in four main categories. By far, the most common category of perceived sensitive information was *mental health* (62/82, 76%), followed by *miscellaneous* (24%), *reproductivity and sexual health* (21%), and *unspecified* (see Table 1). Eleven percent (9/82) emphasized that sensitive information may differ depending on the individual. Only young women cited weight (9/82, 11%) as sensitive. See detailed results in Appendix A, Table A5.

## Discussion

### Principal findings

Most adolescents expressed trust in the log-in process and perceived their health records as secure. However, a large portion desired more control over who should have access to their records, especially those who reported better health. Furthermore, most adolescents had not shared their health information with other online applications. While mental health was frequently reported as sensitive information, many adolescents were nonspecific in their responses, highlighting the potential of individual differences. Lastly and in line with research on adults [27], most adolescents in our survey reported that the PAEHR increased trust in and improved communication with their HCP.

### Comparison with prior work

Adolescents rated almost all security aspects highly. Only the ability to manage who could access the records stood out as an aspect where adolescents were more conflicted in opinions, where significant numbers (41%) desired the ability to manage access. This finding indicates that patient portals may benefit from allowing adolescent patients to see who has read their records. A study based in Australia, where adolescents can independently manage whether their parent or a nominated representative should have access to their records [15], showed that adolescents appreciated being able to distribute record access in case of emergency. Furthermore, we observed that the desire to manage who could access their records was related to reporting better health. This finding is interesting, given that previous research conducted in the United States identified no concerns on parental proxy access among adolescents with serious illness [16,28]. Possibly, adolescents' perceived needs for confidentiality vary according to healthcare issues, where adolescents with milder needs of care are, or can afford to be, more concerned about the confidentiality of their records. Also, adolescents have suggested that having a trusting and open relationship with one's parents may be related to less privacy concerns [29]. While this finding supports allowing adolescents' increased control over their records, differing needs for confidentiality is an important issue for future research. Additionally, most respondents reported that reading their EHR improved trust and communication with HCPs, which supports earlier research [28], including among adult users [30]. This implies that the transparency of online record access holds potential to increase the existing trust in HCPs among adolescents.

Compared with security, there was greater divergence between respondents' views on the two privacy-related statements. Almost half of the participants had no privacy concerns related to adding their own data to the PAEHR while almost a third selected the middle option, that is, did not agree nor disagree with the statement. A minority reported concerns, consistent with previous findings that some adolescents worry

that adding their own data to the PAEHR might confuse HCPs and be potentially harmful [15]. It seems reasonable to postulate that education on health literacy may help to mitigate such worries about the consequences of making own additions to the records. In comparison, privacy concerns were more common with respect to sharing information with other online applications, and most participants had never shared any information from their EHR. Alternatively, adolescents may not consider it appropriate to share health information on social media, as observed by previous research [31]. Nonetheless, the results from this study show that approximately one-third had no privacy concerns with sharing information and almost 15% had done so in the past.

The finding that mental health and sexual health issues are considered sensitive information supports the limited work undertaken [18]. Indeed, the preponderance of responses referring to mental health was notable. For some, worries appeared to stem from an anticipated stigma [32], as they recognized the potential for negative views among those accessing their records. Some feared that previous mental healthcare might lead to not being taken seriously by HCPs in the future. Another commonly mentioned topic by female adolescents was weight, reflecting findings that weight stigma remains prevalent among minors [33]. Recent studies have found that adult patients were offended by the mention of overweight in their records [34] and patients who feel judged about their weight feel lower trust in their HCPs [35]. Thus, potential risks related to how HCPs document weight in EHRs require consideration in clinical practice, where documentation guidance may act as a preventative measure.

Another unexpected finding was that many adolescents refrained from specifying topics of sensitivity. Instead, numerous adolescents referred to "things" that the individual sees as "embarrassing" or "doesn't want others to know," without elaborating further. Female adolescents were more specific in their responses than young men and provided a higher number of specific topics (e.g., referring to depression or eating disorder instead of simply "mental health"); however, this may be explained by an uneven gender distribution. Notwithstanding, the lack of specificity supports the findings of a recent study [36], where EHR administrators cited difficulties in training clinicians about how to determine whether information should be confidential. These findings suggest that young individuals may require the ability to make such decisions independently in their PAEHR.

In this study, a minority had experienced unauthorized access to their EHR or that someone wanted to gain access. This is contrary to previous findings in the United States where a substantial number of parents were accessing their adolescents' accounts [37,38]. A further study using similar machine-learning methods is needed to investigate to what extent safeguards for adolescents' records are being bypassed in Sweden. Such events may be less common, given that the log-in process to the Swedish PAEHR required electronic identification and that parental access is highly restricted after age 13 by regulation. Furthermore, adolescents gain access at age 16, at which point they may be more independent and able to prevent nonconsensual EHR breaches. Some adolescents may allow parents to log into their account, if unwilling or incapable to manage their own care. Still, evidenced EHR breaches stresses the need to explore additional protection of adolescents' EHRs from nonconsensual access. Furthermore, the finding that a few

participants referred to “diagnoses” as particularly sensitive information and others referred to “notes,” indicates that while some do not perceive their diagnosis as sensitive, they wish to conceal the details of appointments. An implication of these findings may be the necessity of technical solutions that allow patients to conceal not only notes from parental view, but any or all types of information in their record.

The findings should be viewed in the light of several limitations. Although this national survey elicited a good response [26], the sample size of 15–19-year-old respondents could be considered as relatively small, limiting the generalizability of the findings. Moreover, it is important to note the study setting, as the regulations of the Swedish PAEHR severely restrict parental and adolescent access between the ages of 13–15. Potential responder biases also need to be considered when interpreting the results, since those who responded to the survey may have different technical skill or interest compared to those who did not complete the survey. There is also a risk of vagueness with respect to some of our survey items including (e.g., “Trusted the log-in process”) and potentially some young respondents may have struggled with these items. This could have been helped by greater disambiguation within the survey, which could have been helped by clarification in the survey, a consideration that should be adopted in future studies. Another limitation of the study is the lack of distinction between different age groups within the 15–19 range, which may overlook potential variations among adolescents. Additionally, the study did not provide distinct gender options beyond man and woman, which may hinder fully capturing the diverse gender identities and experiences of the participants. Furthermore, the survey question on gender could be interpreted as both biological sex or perceived gender identity, as the same word is used for both in Swedish. These limitations should be considered, and future research with larger and more diverse samples could help validate and expand upon these initial findings.

## Conclusion

Adolescents trust the log-in process of the EHR and generally perceive their health records as secure, however there is a notable desire for increased control over access. Particularly sensitive data for adolescents included mental health information, while weight was only mentioned by female adolescents, but importantly, perceptions can vary on an individual level. Though the results of this study are specific to the Swedish PAEHR, where parental and adolescent ORA is highly restricted between ages 13–15, they highlight the importance of addressing security and privacy protections and giving adolescents more control over their health information within any EHR system. Future design of portal policies should consider adolescents' varying and dynamic need for control over access to their PAEHR.

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## Supplementary Data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.jadohealth.2023.12.027>.

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