

Adolescents Identifying Errors and Omissions in Their Electronic Health Records: A National Survey

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Abstract. Patient accessible electronic health records (PAEHRs) have been proposed as a means to improve patient safety and documentation quality, as patients become an additional source to detect mistakes in the records. In pediatric care, healthcare professionals (HCP) have noted a benefit of parent proxy users correcting errors in their child's records. However, the potential of adolescents has so far been overlooked, despite reports of reading records to ensure accuracy. The present study examines errors and omissions identified by adolescents, and whether patients reported following up with HCPs. Survey data was collected during three weeks in January and February 2022 via the Swedish national PAEHR. Of 218 adolescent respondents, 60 reported having found an error (27.5%) and 44 (20.2%) had found missing information. Most adolescents did not take any action upon identifying an error or an omission (64.0%). Omissions were more often perceived as serious than errors. These findings call for development of policy and PAEHR design that facilitates reports of errors and omissions for adolescents, which could both improve trust and support the individual's transition into an involved and engaged adult patient.

Keywords. Adolescents; Patient-accessible electronic health records; Errors; Electronic health records; National survey

1. Introduction

To err is human. Patient-accessible electronic health records (PAEHR), which include clinicians' narrative notes, medication lists, and diagnoses, often include errors, possibly leading to safety hazards [1,2]. As EHRs become increasingly used in decision-making and assessment [3], risks include medication errors [4], and delays or missed diagnoses. However, online record access (ORA) can enable patients to be more involved in their care, for example by ensuring accuracy of information [5]. In this paper, the terms error, mistake, and inaccuracy are used interchangeably; similarly, omission and missing information hold the same meaning.

Parent proxy users have been recognized by healthcare professionals (HCPs) as able to detect inaccuracies in their child's EHR [6,7]. In a study that examined error reports among patients and families in a pediatric hospital [8], 35% reported an error. Still, topic

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experts have also posited the importance of engaging adolescents in their care to support the transition into adult patienthood [9].

While policies and access ages differ across countries and clinical contexts [10], the transition from parent proxy access into individual access commonly occurs during adolescence. The current variety in implementation largely stems from potential ethical dilemmas, as HCPs worry about maintaining adolescents' confidentiality while providing sensitive care for mental health problems, substance abuse, and sexual health [9]. These uncertainties have led to a lack of studies of how adolescents in fact experience ORA [11]. An interview study with adolescents with cancer and blood disorders who had ORA, identified an appreciation for being able to review updates to the record and ensure its accuracy [12]. However, no studies have yet investigated to what extent specifically adolescents find incorrect and missing information in the PAEHR and what they consequently choose to do. In Sweden, the national PAEHR *Journalen* is available by default to citizens from the age of 16, yet it is possible to apply for access from the age of 13. Our aim is to examine adolescents' experiences of identifying errors and omissions in their records.

2. Methods

To answer the research question, we analyzed a subset of items from the NORDeHEALTH 2022 Patient Survey [13]. The full survey consisted of 83 items exploring the opinions of PAEHR users in Norway, Sweden (ethical approval EPN 2021/05229), Finland and Estonia. This paper only analyzed the data from Sweden. Participants were recruited through the national PAEHR *Journalen*. Upon login, patients received a request for voluntary survey participation together with information about the study. Thus, only active PAEHR users were invited to participate; it was not possible to access the survey without logging in. For this paper, only survey respondents between 15-19 years old were included. Though default access is provided at the age of 16, it is possible to apply for access from the age of 13. However, due to an ethical-legal requirement of written parental consent for research participants younger than 15 years old [14], which would complicate survey distribution, those aged 13 and 14 were excluded prior to data collection. For three weeks from January to February 2022, the survey was available to users accessing their EHR via the Swedish national patient portal. Four closed-ended questions from the survey were included in this study.

1. Have you ever found anything in your record you thought was wrong?
2. Have you ever found anything in your record you thought was missing?
3. If yes, did you do any of the following when you found a mistake or missing information in your record?
4. How easy (or difficult) is it for you to notice errors/mistakes in your record?

The third question had an option for a free-text response ('Something else'). The fourth question was assessed on a 1-5 Likert scale from 'very difficult' to 'very easy'. Data was collected on gender (male, female, other) and age. The collected data were managed by Inera AB, the organization managing the national patient portal and PAEHR *Journalen* (using the survey tool Webropol (version 3.0)). The variables were presented descriptively and gender differences were analyzed using a Fischer's exact test.

3. Results

Of 13 008 respondents, 218 were between 15-19 years old (1.7%). Two respondents were excluded due to being younger than 15. Of the 218 adolescents, 60 reported having found an error (27.5%) and 44 (20.2%) reported missing information (Figure 1). There was no statistical difference among genders in finding errors (Fischer’s Exact Test, $p=.074$), yet, 63.6% (7/11) of those that marked gender as “other” reported finding an error (17.9% (7/39) among males and 27.4% (46/168) among females). No gender difference was found for omissions (Fischer’s Exact Test, $p=.322$).

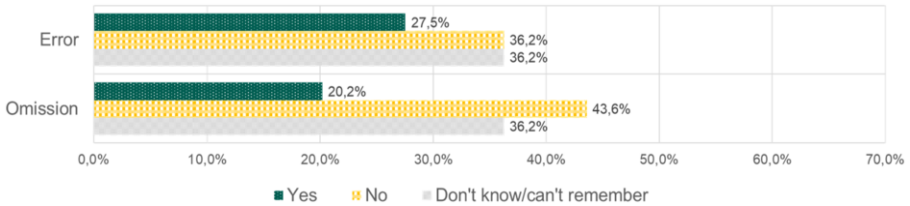


Figure 1. Errors and omissions found by adolescents aged 15-19 (n=218).

Of the adolescents who found an error, one third (20/60) perceived it as somewhat or very serious (Figure 2). While none rated omissions as not at all serious, almost 89% (39/44) assessed them as somewhat or very serious. A larger proportion of respondents were uncertain of the gravity of omissions (5/44, 11.4%) than of errors (2/60, 3.3%).

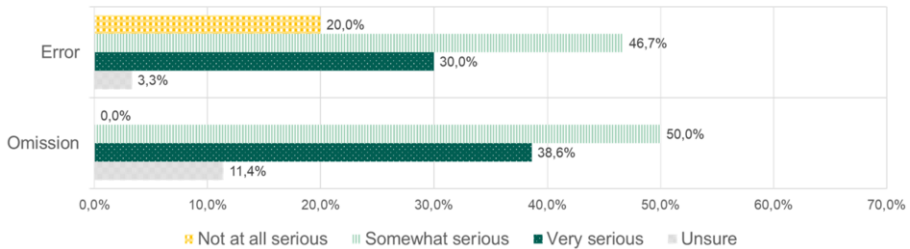


Figure 2. Adolescents’ perception of the gravity of found errors (n=60) and omissions (n=44).

Upon finding errors or omissions, adolescents most frequently reported having done nothing (55/86, 64.0%). Informing the HCP at the next visit or contacting the healthcare unit via telephone was reported by 14.0% respectively (12/86) (Figure 3).

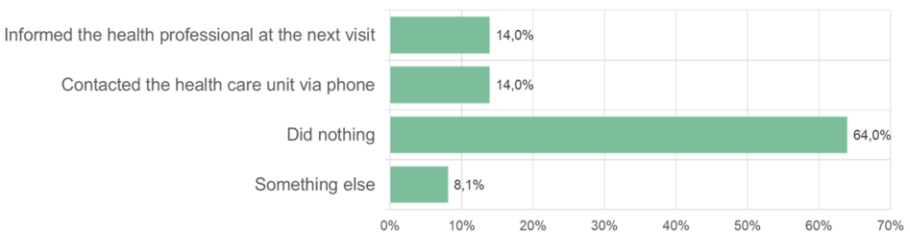


Figure 3. Action taken by adolescents when finding errors or omissions in the PAEHR (n=86).

Seven respondents selected “Something else” (8.1%) and described asking a nurse, informing other HCPs, leaving a complaint, plans to inform future HCPs, plans on applying for the full physical copy of the record as well as contacting the “contact point”. Respondents rated the ease of finding errors or omissions at a mean of 2.64 (SD=1.25).

4. Discussion

Our survey collating 218 adolescent respondents is, to our knowledge, the first systematic examination of adolescents' identifying mistakes in their PAEHR. One fourth of adolescents had identified an error, and one fifth had found omissions. The omissions were more often rated as serious than errors were. A larger proportion of those marking their gender as "Other" reported finding errors in their record than among males and females. This is in line with a recent study where adult transgender people reported recurrently finding errors in their records, such as the wrong name or pronoun [19].

Previous research has suggested that patients hold interest in engaging in safety efforts [15]. Notwithstanding, it was found that compared to the 28% who reported having informed HCPs via phone or during a visit, a majority (64%) of adolescents did nothing when finding a mistake. This may be attributed to the fact there is currently no guidance or instruction in *Journalen* on how to report errors or omissions. Only upon searching the matter online, the general advice is to contact the healthcare provider, which in itself may be a daunting process. Furthermore, since research has found that anonymous reporting systems appear less challenging and confrontational for patients in general [16], it is possible that adolescent patients hesitate to notify HCPs of errors or omissions directly. In addition, respondents may fear repercussions or prefer to report adverse events via electronic media, as reported by a focus group study with adolescent patients based in the United States [17]. Respondents rated the ease of detecting errors and omissions as lower than average. A possible explanation for this is that adolescents appear to have lower self-esteem than other age groups [18], they feel insecurity in clinical environments and may lack health literacy compared with adults [17].

The study has limitations. The sample size was small, which reflects difficulties in recruiting adolescents in research. Data on socioeconomic background or healthcare needs was not collected, limiting our analysis. Furthermore, the terminology may have been confusing, as missing information can be perceived as a type of error. This may have affected participants' responses. The quantitative analysis presented in this study does not give us insight into what type of errors or omissions adolescents find. Also, the clinical relevance of the errors and omissions identified by adolescents cannot be determined. Future studies should further explore these issues. Work is also encouraged in other settings, as patients' expectations on EHRs may differ according to culture [20] and healthcare system. For example, EHR documentation and patient perception of errors are likely to be different in the United States compared to Sweden, due to a larger focus on issues such as insurance coverage and risk of litigation.

5. Conclusions

With the implementation of patient access to their records, accuracy of EHRs is not only critical for maintaining quality of care, but to maintain patients' perception of quality and their trust in healthcare. This study indicates that adolescents can play an important part in identifying errors and omissions in their records, but improved processes for reporting errors and omissions are needed to facilitate adolescents' contribution to improved patient safety. The findings call for development of policy and PAEHR design that facilitates reports of errors and omissions for adolescents, which could improve trust and support the individual's transition into an involved and engaged adult patient.

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