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A growing concern

Online access to minors' health records

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Abstract

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Healthcare worldwide is undergoing a transition where patients are increasingly granted access to their electronic health records (EHRs). However, online record access (ORA) for vulnerable groups like children and adolescents remains a topic of active debate. Minors' experiences of patient-accessible electronic health records (PAEHRs) and related ethical questions remain underexplored.

The thesis aim was to explore stakeholder experiences of online access to minors' EHRs, through six papers: 1) a case study comparing minors' and guardian use of PAEHRs in Sweden and Finland and the use of country-specific access control practices; 2) a literature review summarising knowledge about stakeholder views and experiences on ORA for minors and parents; 3-4) two survey studies examining Swedish adolescents' reasons for reading EHRs, utility, the link between use frequency and encouragement, as well as views on EHR security and privacy, attitudes toward information-sharing, and definitions of sensitive information; and 5-6) two mixed-methods studies exploring the views, awareness and benefits and risks with respect to ORA regulations among Swedish adolescents with serious health issues, their parents, and paediatric oncology HCPs. Findings were analysed using a framework of biomedical ethical principles.

Adolescents in Finland, who receive ORA earlier, showed higher PAEHR use than their Swedish counterparts. In Sweden, few applications for extended access were found. Most prior work was US-based that left minors' experiences, especially beyond chronic illness, largely underexplored. Swedish adolescent portal users viewed information as useful and higher use was related to HCP encouragement. Although security was rated highly, many wished to manage who could access their EHRs. Mental healthcare was the most cited as sensitive. Adolescents with serious health issues, their parents, and oncology HCPs criticised the current gap in ORA during adolescence. Parents were concerned about early adolescent ORA, while HCPs worried about the impact of parental ORA on EHR quality, and lacked knowledge of access extension.

In conclusion, while ORA showed potential for engaging adolescents in their care early and facilitating parental support, risks remain for EHR quality. Education and dialogue among stakeholders, along with addressing HCP concerns, are essential efforts to make ORA an effective tool for enhancing adolescent health outcomes.

Keywords: Online record access, open notes, patient experiences, adolescents, parents, healthcare professionals, paediatrics, oncology, survey, mixed-methods, scoping review

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*We all live with the objective of being happy;
our lives are different and yet the same.*

- Anne Frank

List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I. **Hagström, J.**, Häggglund, M., Holmroos, M., Lähteenmäki, P., Hörhammer, I. (2024). Minors' and guardian access to and use of a national patient portal: A retrospective comparative case study of Sweden and Finland. *Int J Med Inform*, 187:105465.
- II. **Hagström, J.**, Blease, C., Haage, B., Scandurra, I., Hansson, S., Häggglund, M. (2022). Views, Use, and Experiences of Web-Based Access to Paediatric Electronic Health Records for Children, Adolescents, and Parents: Scoping Review. *J Med Internet Res*, 24(11), e40328.
- III. **Hagström, J.**, Blease, C., Scandurra, I., Moll, J., Cajander, Å., Rexhepi, H., et al. (2024). Adolescents' reasons for accessing their health records online, perceived usefulness and experienced provider encouragement: a national survey in Sweden. *BMJ Paediatr*, 8(1):e002258.
- IV. **Hagström, J.**, Åhlfeldt, R-M., Blease, C., Cajander, Å., Rexhepi, H., Moll, J., et al. (2024). Security and Privacy of Online Record Access: A Survey of Adolescents' Views and Experiences in Sweden. *J Adolesc Health*, 75(5), 730-736.
- V. **Hagström, J.**, Blease, C., Harila, A., Scandurra, I., Lähteenmäki, P., Häggglund, M. Adolescents' and Parents' Perspectives on Online Record Access Regulations in Sweden: A Mixed-Methods Study. Submitted to *JMIR Pediatr and Parent*
- VI. **Hagström, J.**, Blease, C., Harila, A., Scandurra, I., Lähteenmäki, P., Häggglund, M. Paediatric oncology healthcare professionals' attitudes to and awareness of regulations for minors' and guardians' online record access: A mixed-methods study in Sweden. Submitted to *BMC Health Serv Res*

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Additional Papers

In addition to the work presented in the thesis, contributions were made during the PhD studies to the following papers:

- **Hagström, J.**, Blease, C., Moll, J., Rexhepi, H., Scandurra, I., Hägglund, M. (2024). Adolescents' and Young Adults' Experiences of Offense from Reading Their Health Records Online. *Stud Health Technol Inform*, 310, 1422–1423. [Conference]
- Hägglund, M., Kharko, A., **Hagström, J.**, Bärkås, A., Blease, C., Cajander, Å., et al. (2023). The NORDeHEALTH 2022 Patient Survey: Cross-Sectional Study of National Patient Portal Users in Norway, Sweden, Finland, and Estonia. *J Med Internet Res*, 25, e47573.
- Kujala, S., Simola, S., Wang, B., Soone, H., **Hagström, J.**, Bärkås, A., et al. (2024). Benchmarking usability of patient portals in Estonia, Finland, Norway, and Sweden. *Int J Med Inform*, 181, 105302.
- Huvila, I., Rexhepi, H., Moll, J., Ghorbanian Zolbin, M., Blease, C., Bärkås, A., Åhlfeldt, R-M., **Hagström, J.**, et al. (2024). Affordance trajectories and the usefulness of online records access among older adults in Sweden. *Digit Health*, 10, 1-15.
- Simola, S., Hörhammer, I., Xu, Y., Bärkås, A., Fagerlund, A.J., **Hagström, J.**, et al. (2023). Patients' Experiences of a National Patient Portal and Its Usability: Cross-Sectional Survey Study. *J Med Internet Res*, 25, e45974.
- **Hagström, J.**, Scandurra, I., Moll, J., Blease, C., Haage, B., Hörhammer, I., et al. (2022). Minor and Parental Access to Electronic Health Records: Differences Across Four Countries. *Stud Health Technol Inform*, 495-499. [Conference]

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Abbreviations

CHERRIES	Checklist for reporting results of internet e-surveys
COM-B	Capability, Opportunity, Motivation, and Behaviour
COREQ	Consolidated criteria for reporting qualitative research
Covid-19	COrona VIrus Disease, official name of Covid-19 virus
EHR	Electronic health record
HCP	Healthcare professional
IT	Information technology
LLM	Large language model
NLP	Natural language processing
ORA	Online record access
PAEHR	Patient-accessible electronic health record
PL	Primary language
PRISMA	Preferred reporting items for systematic reviews and meta-analyses
RCT	Randomised controlled trial
SALAR	Swedish Association of Local Authorities and Regions
SNOMED CT	Systematized Nomenclature of Medicine – Clinical Terms
UK	United Kingdom
UN	United Nations
US	United States
UTAUT	Unified Theory of Acceptance and Use of Technology

Key Concepts

Access control practice	Patient portal practice of allowing or blocking guardian proxy access during adolescence.
Adolescent	In this thesis, the term refers to an individual from the age of 13 up to 20 years old. Definitions of “adolescent” varies across papers in the thesis, depending on the aims and limitations of each study design.
Assent	Agreement of an individual who is not able to give legal consent.
Autonomy	Principle within the biomedical ethical framework of Beauchamp and Childress, referring to the right of patients to make informed decisions about their own medical care without coercion or undue influence from healthcare professionals or others [1].
Beneficence	Biomedical ethical principle concerning healthcare professionals’ obligation to promote beneficial health outcomes and promote patient wellbeing [1].
Confidentiality	Biomedical ethical principle related to healthcare professionals’ responsibility to share information responsibly [1].
Electronic health record	Digital system that stores and manages patient medical documentation as recorded by healthcare professionals. In this thesis, this concept includes <i>Electronic Medical Record</i> and <i>Electronic Patient Record</i> . Abbreviated as EHR.
Epistemic injustice	Concept coined by Miranda Fricker, referring to inequalities in the access, production, or participation in knowledge formation [2].

Experience	Knowledge or understanding gained through subjectively lived experience, pertaining to for example satisfaction, concerns, and literacy.
Healthcare professional	Individual trained to provide healthcare (including but not limited to the following medical professions: physicians, nurses, and physical therapists). Abbreviated as HCP.
Justice	The biomedical ethical principle that all should have the same opportunity to receive care [1].
Minor	Individual under the age of legal responsibility. In this thesis, individuals up to 20 years old are included, even though they are no longer formally considered minors.
Nonmaleficence	The biomedical ethical principle concerning healthcare professionals' obligation to prevent harm, whether through action or inaction, and to carefully weigh the risks and benefits of any treatment or intervention [1].
Online record access	The phenomenon of patients' online access to their electronic health records, typically via a patient portal. Abbreviated as ORA.
Open Notes	Term primarily used in the United States to describe the specific practice of giving patients' access to the free text entries written by healthcare professionals [3].
Parent	Individual who has legal parental rights and responsibilities for a child, i.e., a parent or legal guardian. For readability, the term "parent" was used instead of "guardian".
Patient-accessible electronic health records	Electronic health records that are available to patients via patient portals. Abbreviated as PAEHR.
Patient portal	A secure online website, commonly developed by electronic health record vendors, that houses patient-accessible electronic health records and provides users with access to various types of health information.

Physician	Healthcare professional qualified to practice medicine, including to diagnose and treat illnesses, as well as to prescribe medications.
Privacy	This thesis focuses on informational privacy [4], which refers to control disclosure of personal information, involving concepts such as confidentiality and secrecy.
Proxy access	Ability of one individual to share access to their information with other individuals. In this thesis, proxy access mainly refers to parental proxy access to their child's electronic health records.
Security	In this thesis, security refers to safeguarding measures implemented to protect health information, intended to prevent unauthorised and non-consensual access to electronic health records.
Truthfulness	Biomedical ethical principle of honest and comprehensive transmission of information from healthcare professionals to patients [1].
View	An attitude, expectation, or thought held by an individual.

Introduction

The English word *record* is believed to originate from the Latin *recordari*, meaning “to remember” [5], while the Swedish word *journal* traces back to *diurnalis*, meaning “of the day” [6]. The semantics of these words have changed since the era of Latin, yet they continue to embody our need to recall – and to document – daily medical events, particularly in times of health adversity. This thesis will address a controversial issue with complexities that I believe most of us can relate to, since we have all been young, been parents, or worked in healthcare.

Online access to electronic health records (EHRs) has fundamentally transformed patient engagement: allowing individuals to view their clinical health information (e.g., clinical notes, laboratory tests results, medications, diagnoses, and referral information) can promote patient empowerment by involving patients in their own care [7,8]. However, despite growing implementation of online record access (ORA), research into the effects on minors and parents with this innovation remains limited and poorly understood.

Evolution of Patient Access to Health Records

Medical records are not a modern innovation. Archaeologists have unearthed records on papyrus and clay tablets from ancient civilisations [9], presumably created for educational purposes. In the 18th century, healthcare professionals (HCPs) kept hand-written records as personal aides-mémoires [10]. Systematic documentation emerged in the 19th century, and in Sweden, patient documentation became mandated in 1963 [11]. The length of medical records has grown over time, partly due to the integration of documentation from technological innovations such as X-rays, and the need for clearer notes as multiple HCPs became involved with the same patient. A Swedish 1968 investigation [12] noted the challenge of storing extensive amounts of health records on paper in hospitals, whereupon surveyed HCPs brought attention to the advantages of long-term preservation of medical records within healthcare, legal, and research contexts. The solution came with the advent of information technology (IT) in the late 20th century, that allowed paper-based health records to be digitised into electronic formats [9]. In addition to rapid technological innovation, societal changes would contribute to further, and more debated, transformation of the EHRs.

Until the end of the 20th century, the HCP-patient relationship was traditionally paternalistic in nature, where the HCP had authority to make treatment decisions on behalf of the patient. This model has been challenged during the last few decades, triggering a shift towards person-centred care and transparency, anchored to respect for patient autonomy, reduced HCP dominance, and increased shared decision-making and patient-HCP collaboration. A sign of this shift can be seen in a linguistic analysis of mental health records spanning 1890 to 1990 [13], noting that the first use “we” in a clinical note to refer to the patient and HCP as a collective unit appeared in the 1970s. In this spirit, providing patients with access to their health records was first proposed in 1973 by two American psychiatrists [14]. Decades later, technological advancements enabled the sharing of notes with patients via the Internet and since 2000-2015, patient-accessible EHRs (PAEHRs) via national patient portals have been the norm in the Nordic countries. In Sweden, patients have been able to request paper copies of their EHRs since 1985, as the Patient Record Act was introduced (1985:562) [15].

Since the beginning of ORA implementation, HCPs have voiced concerns about harm to patients [16], expecting patients to worry more, disagree with notes, and HCPs having to deal with a higher workload as a consequence [17]. Over time, concerns have diminished as the negative effects did not materialise to a significant extent [18]. Nevertheless, some HCPs still perceive ORA as complicating their work, and question whether ORA addresses actual needs or is merely a response to political pressures [19]. During the Covid-19 pandemic, the increased use of patient portals led to a surge of patient messages about the EHRs via the portal, which has contributed to job dissatisfaction and even burnout among HCPs [20]. In the United States (US), HCPs also face higher litigation rates than in many other countries, and it is not yet understood whether ORA increases the risk of medicolegal exposure [21]. Legal and ethical issues arise particularly in relation to *proxy access*, which concerns sharing access with other individuals, such as between children and parents.

Adult patients describe various benefits from ORA, such as enhanced empowerment, improved recall of visits, better medication adherence, and a greater sense of control [7,22,23]. Patients with serious illnesses, such as cancer, appreciate ORA for enabling them to track their condition by instantly viewing laboratory tests results [24]. As digital services are becoming the norm in many developed countries for managing daily tasks, such as banking, shopping, and communication, citizens increasingly expect online access to their health information. In particular adolescents, growing up in today’s digital landscape, value technological convenience in all aspects of life, including healthcare [25].

Background on Online Record Access and Minors

Where ORA is implemented for young children, legal guardians, most often parents, are usually provided sole access to the EHR, as the child is not capable to manage their care. In this way, the parent acts as a proxy in health decisions. However, during adolescence, the minor may desire to exercise greater personal autonomy and privacy in their medical decisions. If the parent then has access to the records, they may access information that the adolescent wishes to withhold from the parent. While this may not concern all information in the EHR, types of care that may be considered sensitive include mental health, sexual health, gender identity, and domestic or sexual abuse [26]. As a result, HCPs are faced with ethical challenges in EHR documentation with the risk of inadvertent release of information. These risks are critical, as worries about disclosure of sensitive health information to parents – such as through ORA – can deter young people from seeking medical care or lead them to withhold medically relevant information from HCPs during visits [27]. This may have downstream effects of undermining long-term patient trust. Therefore, young individuals' privacy requires safeguarding [28,29]. The need to protect caregiver privacy has also been raised, in cases where parents reveal confidential information, including their own health or family relations of relevance related to the child's care [30].

Adolescents in Healthcare

Adolescence is a dynamic time of cognitive, social, physical, and emotional development, when individuals are actively forming their sense of identity. Introducing ORA during this stage may be beneficial given some distinctive traits. Sometimes referred to as digital natives [31], adolescents are commonly familiar with navigating the internet. Furthermore, they are curious and have a desire to learn. As they can be forgetful and absent-minded, ORA could be a valuable tool for remembering medical information. Benefits may extend into the long-term, as involving adolescents early in their own care could lead to improved health outcomes and reduced healthcare costs.

While adolescence is often characterised by good health, leading to fewer healthcare visits, a considerable proportion deal with serious health issues. Globally, an estimated 10-30% of youth have a chronic health condition [32]. In Sweden, 30% of 13- and 15-year olds had a chronic illness or disability, as of 2022 [33], and around 350 of 1,6 million children are diagnosed with cancer annually [34]. During the last decade, reports show increased prevalence of mental health issues among minors in the US [35] and Sweden [36], as well as growing rates of self-harm in adolescents across Europe [37] and Asia [38]. While parental support is essential for complex health management, adolescents may gradually, particularly when seeking help for sensitive issues, want to seek healthcare independently and form their own relationship with HCPs.

Most adolescents experience an increase in mental capability to understand the implications of medical procedures. As a result, children are commonly offered greater input into healthcare decision-making as they grow older. Evidence-based approaches suggest that children over 12 may have the capacity to understand and reason about medical information; yet, this is complicated by evidence indicating that adolescents have underdeveloped executive functioning, making them more prone to underestimate risks [39] and engage in potentially harmful behaviours. Also, lower levels of self-esteem have been observed in adolescents compared to other age groups [40]. As HCPs have expressed concerns about adult mental health patients accessing their records [41], adolescent patients may be even more vulnerable.

Concerns about minors' capacity to manage their care have led to policymaker apprehension regarding providing adolescents with ORA, often resulting in limited access. Consequently, in contrast to extensive research on adult patients, there is a paucity of information with respect to minors' views, use, and experiences of ORA, and much uncertainty remains with regard to the consequences of ORA implementation. It is thought that ORA offers information transparency that might contribute to patient empowerment and enhanced healthcare; the sole previous literature review on ORA for paediatric patients and parents observed scarce research focusing on adolescents, indicated mostly positive feedback [42]. Meanwhile, more comprehensive input from parents showed general acceptance of PAEHRs. As the 2016 review addressed only user and caregiver experiences, a review in this thesis included more recent research and the perspectives of HCPs and other stakeholders.

Parents and Guardians as Proxies

Many adolescents depend on their parents for managing their care, especially during early adolescence. For adolescents with complex care needs, such as those with chronic illness, parental proxy access to the child's EHRs may be invaluable as parents often serve as informal caregivers coordinating their child's care. Ford et al. [43] proposed a framework of strategies, suggesting that strengthening the partnership between parents and HCPs could contribute to improved adolescent health. For example, parents can act as intermediaries in communication between their child and HCPs. Possibly due to their role in their child's care, preliminary work indicates that parents of children with chronic illness highly appreciate ORA [44]. However, parental ORA could lead to danger for some children and adolescents, in cases when parents are abusive or not supportive of their child's health needs, such as when seeking birth control. Custody battles or other legal settings can also create difficult situations when parents have access to the child's EHR.

Balancing the risks and benefits of ORA during adolescence has led to various safeguarding measures, with Thompson [45] identifying three key methods: *Confidentiality*, *Family Engagement*, and *Parent Orientation*. With

Confidentiality, parents relinquish access and agree to a confidential relationship between minor and HCP. The *Family Engagement* mode allows both parent and adolescent ORA. In the *Parent Orientation* model, parental control is maintained and the adolescent has no separate access. Each of these approaches offers distinct benefits and risks, and policy-makers globally shape ORA regulations based on regional, cultural, and legal contexts. Examining the various implementations of ORA to date illuminates this complexity.

Global Paediatric and Adolescent ORA Implementation

Although providing patients with ORA is becoming more common, access varies internationally [46]. Currently, institutions in over 20 countries are developing patient portals [47], with continuous adaptation of legal national frameworks to improve use and ensure patients' privacy [47,48]. So far, diverse approaches have been adopted in the EU and globally to manage parents' and minors' access to children's EHRs. These *access control practices* either rely on pre-defined age-based access limits or on access decided on a case-by-case basis [49]. During my PhD, I was the main author of a conference study outlining four countries' frameworks (Sweden, Norway, Finland, and Estonia) [50], finding that national ORA systems in Sweden and Norway apply a minimum access age for minors (age 16) and an age cut-off for parental access (age 12-13). In Sweden, after parents lose access and before minors gain access, both can gain access by application [50,51]. By contrast, Finland has adopted a case-by-case system with no minimum access age for minors, where parental access depends on HCP assessment and minors' consent [50].

Beyond Scandinavia, patients in the United Kingdom (UK) gained access to their primary care notes in 2023. For minors and parents, an approach based on pre-defined access ages has been adopted, with parents losing access when the child turns 11. Continued parental access can be arranged through discussion with the HCP if the young person consents or is not considered competent to make decisions about access. In France, adolescents receive access at 18 years of age when, in turn, the parent loses access [47]. On a European Union (EU) level, the European Health Data Space (EHDS) is a proposal that aims to give all EU citizens access to their EHR [52]. The EHDS states that EU member states should "enable guardians to act on behalf of their dependent children", without providing guidance on how to deal with these aspects.

In the US, where ORA has been increasingly implemented, the OpenNotes movement has worked to make healthcare more transparent through ORA since 2010 [53]. In 2021, the 21st Century Cures Act mandated free electronic patient access to their clinical notes for US healthcare providers [54], usually via online patient portals. Patient portal policies on age and privacy exceptions during adolescence vary across the US due to state laws, but also within states, which informatics administrators have attributed to institutional interpretations of vague and conflicting regulations [55].

Theoretical Background

Principles of Biomedical Ethics

Linking ethical questions and paediatric ORA, this thesis builds on the classic principles of biomedical ethics introduced by Beauchamp and Childress [1]: *autonomy, non-maleficence, beneficence, justice, confidentiality, and truthfulness*, as depicted in Figure 1. The paediatric population has, like the psychiatric and geriatric population, been identified as a particularly vulnerable group requiring unique legal and ethical considerations in ORA implementation [56]. For example, ethical issues with paediatric patient portals may emerge during the transitional phase of adolescence, such as how to protect children’s privacy when parents have proxy access to their information, and the implications of adolescents transitioning to adulthood.

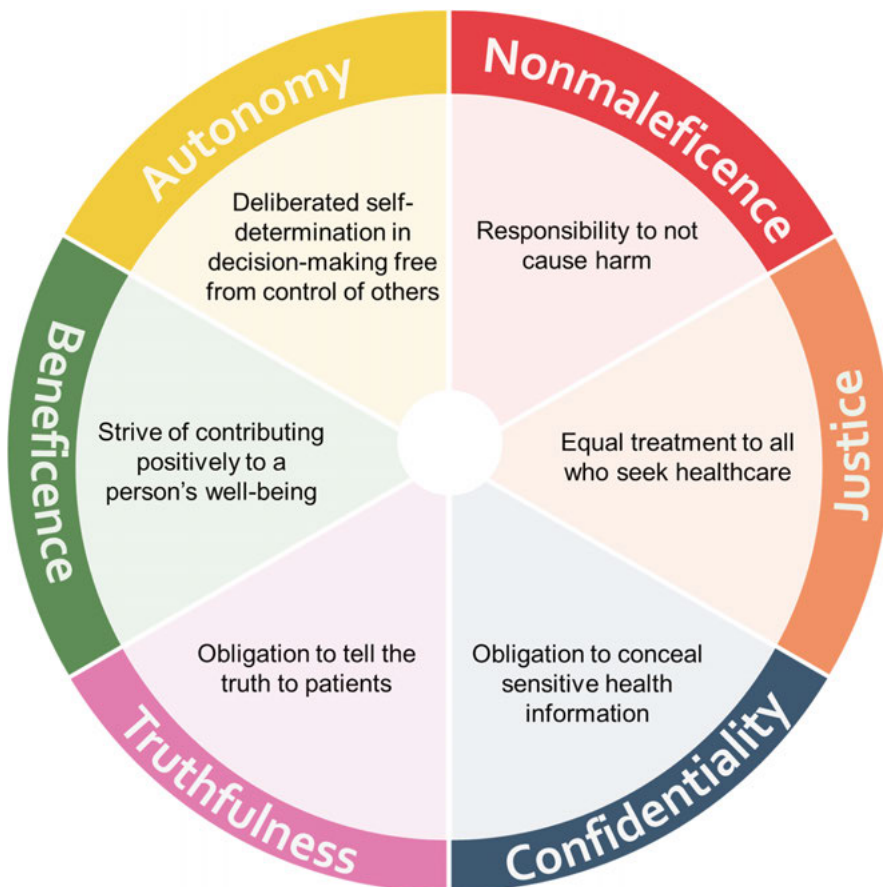


Figure 1. Biomedical ethical principles by Beauchamp and Childress [1].

In healthcare, *autonomy* refers to the right of patients to make informed decisions about their own medical care without coercion or undue influence from HCPs or others. This concept emphasises the importance of respecting a patient's access to understandable health information and their personal values, preferences, and choices regarding their treatment options, even if those choices differ from the recommendations of HCPs. In the view of British medical ethicist Ranaan Gillon, respect for autonomy is the principle that is most often overlooked in medicine [57], as well as the one that should be primarily considered [58].

Nonmaleficence underlines the obligation of HCPs to prevent harm, whether through action or inaction, and to carefully weigh the risks and benefits of any treatment or intervention. In practice, nonmaleficence involves ensuring that the potential harm does not outweigh its potential benefits.

Beneficence in medical ethics concerns HCPs' obligation to promote beneficial health outcomes and promote patient wellbeing [9].

Justice refers to equal treatment of all who seek healthcare, stating that everyone should have the same opportunity to receive care and that resources are to be distributed equally.

Confidentiality refers to HCPs' responsibility to share information responsibly, and informational privacy refers to the patient's right to security of their health data. Some argue that privacy is instrumental in that it is essential in maintaining trust and respect in relationships.

Truthfulness in a healthcare setting refers to honest and comprehensive transmission of information from HCPs to patients, and this obligation is based on respect owed to others and the importance of veracity in fostering trust in the patient-HCP relationship. In relation to truthfulness, the notion of *epistemic injustice* coined by Miranda Fricker concerns inequalities in the access, production, or participation in knowledge formation [2]. This concept encompasses situations where individuals or groups are denied access to information, which can restrict their ability to make informed decisions.

Using an ethical framework has been posited as a strong foundation to develop patient portals. The principles introduced by Beauchamp and Childress was selected due to its importance within medical ethics since its conception in 1979 [57]. Beauchamp and Childress state that HCPs often need to balance the ethical principles, and that limited disclosure to information is sometimes considered justifiable, such as when disclosure would cause the patient harm [1]. In this thesis, the biomedical ethical framework is used to analyse the study findings about ORA and provide topics for further research. Findings from the papers informed the selection of relevant principles for the analysis.

Context

All papers in this thesis, except for Paper II, focused partly or entirely on adolescents and parents in Sweden. Therefore, this section outlines the Swedish context. Paper I was also centred on Finland, with more detail on that setting described in relation to the specific paper. Papers I and II include children aged 12 and younger, however this thesis focuses mainly on adolescents aged 13-19 years old.

Sweden and ORA

Internet Access and Use

Access to internet is today widespread in Sweden [59]. In 2015, almost all families (96%) in Sweden with children aged 7-11 years old had a smartphone [60]. A 2023 report [61] showed that according to parents, 99% of children and adolescents aged 8-19 access the internet, while among adolescents in middle school and high school, internet usage reaches 100%.

ORA implementation and *1177 journal*

Sweden is divided into 21 regions that provide public healthcare providers to registered citizens. Early efforts to provide patients with access to their EHRs were commenced in the Uppsala region in 1997. The Swedish Patient Data Act (2008:355) [62] mandates that healthcare providers must document patient data and ensure security and privacy when sharing them. Once Region Uppsala had implemented ORA, other regions joined the integration of patient access to *Journalen*. Today, patients in all 21 regions have access to their records through *1177 journal* (*Journalen* was re-named in 2023). *1177 journal* can be accessed via the web platform *1177.se*, managed by Inera AB (hereafter referred to as Inera), a company owned by all Swedish Regions and Municipalities through the Swedish Association of Local Authorities and Regions (SALAR). According to publicly available statistics of *1177 journal* [63], there was a rapid increase of usage during the Covid-19 pandemic, with 132,000 users logging in for the first time monthly in 2021, compared with 46,800 in 2024. In 2024, up until October, approximately 1,6 million unique users per month were accessing their EHRs.

The content of *1177 journal* includes for example clinical notes, prescribed medications, lab results, growth curves, vaccinations, diagnoses, maternity care records, referrals, and treatment plans (a main view screenshot is shown in Figure 2). However, availability differs depending on healthcare provider, which can be either the public healthcare providers (regions) or connected private health care providers who have agreed to give access. As of 2021, one of Sweden's 21 regions has decided to exempt child and adolescent psychiatry notes from availability in the national PAEHR service *1177 journal* [64].

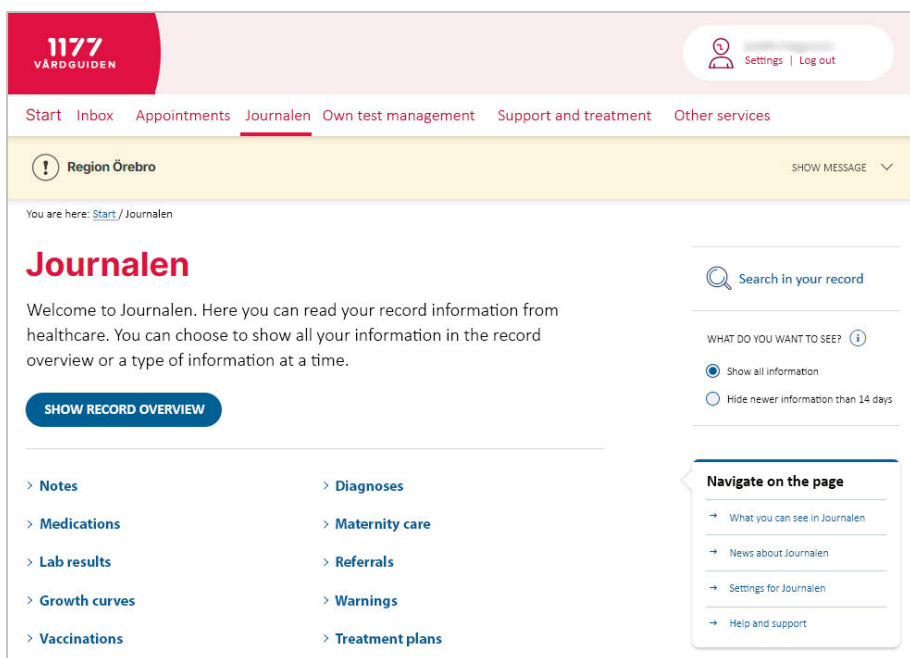


Figure 2. The national PAEHR 1177 journal (manually translated).

1177 journal is not regulated by Swedish law, however a national regulatory framework developed by Inera has been approved by all 21 regions [48,65], including definitions of access age limits intended to protect adolescents' privacy [66]. Parent users of *1177 journal* gain access to their child's EHR at birth by default and lose access when the child turns 13, moving from a *Parent orientation* to a *Confidentiality* approach, according to Thompson [45]. Adolescents gain own access at the age of 16. Thus, when an adolescent is between 13 and 15 years old, neither parent nor adolescent has access to the child's records. This access gap has led to criticism, especially among parents of children with serious illnesses [67,68]. During this period, it is possible for parents and adolescents to apply for extended access outside of the default by submitting a paper application. A separate application is required for each healthcare unit of interest, which must be approved by a HCP who evaluates needs, risks, as well as the minor's maturity and wishes. This process is designed for use in special circumstances, such as for minors with chronic illness or special healthcare needs.

To safeguard information in *1177 journal*, two methods currently exist. First, the EHR system holds a number of "hidden search words" that HCPs can use in documentation to conceal specific information, including "early hypotheses", "violence victim", and "third person". Second, a patient's entire record can be blocked: (1) HCPs can seal parental access for children 12 or younger, (2) adolescents aged 16-18 can request to lock their own access to

prevent parental breaches by coercion, and (3) from age 13, users can choose to block all access, including for HCPs, to their EHR.

Prior to ORA implementation, adolescents and parents could request printed copies of the record, which is still possible. Nevertheless, such requests require the submission of paper forms, an HCP assessment, and, in some cases, financial compensation. This procedure puts a burden on HCPs to administer and distribute print-out copies that may contain extensive material. Also, some patients may find it cumbersome to request access to their records, out of fear of being perceived as difficult or critical, or due to feelings of social awkwardness.

At the time of writing this thesis, proposals for a new framework of age limits and parental and adolescent access have been presented by Inera [69,70] and the Swedish government [71]. The proposals include earlier access for adolescents and longer access for parents, and are currently under review with stakeholders including authorities, organisations, and municipalities. After review and consultation, the proposal will be reviewed by the government.

Child Autonomy in Healthcare

The current framework of access age limits for *1177 journal* does not have legal foundation, because there is no legal age limit for children to participate in decision-making about their health in Sweden [72]. The Patient Act [73] states that the best interest of the child should be accounted for. While this concept is difficult to define, it is stated that the best interest of the child does not necessarily equate to the child's wishes. Restrictions of a child's autonomy are intended to protect the child, as they are not yet fully developed and are considered unable to understand the implications of some decisions. As a result, parents have decision-making capacity and need proxy access to the information about the child's health. The Children and Parents Code [74] holds that parents have the right and responsibility to make decisions for their child until 18 years of age. Still, the Patient Act states that parents should not receive more information than "what is considered necessary". As the child grows up, the parent is supposed to take increasing consideration of the child's wishes in healthcare decisions. The Patient Safety Act [75] mandates that the treating HCP should assess the child's maturity and age, with the idea that the child's decision-making is to gradually progress into autonomy. Under the Public Access to Information and Secrecy Act [76], confidentiality of the child's information does not extend to parents unless the child has autonomy in the matter. According to the Patient Act, the child must be competent to decide in order to assent to care, where *assent* refers to agreement of someone not able to give legal consent. Parameters in assessing the child's decision competence include type and degree of care measure, as well as the child's maturity, with some consideration of age.

Rationale for the Thesis

Providing patient access to minors' records is a debated topic, much due to minors' developing capacity to manage their own care and confidentiality concerns related to parental proxy access. In particular, adolescence is a critical period for dealing with health issues, as young people must balance their need for parental support with an increasing desire for autonomy and privacy. Parental access to their child's EHRs can compromise the child's confidentiality, however restricted parental access can deprive the parent of legitimate access to important information. While access to their EHRs can empower adult patients and enhance their sense of control, confidentiality issues and a lack of clear guidance have resulted in varied ORA implementation for adolescents and parents across different providers and countries. To date, little attention has been paid to ORA in the context of adolescent patients. Even in the Nordic countries, where national patient portals have been accessible for more than a decade, a knowledge gap persists regarding the experiences of ORA among Swedish adolescents, parents, and HCPs. Furthermore, no previous study has analysed paediatric ORA from an ethical perspective.

This thesis aims to bridge these gaps by applying a range of methods (case study, scoping review, surveys, and interviews) to explore adolescents', parents', and HCPs' perspectives on ORA. Results will be analysed using the framework of biomedical ethical principles suggested by Beauchamp and Childress [1]. Enhancing our knowledge about minors', parents', and HCPs' perspectives on ORA is essential to enable the design of informed policies and educational resources for patient portal users and HCPs. Applying an ethical lens will be valuable when addressing the debated question surrounding paediatric ORA implementation and its implications for the vulnerable population of minors. Ultimately, this approach aims to disentangle the potential of patient portals in supporting child and adolescent health.

Aims

Drawing on the biomedical ethical framework outlined [1], the principal aim of this thesis was to explore experiences of online access to minors' health records. The specific aims of the papers were:

- I. To describe and compare minors' and guardian proxy users' PAEHR usage in Sweden and Finland, and to investigate the use of country-specific access control practices.
- II. To identify, categorise, and summarise knowledge about various stakeholders' views, use, and experiences of EHR access for children, adolescents, and parents.
- III. To explore Swedish adolescent PAEHR users' reasons for reading their records, experiences of having been encouraged by HCPs to read them, the link between encouragement and usage frequency, as well as the perceived usefulness of information and functions.
- IV. To explore Swedish adolescent PAEHR users' views on PAEHR security and privacy, experiences of non-consensual access, attitudes to sharing information, and perceptions of what constitutes sensitive information.
- V. To explore perceived benefits and risks of using the PAEHR, and views and awareness of the national framework among Swedish adolescents with serious health issues and their parents.
- VI. To explore Swedish paediatric oncology HCPs' views, awareness, and perceived benefits and risks with respect to ORA regulations.

Methods

To meet the aim of exploring experiences of online access to minors' health records, I have chosen to use a combination of qualitative and quantitative methods. The studies in this thesis are presented in six papers. The aim of Paper I was to examine usage of PAEHRs and access control practices, which prompted a case study of two countries. Paper II consisted of a scoping review examining the literature. Papers III and IV investigated Swedish adolescent PAEHR users' experiences, by analysing findings from an online national survey. Lastly, Papers V and VI aimed to collect stakeholder views on ORA regulations, resulting in the use of a mixed-methods design with surveys and interviews. Table 1 presents an overview of the papers, the context in which they were performed, and the methods used.

Table 1. Overview of papers included in the PhD project.

	Design	Data collection	Setting	Data	Data analysis
I	Observational	Case study	Sweden and Finland	NA	Descriptive
II	Scoping review	N/A	Global	74 studies	Thematic analysis
III	Quantitative	Online survey	Sweden	218 adolescents using <i>1177 journal</i> (age 15-19)	Descriptive
IV					Fisher's Exact Test
					Descriptive
					Kruskal-Wallis Test
					Content analysis
V	Convergent mixed methods	Surveys and interviews	Sweden	31 adolescents with serious health issues (age 13-19)	Descriptive
VI				57 parents	
				95 oncology HCPs	Thematic analysis

The studies in this thesis were performed within NORDeHEALTH [77], an international research project including four Nordic countries (Sweden, Norway, Finland, and Estonia). The project aimed to identify the challenges and opportunities in healthcare digitalisation, focusing on national portals giving patients online access to their EHRs, without specifically addressing paediatric ORA. In 2022, a national survey was conducted in the four countries, of which Papers III and IV used the Swedish data. This thesis contributed by providing insights to patient proxy ORA in a paediatric context.

Paper I: Case Study

A case study that aimed to describe and compare minors' and guardian proxy users' PAEHR usage in Sweden and Finland, and to investigate the use of country-specific access control practices.

Design

Retrospective, observational case study [78] of Sweden and Finland.

Setting

In 2022, Sweden's population was 10,549,347 people (minors aged 10-17: 997,263) [79] and Finland's was 5,563,970 (minors 10-17: 598,075) [80]. The national PAEHR service in Finland is *My Kanta* [81], which is provided by the Finnish institution Kela, and holds content similar to what is available in the Swedish national PAEHR *1177 journal* (described under *Context*), including visit notes, laboratory test results, medications, and vaccinations. Currently, Finland has no lower access age [50], thus minors can access their own records when they have acquired an electronic identification. As of writing, Finland's practice regarding guardian access was in transition: All guardians had default access to their child's records until the child's age of 10 until October 2020, after which healthcare organisations could implement the new practice where granting of guardian access to minors' EHRs follows a specific procedure. For each care event, the 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 selects 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 to parents.

The prior approach was *Family Oriented* until the child turned 10, then based on *Confidentiality* [45]. The approaches are now more mixed. The practice is based on Finnish patient law regulating minors' rights to decide about their care and is mandatory to implement. During the study period (January 2021-December 2022), the adoption of this practice by healthcare organisations rose from 3% to 65%. As such, a substantial part of organisations remained in the old practice granting guardians until the minors turned 10.

Data Collection

Use statistics were collected for *1177 journal* from Inera by two Sweden-based authors (JH and M Hägglund) and for *My Kanta* from Kela by two Finland-based authors (IH and M Holmroos).

Table 2. Data acquired for Sweden and Finland.

Inclusion criteria	Sweden	Time span	Finland	Time span
Minors' logins (unique users)	Yes	2018-2022	Yes	2021-2022
Guardian proxy access	Yes	2018-2022	Yes	2021-2022
Use of access control practices	Yes	2018-2022 ^a	Yes ^b	2021-2022

^a For two regions, data on access extensions was available only for 2020-2022 and 2021-2022.

^b Data regarding medication prescription events.

Data on minors' use included unique minor users' logins in both countries. Yet, data on guardian access differed; Swedish data included unique guardians accessing their minors' record, while Finnish data consisted of the total number of minors per year on behalf of whom a guardian had proxy-accessed their records. As displayed in Table 2, the years of 2018-2022 were covered for Sweden and 2021-2022 for Finland. No national statistic on access extensions was available in Sweden, since applications were administered independently by the 21 regions. All regions were contacted, whereof five provided the data.

Data Analysis

The data consisted of 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 [79] and Finland [80]. Data were presented descriptively and no statistical tests were conducted.

Paper II: Scoping Review

A literature review that aimed to identify, categorise, and summarise knowledge about various stakeholders' views, use, and experiences of EHR access for children, adolescents, and parents.

Design

A scoping review based on Arksey and O'Malley's framework [82], following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [83]. Further details regarding the methods used are available in the published protocol [84].

Material

Eligible papers that focused on ORA for children, adolescents, and parents were included (n=74).

Data Collection

A comprehensive literature search on three databases (PubMed, CINAHL, and PsycINFO) was conducted by a research librarian at Uppsala University, who provided the research team with the search results. Search terms included were related to 3 key concepts: (1) EHR, (2) sharing EHRs with service users, and (3) paediatric or adolescent access. The references of the identified articles were scanned backward to identify prior work to consider for the research topic. The inclusion and exclusion criteria are presented in Table 3.

Table 3. Criteria for inclusion and exclusion in the scoping review.

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none">• Patient user population: children, adolescents, and parents• Population studied: children, adolescents, parents, HCPs, and other stakeholders• Outcomes: views, use, or experiences of access or proxy access to PAEHRs• All study designs	<ul style="list-style-type: none">• Not written in English• Published outside the study period between 2005 and 2021• No focus on paediatric PAEHRs

Note: Patients aged ≤ 12 years were defined as children, ages 13 to 18 years as adolescents, and ages ≥ 18 years as adults. Age 19-20 was included if a participant group comprised mostly adolescents.

The search results were compiled in the Rayyan (Rayyan Systems Inc.) web application [85], where duplicates were removed. All authors partook in screening the article titles, abstracts, and keywords with consideration of the eligibility criteria. Next, full-text articles were assessed for eligibility. The articles were divided between the investigators so that each article was assessed by at least 2 people. The first author set up a Microsoft Excel spreadsheet to which the researchers added information independently, including study characteristics: type of identification, title, authors, year, journal, etc. Group discussions were held as needed, with a third reader involved if necessary.

Data Analysis

A deductive thematic analysis [86] was conducted, using pre-defined key themes adapted from a previous scoping review of the literature on ORA in mental health [87]. Each group of stakeholders was assigned to 2 authors who were responsible for analysis and drafting of that result section. Still, the first author assisted in the analysis and result drafting related to all stakeholder groups. Authors read the studies belonging to their assigned stakeholder

group, and coded the data based on the predefined themes. Next, themes were reviewed and refined.

To enhance the trustworthiness of the analysis and gain further insights, the results were shared with stakeholder representatives, including a paediatric oncologist, members of a young patient council at a public Swedish hospital, and the Ombudsman for Children in Sweden. The material was distributed via email and representatives could provide their thoughts in text via email or verbally during a virtual meeting.

Papers III-IV: National Patient Survey

Two studies using data from adolescent respondents in Sweden from the NORDeHEALTH 2022 Patient Survey [88], an online survey distributed in the national PAEHRs in Sweden, Norway, Finland, and Estonia. Paper III explored Swedish adolescent PAEHR users' reasons for reading their medical records, the link between HCP encouragement and EHR usage frequency, as well as perceived utility of information and functions. Paper IV examined adolescents' views on PAEHR security and privacy, experiences of non-consensual access, attitudes toward information-sharing, and views on what is sensitive information.

Design

Quantitative, cross-sectional studies using survey data. Reporting followed the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) [89]. Paper IV included a free-text question which added a qualitative element, however the question was analysed both qualitatively and by frequency.

Participants

Swedish survey respondents aged 15-19 years old were included (n=218). Convenience sampling was utilised [90]. Patients logging into *1177 journal* received a voluntary participation request and study information. No quotas were set for demographic characteristics, such as gender or age.

Data Collection

The survey was designed within the international research project NORDeHEALTH [88], and item selection was informed by prior research [7,22,91]. The Swedish version of the survey consisted of 45 questions (38 close-ended and 7 free-text), with various response options (5- and 7-point Likert scale, multiple choice, and free-text). Perceived usefulness of various functions was examined, most of which did not exist in *1177 journal*. Both Papers III and

IV included demographic data. Based on their respective study aims, Paper III included five questions and Paper IV included ten questions, as indicated in Figure 3. The survey, built using Webropol (Webropol Sverige AB), was available during three weeks in January to February 2022.

NORDeHEALTH 2022 PATIENT SURVEY

SOCIO-DEMOGRAPHIC INFORMATION

- ▲ 1. Gender
- ▲ 2. Age
- 3. Education
- 4. Healthcare education
- 5. Employment status
- 6. Region

EXPERIENCE WITH HEALTHCARE

- ▲ 7. Health status
- 8. Have you received any care in the last 2 years?
- 9. Have you read your health information from cancer care?
- 10. Have you read your health information from mental care?
- 11. Level of mental care
- 12. Length of mental care
- 13. Has your care been discussed at an MDT?
- 14. Were you invited to an MDT?
- 15. Free-text description of MDT experience
- 16. Do you have access to the MDT documentation?

EXPERIENCE WITH ORA THROUGH PATIENT PORTAL

- 17. Frequency of HR access in the last 12 months
- Please evaluate your experience with the portal:*
- 18. ... The system meets my needs.
- 19. ... Using the portal is a frustrating experience.
- 20. ... The portal is easy to use.
- 21. Have you had a very positive experience?
- 22. Free-text description of positive experience
- 23. Have you had a very negative experience?
- 24. Free-text description of negative experience
- 25. Did any of the following encourage you to read your HR?

REASONS FOR USING PATIENT PORTAL

- *I read my health record online:*
- 26. ... Out of general curiosity
- 27. ... To improve my understanding of my health issue
- 28. ... To prepare for a consultation or hospitalization
- 29. ... To get an overview of medical history / treatment
- 30. ... To be sure I understood what the HCP said
- 31. ... To remember care plan / follow recommendations
- 32. ... Because I suspect inaccuracies
- 33. ... To share documents with relatives
- 34. ... To share documents with friends
- 35. ... To share documents with HCPs without access
- 36. ... Because I'm not sure I got the right care
- 37. ... Other
- ▲ *Having access to my health record:*
- 38. ... Helps me trust my HCP more
- 39. ... Better communication between me and HCPs

ERRORS, OMISSIONS, & OFFENCE

- 40. Have you found anything in your HR that was wrong?
- 41. How important was the worst mistake to you?
- 42. Free-text description of the worst mistake
- 43. Have you found anything that was missing?
- 44. How serious was the most important omission?
- 45. Free-text description of the most important omission
- 46. How did you react to the mistake / omission?
- 47. How easy it is for you to notice mistakes in HR?
- 48. Have you ever been offended by something you read?
- 49. Free-text description of offence

SECURITY & PRIVACY

- ▲ *What is your opinion on information security and privacy?*
- 50. ... My HR generally maintains a high level of security
- 51. ... I trust only authorized HCP are accessing my HR
- 52. ... Patients should see who accessed their information
- 53. ... When I log in to the HR, I trust the log-in process
- 54. ... I have no privacy concerns with entering information in HR
- 55. ... I have no privacy concerns with copying my information from the HR to other online applications
- 56. ... I would like to manage who should have access to my HR
- ▲ 57. Frequency of copying information into HR
- ▲ 58. Experience with someone demanding access to your HR
- ▲ 59. Who demanded access?
- ▲ 60. Experience with unwanted access to HR
- ▲ 61. Who accessed your HR without your consent?
- ▲ 62. Do you consider some health information sensitive?
- ▲ 63. Free-text example of sensitive information

USEFULNESS OF PORTAL INFORMATION & FUNCTIONS

- *How useful would it be to have this information on the portal:*
- 64. ... Referrals
- 65. ... List of all pharmaceuticals / my medications
- 66. ... Overview of vaccinations
- 67. ... Test results
- 68. ... Clinical notes from primary care
- 69. ... Clinical notes from hospital care
- 70. ... Overview of all healthcare contacts
- *How useful would it be to have this function on the portal:*
- 71. ... Core/summary record
- 72. ... Access and manage children's information
- 73. ... Access and manage family members' information
- 74. ... See log data
- 75. ... Block clinical notes from some HCPs
- 76. ... Contact HCPs electronically and ask questions
- 77. ... Point out errors in the HR
- 78. ... Write text comments in the HR
- 79. ... Contribute with health information
- 80. ... Contribute with self-monitoring information
- 81. ... Contribute with expectations about healthcare visit
- 82. ... Order and manage certificates
- 83. ... Legal document
- 84. ... Other

HCP - healthcare professional, HR - health record,
MDT - multidisciplinary meeting, ORA - online records access

Figure 3. Survey questions and their inclusion in Paper III (marked with a green circle ●) and Paper IV (orange triangle ▲), adapted from [88].

Data Analysis

Only completed questionnaires were analysed. Aside from descriptive statistics used for calculating percentages for different response options, non-parametric 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 SPSS 28.0 version (IBM Corp) was used for all quantitative analyses.

Paper III

The Fischer's Exact Test was conducted to identify relationships between use frequency and encouragement to read. The use frequency response options *This is my first time* and *2–9 times* as well as *10–20 times* and *More than 20 times* were merged for analysis.

Paper IV

The Kruskal-Wallis Test was used to assess differences in ratings on security and privacy by health status. Free-text answers on information perceived as sensitive were examined in Microsoft Excel through content analysis, using an inductive approach [86]. For familiarisation with the data, responses were read thoroughly by the first and the second author. Next, the data were divided into smaller meaning units and grouped into potential themes by interpretation of patterns in the data. Themes were refined and reviewed to ensure accurate data reflection.

Papers V-VI: Mixed Methods

Design

Two convergent mixed-methods studies utilising online surveys and semi-structured interviews. The papers examined views, awareness, and perceived benefits and risks with respect to ORA regulations, where Paper V focused on Swedish adolescents with serious health issues and their parents, and Paper VI focused on Swedish paediatric oncology HCPs. The mixed-methods approach was based on a pragmatic worldview, determining that diverse types of data would provide a more complete understanding of the research problem [90]. Reporting followed the Consolidated criteria for reporting qualitative research (COREQ) checklist [92].

Participants

Recruitment of participants in qualitative research is intended to capture a sample that will help the researcher understand the problem at hand [90]. In Papers V and VI, criterion sampling was used [93], as participants needed to share a certain experience to be eligible.

Paper V

Included were adolescents aged 13-19 years old with serious health issues (n=31 surveyed, n=8 interviewed) and parents of adolescents aged 13 or older with serious health issues (n=57 surveyed, n=17 interviewed). Eligibility required prior access of the EHR and both parents of one child could partake. Study participants were recruited via study advertisements on patient organisations' social media and by HCPs during clinical visits at Uppsala University Hospital. Due to recruitment difficulties, additional methods were used, such as advertising in paediatric clinic waiting rooms and mailing former patients at the paediatric oncology clinic at Uppsala University Hospital. An initial focus on cancer was expanded in May 2023 to include any serious health issue.

Paper VI

Paediatric oncology HCPs were included (n=95 surveyed, n=13 interviewed). Those eligible: (1) were HCPs treating children and adolescents with cancer; and (2) had experience of documenting in the EHR. Recruitment occurred in person at Uppsala University Hospital and by mail-out at hospitals and clinics using contact lists.

Data Collection

Surveys were conducted allowing respondents to express interest in participation in an individual interview at the end. Those interested had to provide their contact information (phone number and/or e-mail address).

Surveys

The authors developed three survey instruments: one for adolescents, one for parents, and another for paediatric oncology HCPs. The selection of themes and items in Table 4 was informed by prior work on ORA [22,94]. Surveys consisted of 13 questions for adolescents, 14 for parents, and 18 for HCPs.

Table 4. Overview of surveys and included themes for each group.

Theme	Adolescents	Parents	Oncology HCPs
Age and parental consent	✓		
Diagnosis/child's diagnosis	✓	✓	
Work experience			✓
Experience of using <i>1177 journal</i>	✓	✓	
Views on age limits and access extension	✓	✓	✓
Awareness of age limits	✓		
Awareness/experience of access extension			✓
Impact of ORA on adolescents and parents	✓	✓	✓
Sociodemographic characteristics	✓	✓	✓
Interview participation	✓	✓	✓

Questions were optional, except for those pertaining to inclusion criteria, consent, and contact information. Recognising the value of involving patients in research [95,96], input from adolescents, parents, and paediatric oncology HCPs was gathered to revise the surveys.

The survey was mainly conducted online using REDCap (Vanderbilt). If recruited in clinics or at hospitals, participants could fill in the survey on paper, however, they were encouraged to fill in the survey online, which they could access by scanning a QR code on the paper survey.

Interviews

Survey respondents who had expressed interest in interview participation were contacted by the first author in the means that they preferred, thus via text message or e-mail. When contacted, participants received information about the study and were provided with options for date and time for an interview.

A semi-structured interview guide approach was adopted [93]. Interview guides were designed by the authors based on prior work on ORA and included similar themes as the surveys. Interviews were conducted via telephone or video-conferencing software, based on the participant's preference. Each interview began with the collection of demographic and clinical information (e.g., "how old are you" (adolescents, parents, and HCPs) and "when were you diagnosed" (adolescents)), followed by questions about their views and experiences [97] (e.g., "what is your opinion on the current regulatory framework" (HCPs), "how did you feel when you realised you no longer had access to your child's records" (parents)). Interviews were audio-recorded, and transcribed verbatim mainly by a professional transcriber (JH transcribed eight interviews). Interviews were performed until saturation was reached, that is when no new themes appeared to arise. Data were collected for Paper V between March 2022 and November 2023, and between February 2022 and April 2023 for Paper VI.

Data Analysis

Interview transcripts were imported into the data analysis software NVivo (v1.7.2) [98,99] and analysed by JH and MH using qualitative thematic analysis. An inductive approach was adopted due to the exploratory approach and aim to discover patterns, themes, and categories [97]. Coding categories were derived from raw data [98]. The analysis followed the six steps of Braun and Clarke [86]: First, the interview data were thoroughly read to achieve familiarisation. Next, data were aggregated into units of codes. Third, codes were categorised into themes. Fourth, themes were reviewed against the data. Themes were then refined and reviewed, and lastly written up along with the creation of a code book.

Ethical Considerations

All papers followed the principles of the Declaration of Helsinki [100].

Paper I was approved by the Swedish Ethical Review Authority (EPN 2023-02939-01). An ethical amendment was obtained on October 5, 2023 (EPN 2023-05735-02), as this was needed to acquire data from Inera. Ethical approval was not necessary in Finland to retrieve data from Kela. Paper II, being a literature review, did not require ethical approval as no sensitive information was collected.

The national survey used in Papers III and IV was approved by the Swedish Ethical Review Authority (EPN 2021/05229). Participants provided informed electronic consent before the appearance of survey items and there was no financial incentive. The survey was anonymous. Due to an ethical-legal requirement of parental consent for participants younger than 15 years old [101], which would complicate survey distribution, a decision was made to exclude those aged 13 and 14.

Papers V and VI were approved by the Swedish Ethical Review Authority (EPN 2021/05282). Three ethical amendments were obtained on March 4, 2022 (EPN 2022-00716-02), October 3, 2022 (EPN 2022-04589-02), and April 5, 2023 (EPN 2023-01541-02). The amendments were conducted due to difficulties in recruiting adolescents, and enabled additional participant recruitment methods and broader inclusion criteria. Materials were tailored to suit the targeted group. For example, study information for adolescents was designed to enhance understanding, with input from a PhD student specializing in ethics in paediatric healthcare research. Electronic consent was provided by submitting the survey and verbal consent was provided at the start of interviews. Age was mandatory for adolescents, and subsequent written parental consent for those aged 13 and 14. Based on the participant's preference, interviews were conducted via telephone or video-conferencing software. If selecting video-conferencing, the participant could choose not to turn on their video, for privacy reasons. At the start of each interview, the interviewer (JH) provided information about the conduct of the interview and the reasons for the research. The interviewer had no prior relationship with any of the study participants. There was no financial incentive for survey participants, however, interview participants received a gift card worth approximately 20 euros. Information about the incentive for interview participants was not included in the study advertisement on social media, but was provided in the study information and at the end of the survey. During manuscript writing, the authors carefully considered how to present participants' diagnoses in the sample characteristics while preserving anonymity. Due to the possibility for members of the same family to participate, there was a risk of participants identifying other family members [102].

Results

In this section, I will outline the key results from each paper in the thesis. First, relationship between the papers is described, as shown in Figure 4.

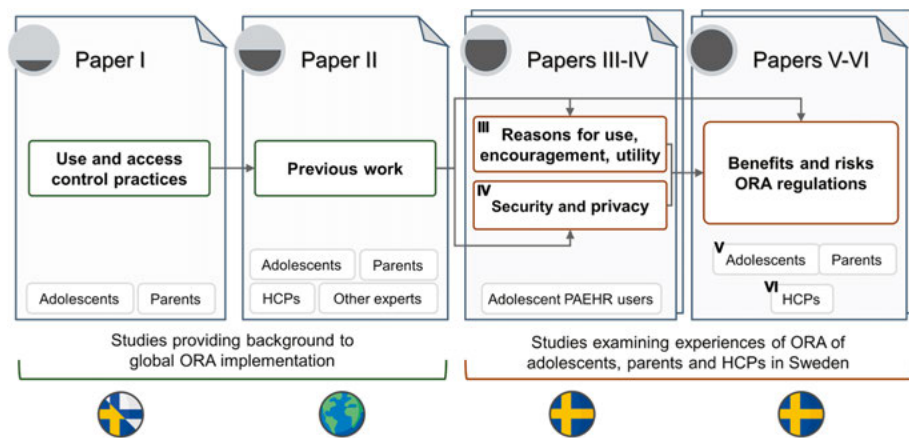


Figure 4. Relationship of the six papers in this thesis.

Paper I aimed to investigate usage of PAEHRs and access control practices among minors and guardians in Sweden and Finland, providing first insights into a real-world implementation. Findings from Paper I helped to contextualise the themes identified in the literature review conducted in Paper II, which synthesised themes of stakeholders' views, use, and experiences of EHR access for children, adolescents, and parents. Paper II revealed that few studies had focused on adolescents, and those that did involved mainly adolescents with chronic illness, many of whom had not accessed their PAEHRs. Also, most research had been US-based. These findings inspired the participant selection of Papers III and IV, which explored Swedish adolescent users' experiences with PAEHRs through an online survey. Additionally, Paper II informed the design of surveys and interview guides in Papers III-VI, ensuring that themes were relevant to adolescents, parents, and HCPs. Finally, Papers V and VI built on the findings from Papers III and IV, and used a mixed-methods approach to gather the perspectives of Swedish adolescents with serious health issues and their parents (Paper V), as well as of paediatric HCPs (Paper VI). These last two papers also examined views on ORA regulations, which had not been addressed in prior research.

Minor and Parental Use of National PAEHRs (Paper I)

The first research aim was to describe and compare minors' and guardians' access of the national PAEHRs and use of access control practices in Sweden and Finland. This aim led to the conduct of an observational case study [103].

Minors' and Guardians' Logins

Minors

In Sweden, adolescents gain own access by default at the age of 16. In 2022, more than half of Swedish minors logged into their records at age 16, as illustrated in Figure 5. In Finland, where there is no minimum access age, a somewhat larger proportion of peers accessed their records in the same year, and the increase by age 17 was almost 15% higher. The highest proportion of minors logging in occurred at 17 years old in both Sweden (60%) and Finland (85%). Minors' logins increased annually between the ages of 13-17 in both Sweden and Finland, with one exception: minors' logins to the Finnish PAEHR was higher in 2021 than 2022 for ages 16 and 17. A growing proportion of minors in Sweden and Finland accessed their records with age.

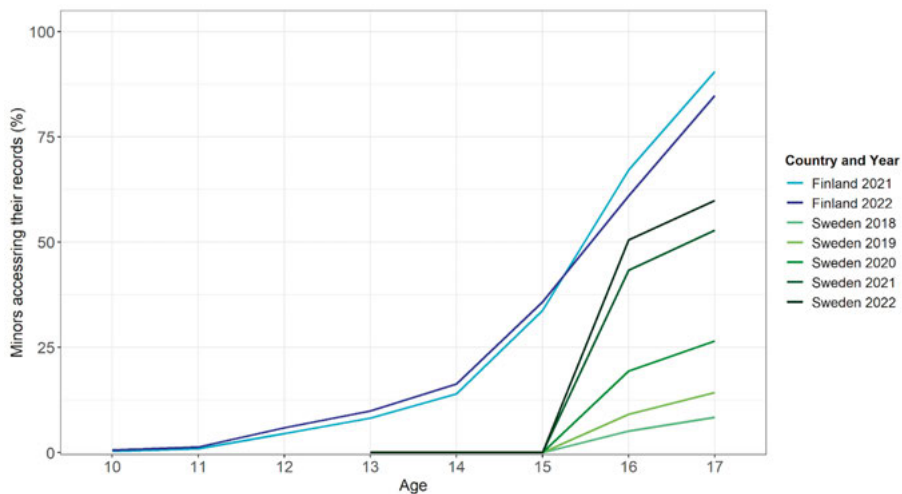


Figure 5. Proportions of minors (10-17 years old) logging into the PAEHR in Sweden (2018-2022) and in Finland (2021-2022).

Very small proportions of minors between 13-15 years old accessed their PAEHR in Sweden, since ORA was only possible by application prior to age 16. By comparison, about 10% of 13-year-olds and 36% of 15-year-olds in Finland accessed their PAEHR in 2022. 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%.

Guardians

In Sweden, parent users of *1177 journal* gain access to their child's EHR at birth by default and lose access when the child turns 13. As shown in Figure 6, Swedish guardians' logins have increased over time. The year of 2021 was the only exception to this trend, with a higher guardian proxy use for ages 6-12 than in 2022. The highest use was recorded for new born children for all years, followed by decreased use with the age of the minor until loss of access when the child turned 13 (19% for age 12 in 2022). Only small proportions of guardians of minors aged 13-15 years old were accessing the Swedish PAEHR (less than 1% per age and year). In Finland, around half of minors' records were accessed by a guardian during 2021 (54%) and 2022 (46%).

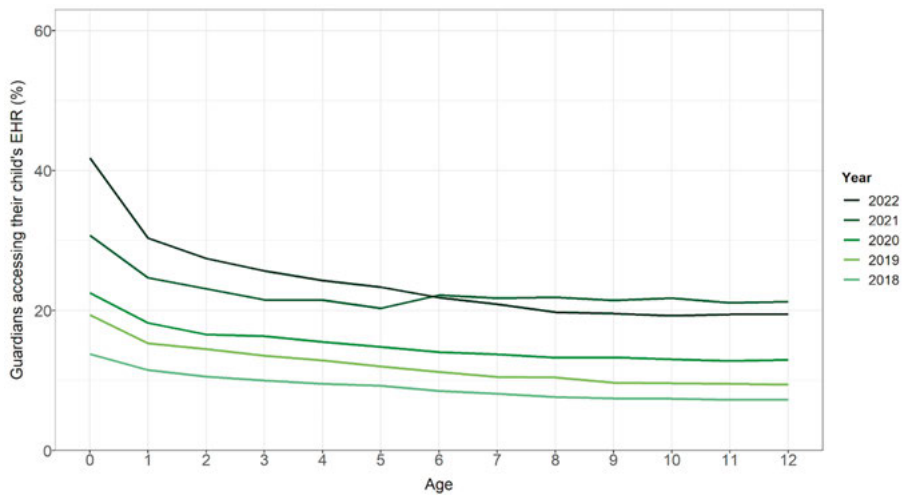


Figure 6. Proportions of guardians accessing their minors' records in the Swedish PAEHR between 2018 and 2022, sorted by year and minor's age.

Note: In Sweden, Covid-19 vaccinations were only given to children over 12 years. However, all age groups were tested and results were made available in the PAEHR in most regions.

Use of Access Control Practices

According to the framework in Sweden, neither parent nor adolescent has access to the child's records when an adolescent is between 13 and 15 years old. During this time, adolescents and parents can apply for access extension under special circumstances. As presented in Figure 7, applications for extended guardian access have been more common than minors' application for gaining early access to their own medical records. In three of five regions observed, there were almost no cases of applications for minor access. There was also interregional variety, where two regions showed higher numbers of minors' applications. In 2022, the highest total number of applications was found in Västernorrland, the region with the smallest population among those included.

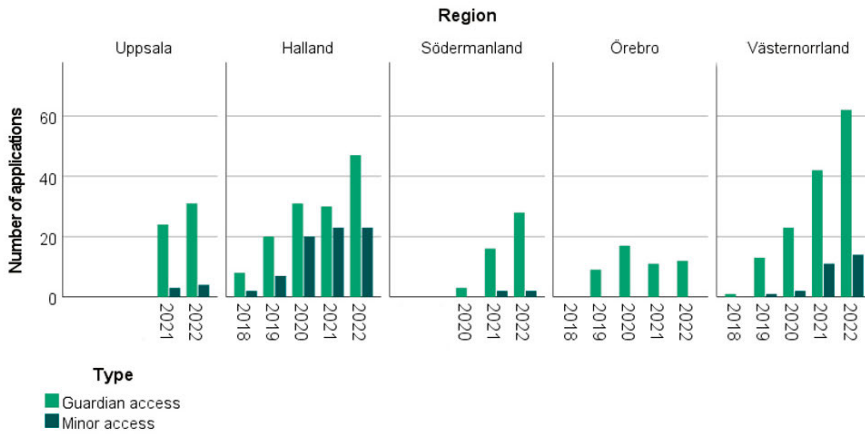


Figure 7. Number of applications for extended access for minors and guardians to the Swedish PAEHR in five regions in Sweden, between 2018-2022. Regions are ordered in population size, Uppsala being the biggest and Västernorrland the smallest.

In Finland, the HCP is to select one of four options for each care event or prescription based on their assessment the minor’s decision-making capacity (described under *Setting* within *Methods* for Paper I). In 2022, the most selected maturity assessment option was *Minor does not have decision-making capacity, and the event note is made accessible for parents*. A fifth of the assessments resulted in the decision-making capacity being considered as unknown. In cases where the minor is mature enough, the minor can consent to grant parental access. Nearly all (96%) minors assessed to have decision-making capacity permitted information disclosure to guardians.

Summary

More than half of adolescents aged 16 and 17 in both Sweden and Finland accessed the EHR, and PAEHR use was higher among adolescents in Finland, where there was no minimum access age. There were few applications for extended access in Sweden, with the majority concerning parental access. In Finland, most minors assessed to have decision-making capacity allowed disclosure of information to parents. This observational case study suggested that notable proportions of adolescents and parents in the Nordic countries were accessing the national PAEHR services. The findings, however, did not provide insight into minors’ and guardians’ perspectives on ORA, nor how HCPs perceive this practice and its impact on their work. Therefore, Paper II will explore the literature conducted to date, of stakeholders’ views, use, and experiences of minors’ and parents’ access to minors’ EHRs.

Stakeholder Views, Use and Experiences of ORA (Paper II)

The second aim, of identifying, categorising, and summarising stakeholders' views, use, and experiences of EHR access for children, adolescents, and parents, led to the conduct of a scoping literature review [94]. Since the publication of the sole previous review in 2016, a significant body of new research was expected to have been published in this rapidly evolving field.

Study Selection and Characteristics

The literature search resulted in 4,817 records, of which 4808 were retrieved via the database search and 9 were identified via other sources. After removing duplicates, 4,803 of the records were screened by title, abstracts, and keywords. In total, 4,693 of the records were excluded in this process, resulting in 110 full-text articles that were assessed for eligibility. Finally, 74 articles were included. The studies were mainly viewpoint papers or used quantitative methods, and 92% were based in the US. No studies from Sweden were found.

Perceived Benefits and Risks

Adolescents

Among the papers, a fifth focused on children and adolescents. Adolescents reported low knowledge about EHR functionality [25,104], in the US (aged 13-18) as well as in Australia (15-16), where adolescents have access to a national PAEHR from age 14. Adolescents who had not accessed their records expressed a strong interest in access [25,104–107] and a wish to receive information about EHRs from HCPs according to their future needs [25,106].

Several benefits were reported. For example, better recall was expected by adolescents who did not access their records [25,108]. Adolescents aged 13-17 with cancer and blood disorders reading their EHRs confirmed that ORA helped them remember information from visits, as well as provided the ability to ensure accuracy and ask informed questions, reduced anxiety, and enhanced illness knowledge [109]. They also anticipated that PAEHRs could support the transition from paediatric to adult care. Both adolescents with and without ORA experience foresaw empowerment [106,108,110], where one US high school senior with haemophilia using a patient portal suggested that the EHR could be jointly managed by themselves and their parents during the transition to adult care, yet added that views on parent management may depend on the adolescent's relationship with their parent [110]. A US study found that ORA led psychiatric patients' trust in their health provider to either increase or remain the same [111]. Studies in psychiatry [111] and gastroenterology [112] observed adequate literacy and high satisfaction among adolescent patients.

Adolescents imagined and reported fewer risks than benefits. Low medical literacy and parental non-consensual access was anticipated by adolescents without ORA [105,106]. However, adolescents aged 13-17 with cancer or a blood disorder with ORA experience expressed no concerns about what their parents would see in their EHR [109]. In a New York institute for primary and mental health care providing a patient portal where parental disclosure required minor's consent if older than 10 years, no complaints about confidentiality had been filed from adolescents since implementation [113].

Parents

Studies on parents comprised almost half, and was the largest group. Parents were predominantly positive about ORA; experienced benefits included better recall [3,114–116], improved parental knowledge and understanding of their child's health [117–120], a sense of control [117], enhanced communication and partnership with providers [44,115,117,118,121–123], error detection [109,118,121,123,124], and not having to bother HCPs for information [120–122]. Parents of children with cancer or chronic illnesses reported effects of reduced anxiety [44,120]. Parents of hospitalised children with and without experience of ORA stated that ORA can empower parents and improve their ability to advocate for their child [44,118,121,125,126]. One US study [109] found that ORA aided parents of teenagers with cancer would in acting as the intermediary in healthcare, as teenagers preferred to discuss their health with their parents rather than with HCPs.

Parents without ORA reported concerns about increased confusion, distress or anxiety [125], and information being released without face-to-face communication [125,127]. Consistent with this, parents with ORA mentioned encountering challenging medical jargon [114,120,126,127] and not being able to interpret complex results without context or explanation [121]. Another worry was that parental ORA could increase the workload and lead to complications [125,127], or restrict communication through the record between HCPs [127]. Both parents with and without experience of ORA worried about impairing the relationship with the provider [44,125], and in turn negatively impact collaboration [125]. Furthermore, parents were concerned that adolescents may not reveal sensitive information to HCPs if they know it will be visible to the parent [127].

When it came to adolescents accessing their own records, parents recognised that ORA could help the teen could take better control of their own care [106,120], and that ORA would be useful when transitioning to adult care, or to another care provider [109,127]. Some parents worried that teens may not understand all medical information [106], and that negative results immediately available to the teenager could cause anxiety [109]. They suggested that adolescents might use the portal inappropriately and need education [106,110]. Parents also had privacy concerns; that the portal might get hacked or that the teen would be pressured to share information [128].

Healthcare Professionals

Comparatively few studies (15%) focused on HCPs. HCPs without ORA experience predicted benefits from ORA including information reinforcement, improved parental knowledge and empowerment, enhanced parent communication and partnership with providers, and increased provider accountability and documentation quality [125]. Another anticipated benefit was that parents may help identify incorrect information [126], and that parents may be reassured of the care provided to their child. In a study of HCPs with experience of sharing access at a children's hospital in the US [116], almost all wanted patients and parents to continue to use the portal. In the study, patients and/or parents reportedly asked questions about information they read including laboratory results, medications, and errors/mistakes in their care. A study in Australia [129] found that staff appreciated enhanced communication with patients especially around coordinating appointments with parents. Moreover, US physicians recounted experiences of greater transparency, improved documentation, reassurance or validation of concerns, and enhanced care plan clarity [117].

The leading concern was maintaining patient confidentiality for children and adolescents [25,110,130,131]. Due to worries about parents accessing their adolescents' EHRs, HCPs reported precluding sharing information. They also described a lack of HCP familiarity with PAEHR utility and technical implementation among minors [25,110]. Given the fact that all HCPs involved in the child's care may not be aware of what information in the record is private from parents, versus what the parent needs to know, HCPs noted omitting or concealing information, and utilising codes on the EHR intended to alert other providers to confidential information [131]. Moreover, HCPs worried that parents would be confused by reading their child's notes [117]. In the US, concerns were raised about the increased workload as a result of the time spent updating parents, and a heightened risk of malpractice lawsuits resulting from parental access [126].

Other Stakeholders

The second largest group of the included studies was composed of other stakeholders' viewpoints (41%). Three types of stakeholders were identified: (1) experts such as HCPs, IT experts, or researchers; (2) policy-makers; and (3) the public. These papers focused mainly on concerns associated with ORA. Still, several papers posited that adolescent patients with chronic illnesses benefit the most from parents having ORA [28,132]. A potential advantage was anticipated from adding educational materials to the patient portal, which may facilitate literacy and comprehension for families [133–135].

Perceived risks were primarily related to confidentiality [135–145]. Gynaecological and psychiatric HCPs reported that adolescents may be less willing to seek health care if they are uncertain about confidentiality [143,144], and

most respondents in a public opinion survey [29] deemed adolescents less likely to discuss sensitive issues with HCPs when parents had access to their EHRs. Such concerns called for an option for HCPs to label information as confidential [28,132,137,144,146], an ability for adolescents to restrict parental access [141,147], and that the release of sensitive information to the parent should require the adolescent's consent [141]. Studies highlighted the possibility for the definition of "sensitive" to vary [132,142], and for any portal features to contain such information [144]. The need to protecting caregiver privacy was noted [136,137], and HCPs favoured customisable controls of information display for both parents and adolescents [28]. Some argued that portal access for adolescents should be limited until technical solutions for privacy protection are in place [28], while others asserted a lack of stakeholder investment in PAEHR development for this age group [148].

Several studies prompted considering family circumstances [49,149], and some raised concerns about the effect of pre-defined age limits for patient and parental access on families relying on EHR access in the care for a child [132]. Conversely, default ages may enable long-term consistency [49,132], allow for automated notifications, and facilitate policy making [49].

ORA education for various stakeholders was frequently advocated [146,147,150], for example, that early HCP-initiated conversations with parents and adolescents may reduce parental concerns, increase acceptance [49], and set clear expectations [30]. Obstetrician-gynaecologists have argued that adolescents need to be informed if parents will have access to the EHRs [145], and others stated that, when possible, parents should be informed of how to extend access to the child's EHR [151]. The risk of confidentiality issues from insurance claims was noted in US studies [141,145,146,150], especially when HCPs lacked information about information visibility in PAEHRs. Some noted a need of guidance for HCPs [28,30,54] and training graduate students [142], as well as for communication between staff and EHR vendors [132].

Summary

The literature review revealed that most research was US-based and no studies identified came from a Nordic country, including Sweden. Only a few studies had focused on adolescents, mainly involving those with chronic illness, many of whom had not accessed their PAEHRs. Moreover, a lack of knowledge about patient portals was observed among adolescents and little was known about adolescents who use patient portals, including their experiences of encouragement to read EHRs and their views on security and privacy. Confidentiality emerged as a concern among all groups with experience of ORA, except for adolescents. As a preliminary empirical investigation conducted in a Scandinavian setting, Papers III and IV examined perspectives on these topics among adolescent users of the national PAEHR in Sweden.

Adolescent Users' Experiences of the Swedish PAEHR (Papers III-IV)

Two aims of this thesis were related to the examination of Swedish adolescents' experiences of reading their EHRs. Paper III [152] explored reasons for reading EHRs, the link between HCP encouragement and EHR use frequency, as well as perceived usefulness of information and functions. Paper IV [153] investigated views on security and privacy, experiences of non-consensual access, attitudes to sharing information, and definitions of what is sensitive information. Papers III and IV used NORDeHEALTH survey data from adolescent respondents in Sweden.

Sample Characteristics

During the study period, 23,855 users opened the survey, and 15,867 (67%) started filling it out. Of these, 13,010 (82%) submitted the survey. Of 13,008 respondents who completed the survey, 218 were 15-19 years old (2%) and were included in Papers III and IV. Of the 218 participants, most identified as women while eleven (5%) selected their gender as "other". Two out of five had logged in 1-9 times and the remaining had logged in 10 times or more.

Encouragement to Read, Utility, and Reasons for Use (Paper III)

A majority of respondents reported that no one had encouraged them to read their EHRs online. By contrast, one fifth (22%) stated that they had been encouraged by a HCP, and such encouragement was related to higher frequency of use ($p=0.018$). Hence, those who reported higher use were more likely to have been encouraged by a HCP.

All information types were considered useful by more than three-fourths of participants. A majority (79%) of adolescents agreed that they valued the possibility of pointing out errors that they may find in the EHR. Still, only 18% suspected inaccuracies in the EHR. Although most functions were perceived as useful by most respondents, four functions were considered useful by less than half of respondents: *accessing information and managing services for children and for family members, contributing information about expectations for the healthcare visit and blocking specific clinical notes from certain HCPs/medical staff.*

The most common reason for reading the EHR was out of general curiosity. Three additional reasons were selected by more than half of respondents: *to get an overview of one's medical history and/or treatment, to ensure having understood what the physician or nurse said, and to improve one's understanding for one's health issue.*

Security, Privacy, and Sensitive Information (Paper IV)

Almost all adolescents reported trusting the log-in process. Most perceived the EHR to be secure, trusted that authorised medical staff were the only other individuals accessing the EHR, and agreed that patients should be able to see who had accessed their information. Two thirds indicated that ORA facilitated trust in healthcare and enhanced communication with HCPs. The vast majority reported no experience of anyone demanding access or accessing their EHRs non-consensually, or sharing health information on other online applications.

Overall, 78% agreed that patients should have the ability to view who had accessed their EHR, and the proportion of adolescents who expressed that they wanted to manage who has access to their EHRs was larger (41%) than that who did not (34%). Furthermore, those who reported better perceived health were more likely to want to desire the ability to manage who should access their EHR ($p = .009$). More than half of adolescent users (56%) perceived some health information to be sensitive. Based on free-text descriptions provided, four main categories emerged: *Mental health*, *miscellaneous*, *reproductive and sexual health*, and *non-responses* ($n=1$). *Mental health* was mentioned by 76% of adolescents and concerned for example self-harm and suicidality, neurodevelopmental disorder diagnoses, eating disorders, and depression. One-fourth of adolescents cited elements defined as *miscellaneous*, such as diagnoses, care related to crime or abuse, and weight. One in ten stated that sensitive information may differ depending on the individual. Lastly, one-fifth referred to *reproductive and sexual health* (e.g., gynaecological care, sexually transmitted diseases, and pregnancy).

Summary

Adolescent PAEHR users considered all included information types as highly useful. Those encouraged by HCPs to read their EHRs accessed it at a higher frequency, yet few reported receiving such encouragement. While most valued error rectification, few suspected inaccuracies. Most rated EHR security highly, still, more desired the ability to manage control to EHRs than did not. Perceived better health was related to wanting to control access to one's EHRs. Mental health was commonly seen as sensitive, but respondents also referred to sexual health and a variety of other issues, and indicated that definitions of what is sensitive information may depend on the individual. The primarily quantitative findings offered limited insight into adolescents' reasoning related to ORA, and the survey scope did not allow a focus on adolescents' and parents' perspectives regarding access age limits. To deepen our understanding, Papers V and VI applied a mixed-methods approach to study views and awareness of ORA regulations among adolescents, parents, and HCPs. As Paper II highlighted the unique benefits of ORA for families with complex healthcare needs, Papers V and VI focused on serious health issues.

Adolescent, Parent and HCP Views on ORA Regulation (Papers V-VI)

The aims of Papers V and VI were to explore the views, awareness, and perceived benefits and risks with respect to ORA regulations among adolescents with serious health issues, their parents, and paediatric oncology HCPs in Sweden. A mixed-methods approach was employed to meet these aims, using surveys and semi-structured interviews.

Sample Characteristics

Of 42 adolescents, 70 parents, and 124 HCPs who began responding to the survey, 31 (74%), 57 (81%), and 95 (77%) completed the survey and were included. Most participants were female among adolescents, parents, and HCPs. The recruitment flow is illustrated in Figure 8.

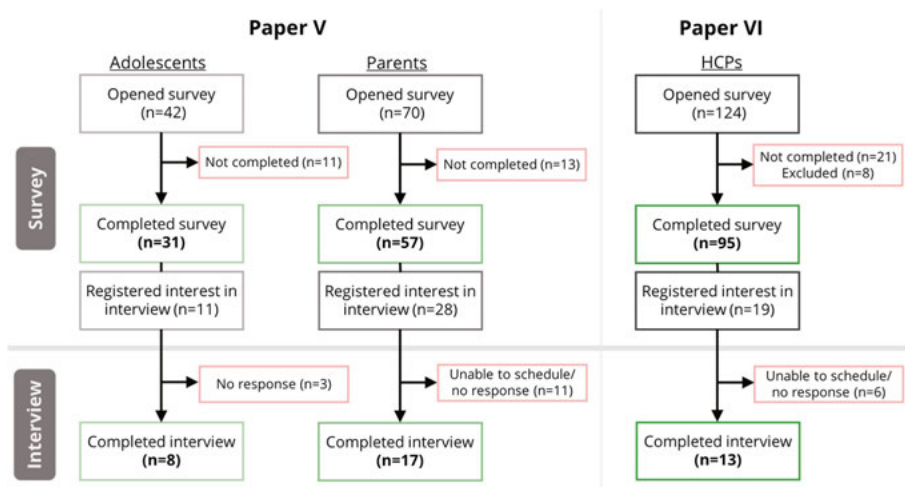


Figure 8. Recruitment flow of the studies in Papers V and VI.

Adolescents with Serious Health Issues and their Parents (Paper V)

Although most survey participants were women among both adolescents and parents, the gender distribution was more balanced among adolescents than parents. Most adolescents participating in the survey were 17 years old, with cancer as the most frequently reported diagnosis. Of adolescent interview participants, most were 18 and half were men.

Among parent survey participants, the majority had a child aged 13 years old and the most common child diagnosis was juvenile arthritis. Almost all parents had Swedish as their primary language (PL). Child age was higher among parents participating in an interview, at age 17. Demographic characteristics of interview participants are listed in Table 5.

Table 5. Demographic characteristics of adolescent and parent participants based on survey responses.

Characteristic	Adolescents			Parents		
	Interview (n=8)	No interview (n=23)	All (N=31)	Interview (n=17)	No interview (n=40)	All (N=57)
Gender, n (%)						
Man	4 (50)	9 (39)	13 (42)	3 (18)	6 (15)	9 (16)
Woman	4 (50)	11 (48)	15 (48)	13 (77)	34 (85)	47 (82)
Other	0 (0)	1 (4)	1 (3)	0 (0)	0 (0)	0 (0)
Don't know/don't want to state	0 (0)	2 (9)	2 (6)	0 (0)	0 (0)	0 (0)
Missing	0 (0)	0 (0)	0 (0)	1 (6)	0 (0)	1 (2)
Child age, n (%)						
13	1 (13)	1 (4)	2 (6)	1 (6)	17 (43)	18 (32)
14	0 (0)	0 (0)	0 (0)	3 (18)	9 (23)	12 (21)
15	2 (25)	4 (17)	6 (19)	5 (29)	5 (13)	10 (18)
16	1 (13)	4 (17)	5 (16)	0 (0)	2 (5)	2 (4)
17	0 (0)	10 (44)	10 (32)	8 (47)	5 (13)	13 (23)
18	3 (38)	4 (17)	7 (23)	0 (0)	1 (3)	1 (2)
19-25	1 (13)	0 (0)	1 (3)	0 (0)	1 (3)	1 (2)
Child's diagnosis, n (%)^a						
Juvenile arthritis	2 (25)	7 (30)	9 (29)	4 (24)	17 (43)	21 (37)
Cancer	2 (25)	9 (39)	11 (35)	9 (53)	10 (25)	19 (33)
Gastrointestinal diseases	2 (25)	3 (13)	5 (16)	0 (0)	5 (13)	5 (9)
Mental health	1 (13)	3 (13)	4 (13)	1 (6)	4 (10)	5 (9)
Diabetes	0 (0)	2 (8.7)	2 (6)	1 (6)	3 (8)	4 (7)
Other	3 (38)	1 (4)	1 (3)	3 (18)	8 (20)	11 (19)
Swedish proficiency, n (%)						
Primary language (PL)	-	-	-	13 (76)	40 (100)	53 (93)
Not PL, but advanced skills	-	-	-	3 (18)	0 (0)	3 (5)
Missing	-	-	-	1 (6)	0 (0)	1 (2)

^a Participants could select all that applied, so the total can exceed 100%.

Of the 31 adolescent and 57 parent survey respondents, 8 adolescents (26%) and 17 (30%) parents completed an interview. Interviews ranged between 13-38 minutes for adolescents and 24-55 minutes for parents. Five interviewed parents (29%) reported having a medical profession. Two were parents of the same child, and none had an adolescent partaking in the study. All interviewees rated their digital literacy as moderate or higher. Ten adolescent survey respondents and two interviewees reported not having read their EHRs.

Paediatric Oncology HCPs (Paper VI)

Most oncology HCPs responding to the survey were women, worked as nurses, and were aged 25-34 years old. Regarding profession, 17 selected *other*, citing for example physiotherapist and unit manager. Five identified as a paediatric or specialist nurse and were categorised under *Nurse*. Participants' demographic characteristics and work experience are listed in Table 6.

Table 6. Demographic characteristics of HCP participants based on survey responses.

Characteristic	HCP		
	Interview (n=13)	No interview (n=82)	All (N=95)
Gender, n (%)			
Man	3 (23.1)	8 (9.8)	11 (11.6)
Woman	10 (76.9)	74 (90.2)	84 (88.4)
Other	0 (0)	0 (0)	0 (0)
Age, n (%)			
18-24 years	1 (7.7)	5 (6.3)	6 (6.3)
25-34 years	3 (23.1)	23 (29.1)	26 (27.4)
35-44 years	2 (15.4)	19 (24.1)	21 (22.1)
45-54 years	5 (38.5)	12 (15.2)	17 (17.9)
55-64 years	1 (7.7)	20 (25.3)	21 (22.1)
65 years or older	1 (7.7)	0 (0)	1 (1.1)
Missing	0 (0)	3 (5.7)	3 (3.2)
Years of experience, n (%)			
One year or less	1 (7.7)	6 (7.3)	7 (7.4)
2-5 years	2 (15.4)	27 (32.9)	29 (30.5)
6-10 years	0 (0.0)	14 (17.1)	14 (14.7)
11-15 years	4 (30.8)	10 (12.2)	14 (14.7)
16-20 years	2 (15.4)	8 (9.8)	10 (10.5)
20 years or more	4 (30.8)	17 (20.7)	21 (22.1)
Missing	0 (0)	0 (0)	0 (0)
Profession, n (%)			
Physician	4 (30.8)	18 (22.0)	22 (23.2)
Nurse	8 (61.5)	53 (64.6)	61 (64.2)
Other	1 (7.7)	11 (13.4)	12 (12.6)

Of 95 HCPs who completed the survey, 19 (20%) agreed to partake in an individual interview. Subsequently, six participants did not partake in interviews due to scheduling difficulties or a lack of communication, leaving 13 (68%) interview participants. Interviews ranged between 20-79 minutes. Most HCPs who participated in interviews were women, with a mean age of 45 years old and 15 years of experience. While 43% of survey respondents had over 10 years of experience, this proportion was 77% among interview participants.

Perceived Benefits and Risks

Benefits

Six themes emerged in interviews relating to perceived **benefits** of ORA, as reported by adolescents, parents, and paediatric oncology HCPs: *Empowering adolescents*, *Improved emotional state*, *Enhanced documentation accuracy*, *Improved partnership and communication*, *Supported parental care management*, and *More prepared for appointments*. As shown in Table 7, the six themes of benefits were reported by all three groups.

Table 7. Themes of benefits reported by adolescents, parents, and paediatric oncology HCPs.

Theme	Adolescents	Parents	HCPs
<i>Empowering adolescents and parents</i>	x	x	x
<i>Improved emotional state</i>	x	x	x
<i>Enhanced documentation accuracy</i>	x	x	x
<i>Improved partnership and communication</i>	x	x	x
<i>Supported parental care management</i>	x	x	x
<i>More prepared for appointments</i>	x	x	x

Note: All themes were reported by more than 1 participant.

Empowering adolescents: Adolescents, parents, and HCPs stated that ORA enhanced adolescents’ and parents’ recall of visits, and allowed them to track the illness and better understand their care history. Adolescents valued being able to learn about care events they were too young to remember. All groups held that ORA allowed adolescents to reflect on their own and facilitated a gradual transition into adult healthcare. One adolescent commented:

It could be good to learn how to do things when you get older. When [your parents] might not be there. [13-year old male with cancer]

Parents and HCPs mentioned that ORA enabled adolescents to become more involved in their own care.

Improved emotional state: Adolescents and parents reported an increased feeling of control from gaining more knowledge and understanding about the child’s health condition. Also, a greater feeling of safety was related to having immediate access to test results. Consistent with this, HCPs reported that ORA appeared to reduce anxiety of worried parents, as illustrated by this comment:

It’s stressful for all parents even if they can read the EHR, but [without ORA] it becomes an increased stress because then they are on pins and needles, waiting for a doctor to call. [nurse with 22 years of experience]

One adolescent described it as fun and nostalgic to read notes from childhood. Some adolescents felt reassured by reading the EHR with parents, or simply knowing their parents had ORA. While one adolescent imagined that ORA provided parents with a feeling of safety, parents did not expect it to benefit adolescents emotionally.

Enhanced documentation accuracy: Adolescents with ORA experience and parents stated that ORA allowed them to ensure that the information was correct and that HCPs had understood them. One adolescent commented:

We always have a discussion during appointments and such. But they don’t write down word for word what we have said ... and sometimes there are misunderstandings, then it’s always good to be able to go back and check. [18-year old male with inflammatory bowel disease]

HCPs recognised that ORA enabled adolescents and parents to notify HCPs of inaccuracies or HCP misunderstandings that they identified in the EHR. Some pointed out that errors often resulted from parents misunderstanding the EHR, or HCPs misunderstanding the patient or parent.

Improved partnership and communication: Parents reported that access to test results alleviated the need to call the clinic. In line with parents' reports, HCPs observed that when parents lost access at the adolescent's age of 13, they began calling to request new test results and that nurses needed to print written information from clinical appointments. A small number of HCPs stated that while they saw potential in using the EHR to communicate test results to families, they were currently unable to know whether adolescents and parents would in fact see it. Another benefit noted by parents and HCPs was that ORA kept parents involved with the child's care even if unable to attend an appointment. Some parents remarked that EHRs provided more information than otherwise communicated, such as positive test results.

Adolescents and parents described that ORA improved communication by allowing them to read the EHR together at home, in preparation for visits or to debrief afterwards. This provided adolescents with the opportunity to ask parents questions in a safe environment, that they could convey to HCPs. Also, ORA offered something to focus on when talking together about the child's health, as noted by one parent:

You can sit together and reflect. Because otherwise it's somewhat difficult to just "now we're going to talk about this" ... and then they want to go on social media or something like that. Maybe you can have a little focus on this. [mother of 17-year old with juvenile arthritis]

Older adolescents indicated that their perceived need for parental EHR access had decreased over time, partly because of their increasing ability to independently communicate with HCPs. One nurse envisioned that reading results in their EHR would aid adolescents in their understanding of why treatment was needed and motivate them to attend appointments.

Supported parental care management: Participants of all groups reported that parental access to their child's EHR facilitated their management of medications and appointments, improved recall and enhanced understanding about the child's health issue. In addition, parents pointed out that ORA facilitated the handling of insurance errands. Insights into test results were especially beneficial; it helped parents predict upcoming hospitalisation, prepare their child mentally and emotionally, understand the child's true condition when they claimed to feel well to avoid going to the hospital, respond quickly to symptoms to prevent suffering, and motivate their child to take medications:

It has been good to track [test results], because then you can also tell [the child] that "you have to eat this vitamin because there is a deficit." It's not like I give her medication because it's fun. [mother of 14-year old with cancer]

HCPs noted that ORA alleviated the pressure on busy and worried parents to remember every detail from a visit, allowing them to better support their child and easing the burden on the child.

More prepared for appointments: Adolescents, parents, and HCPs reported that ORA facilitated preparing questions prior to appointments. Some parents described how ORA enabled preparations critical for their situation. For example, a mother of a 14-year old with cancer found ORA valuable as she was able to prepare her child for healthcare discussions, who, due to mild autism, struggled to process information during appointments.

Risks

Seven themes emerged in interviews relating to perceived **risks** of ORA, as reported by adolescents, parents, and paediatric oncology HCPs: *Emotional distress and confusion*, *Threat to confidentiality*, *Increased burden on adolescents and parents*, *Decreased documentation quality and accuracy*, *Increased HCP workload*, *Low usability*, and *Technical limitations*. The themes are displayed in Table 8. Adolescents and parents described similar risks, while three themes were almost exclusively cited by HCPs.

Table 8. Themes of risks reported by adolescents, parents, and paediatric oncology HCPs.

Theme	Adolescents	Parents	HCPs
<i>Emotional distress and confusion</i>	x	x	x
<i>Threat to confidentiality</i>	x	x	x
<i>Increased burden on adolescents and parents</i>	x	x	x
<i>Decreased documentation quality and accuracy</i>		/	x
<i>Increased HCP workload</i>		/	x
<i>Low usability</i>	/		
<i>Technical limitations</i>			x

Note: Themes reported by 1 participant are marked with / and themes reported by 1< are marked with x.

Emotional distress and confusion: Adolescents, parents and HCPs expressed the potential of increased worry among adolescents and parents from not understanding the EHR. Adolescents reported a downside of ORA in difficult medical jargon, potentially causing feelings of worry and frustration. Bad news communicated via the EHR before HCPs had the opportunity to explain it was a concern, particularly among parents and HCPs, as one parent put it:

One day it may pop up and boom, she has cancer everywhere and they can't do anything. And if you find out in her EHR, and the doctor hasn't called and explained. Then you get a little frustrated. [mother of 13-year old with cancer]

Still, most parents desired information in spite of the risks. A common idea was that while other parents may worry, they themselves were not ones to worry. Some HCPs observed that a minority of parents compulsively checked the EHR, which seemed to be a way to cope with a loss of control.

A few older adolescents reported that their close contact with HCPs reassured them that they would not receive bad news in the EHR without prior communication. Some adolescents and parents explained that their worry did not derive from accessing negative information in the record but from the development of the illness. Parents also expressed concern about their adolescents reading alone, whether it be abnormal or negative test results, or learning about difficult medical events from childhood. This led them to stress the need for a parent present to answer questions and provide explanations. This worry was echoed by one female adolescent, who recalled feeling down in the past from reading about earlier traumatic healthcare experiences.

There were some suggestions from oncology HCPs that sole adolescent ORA could lead to difficult family dynamics, as adolescents may withhold EHR information from parents to avoid causing worry. Also, one nurse stated that the brevity and simplistic nature of information in the EHR could alarm parents, who may be unaware of complexities of the clinical context behind it:

When [HCPs] present the results for examination or things like that, I sometimes think that parents don't understand that there have been many discussions, many involved parties with opinions who are experts in their fields who have said something. [nurse with 13 years of experience]

Threatened confidentiality: Adolescents, parents, and HCPs considered risks of sensitive information about the adolescent becoming visible to the parent or other individuals. This was the only concern that adolescents reported on the subject of parental access to their EHR. Several adolescents were vague about what that sensitive information might be, using terms such as “something one wants to hide”, or, as one adolescent described it:

If there's something I don't want them to know or something, they'll be able to see it, or they'll be able to see all the notes that you might feel... “They don't need to see this note.” [18-year old female with inflammatory bowel disease]

Meanwhile, parents commonly specified sensitive information healthcare related to mental or sexual health. Several HCPs stressed that difficulties related to confidentiality were more common outside oncology. However, they stated that adolescents with cancer might still have questions about sex and alcohol – topics that can affect or be affected by the treatment – which they prefer to keep private from their parents. One HCP described a difficult case where a divorced parent had read information in the child's EHR about the other parent, which concerned potential alcohol abuse, which had made them distrustful.

Adolescents, parents, and HCPs recognised that privacy may be a problem in some families where parents want to exercise control and may not focus on the child's best interest. All groups stated that hypothetically, when adolescents had access, parents may access their child's account by coercion. Parents and HCPs stressed that adolescents may conceal information or refrain from

seeking healthcare if worried about their parents accessing the EHR. Some HCPs recounted cases of controlling parents reading their adolescents' EHRs without consent, such as this physician:

Sometimes we have girls who have asked to have their EHR deleted because their parents force them to log in to 1177, while they stand next to them and read. [physician with 12 years of experience]

All groups, although only one adolescent, stated the risk of young adolescents sharing information with peers or on social media.

Increased burden on adolescents and parents: Adolescents (without ORA) and parents, and oncology HCPs reported that sole adolescent access could lead to an excessive burden for adolescents, who, especially when ill, wished to rely on their parents. One parent commented:

[The teen] might have to bear too much responsibility. [father of 15-year old with juvenile arthritis]

Oncology HCPs emphasised that when it came to serious illnesses, the responsibility is huge, especially in case of adverse health events. Inability to take responsibility could lead to no-shows for appointments and treatments. HCPs also mentioned the risk of increased burden on parents leading to high levels of stress. An additional issue was perceived in one party having to inform the other, and risk of conflict from not conveying important information, potentially leading to the question "why did you not tell me?".

Decreased documentation quality and accuracy: HCPs expressed a concern about documenting sensitive information about either the child or the parent, or hypotheses related to the illness. One parent recognised that HCPs may feel compelled to omit sensitive information from the EHR, which would be negative for children in the future. This concern was confirmed by some HCPs, reporting that omitted information would sometimes be communicated outside of the record, which was seen as a patient safety risk:

One has to omit important current information, instead we have to write on paper notes and try to convey important information between ourselves, which can mean a patient safety risk, that we can't write things down in the records as one would wish. [physician with 12 years of experience]

Several HCPs described a perceived need to be cautious when writing EHRs or delaying the release information to avoid worrying or upsetting parents, which could lead to misunderstandings and among HCPs and affect care.

Increased workload: A few parents speculated that ORA led to an increased workload on HCPs, such as that adolescents might send many messages via the patient portal. Otherwise, all reports about increased workload

came from HCPs, who pointed out primarily parents as generating more work. One physician remarked:

[Parents] receive news where we can't provide support in the same way, and we are noticing now, it creates a lot of extra work for us in healthcare when we have to take care of this anxiety afterwards. Or they call and ask what it means, what it indicates, and so on. [physician with 12 years of experience]

Some HCPs perceived that a few parents read the records compulsively, even during visits, which disrupted the work environment. Although understanding this behaviour and underlining that it was not very common, HCPs found it stressful. One HCP mentioned the risk of aggression or violence from frustrated parents, considering that HCPs' names were visible in the EHR.

Low usability: One adolescent commented that the portal was difficult to navigate and some headings were unclear, causing them to spend more time searching for the desired information.

Technical limitations: Some HCPs perceived the available hidden search words to not sufficiently cover the topics that cause a need for concealment. Furthermore, they reported that differences in information availability between regions created inequality among patients.

Views on and Awareness of ORA Regulations

Survey Findings on Stakeholder Views of ORA Regulations

Nearly all adolescents reported a desire to access their EHRs. Low knowledge about the access age limit was observed: only around a third knew that the access age limit was 16 years old, and almost as many guessed the age of 13. Of those aged 16 or older, 40% reported lacking access to their EHR despite this being the default. Two-thirds wanted their parents to access their EHR after they had turned 13 years old, as shown in Figure 9. A larger proportion of parents (69%), compared to half of adolescents, agreed that 16 is an appropriate age to gain ORA. Few parents and HCPs agreed that the gap in ORA for parents and adolescents between the ages of 13 to 15 was a good thing. A higher percentage of parents (94%) than HCPs (74%) were positive about the possibility of parents applying for extended access for parents beyond the default, however, a lower percentage of parents than HCPs supported adolescents' earlier access. While over half of HCPs considered parental ORA useful for their work, responses diverged concerning the utility of adolescents' ORA.

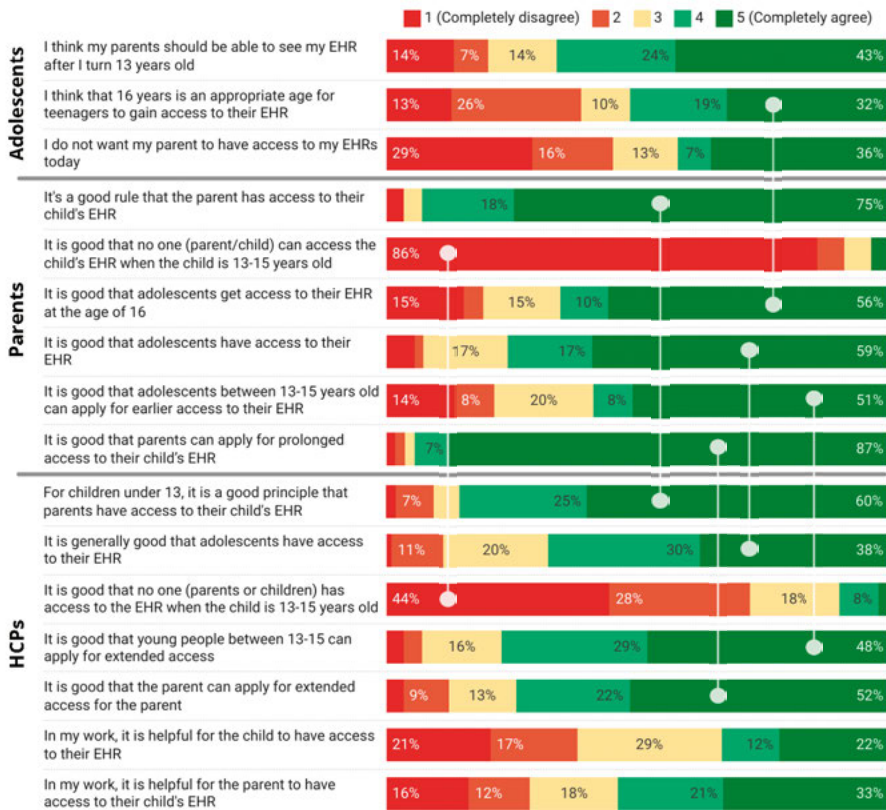


Figure 9. Ratings on statements related to ORA and current regulations.

Survey Findings on HCPs' Awareness of Extended Access

Three out of five HCPs knew that parents can apply for extended access, and a similar number did not know the procedure of application. Even fewer HCPs – only a fifth – knew that adolescents were able to apply for earlier access. Of these, two thirds did not know the procedure for applying. Almost half of respondents who were aware of the possibility to apply for access extension did not know whether they were authorised to approve such applications.

Interview Findings on Stakeholder Perspectives of ORA Regulations

Four themes emerged relating to adolescents', parents', and oncology HCPs' views on ORA regulations: *Lack of knowledge*, *Challenges of the access gap*, *Balancing adolescent privacy and parental support*, and *Regulatory change*.

Lack of knowledge: Adolescents, parents, and oncology HCPs reported a lack of knowledge related to various components of ORA. One 13-year old adolescent mentioned that he did not know much about the content of *1177 journal*, as his parents primarily managed his care. In contrast, several parents reported that despite notifications, they did not know that they would lose access when the child turned 13, believing that HCPs would ensure continued

ORA given their situation. Most HCPs perceived that parents were confused and shocked upon losing access to their child's records at age 13. Additionally, HCPs reported being largely unaware about information availability to adolescents and parents, and their subsequent use of ORA. One HCP asserted a widespread lack of information in healthcare:

I think the parents are quite aware [they will lose their access]. However, the healthcare system does not always know about it. They have no idea that parents do not have access to the health record. [nurse with 22 years of experience]

Another HCP described how, at their institution, young patients began missing appointments because no one knew notifications were sent via the portal to adolescents starting at age 16. It took some time for HCPs to realise the cause of this issue. All groups displayed a lack of knowledge about the possibility of access extensions (especially adolescents' ability to apply for earlier access) and the application procedure. On this issue, one adolescent stated:

I found out just a month ago from someone at a primary care clinic, that you have to order it and then you'll get it on paper... but, that you can get earlier [digital] access or so, I haven't heard anything about. And it's probably because even when you ask your physician at the clinic, they don't know either. [15-year old female with asthma, allergies, and mental health issues]

Challenges of the access gap: Particularly, parents expressed frustration and desperation the gap in access their access, yet some adolescents voiced similar concerns. Losing access made it difficult for parents to track their child's illness as they were unable to check test results, manage appointments, or view medications that needed refills. Instead, they had to travel to the pharmacy for medications and call HCPs for test results during specific time frames, which created a sense of burden on the healthcare system. Oncology HCPs expressed concern over the access gap for adolescents aged 13-15 and their parents, noting that parents need to call in for test results and struggle to keep track of what is going on. In addition, HCPs reported confusion around the regulation:

It's also very strange because then you think, what is it between 13 and 16 that makes it sacred so that no one can access it? Because I mean, if you have a child who gets sick at 12 years and 9 months, then the parents will still want to have an understanding of what's going on. [nurse with 13 years of experience]

The possibility of applying for extended access offered little relief, since most adolescents and parents who had applied described the process as cumbersome: identifying the right form; each unit required a separate application; long waiting times; and parents needed to frequently bring up the issue to HCPs, who often lacked knowledge. As a result, one adolescent, several parents and one HCP (with personal experience of applying) reported giving up

on their applications, with one parent waiting two years for a signature. While most HCPs had not received an application, nearly all who had found the application procedure as challenging, particularly as parents of children with cancer live in a chaos. A few HCPs without experience of receiving such applications noted that the process of applying appeared straightforward.

Balancing adolescent privacy and parental support: Adolescents, parents, and oncology HCPs perceived that needs for adolescent and parental ORA depended on adolescents' maturity and interest, which may not correlate with age. Oncology HCPs described that seriously ill adolescents "tend to regress" during the illness period and rely on parental support, regardless of age. Advocacy for early adolescent ORA was often related to individual rights and the ability to participate in their own care, valuing the opportunity for interested and mature adolescents to engage in their own care before reaching adulthood.

I think maybe you can have access slightly earlier, so that you can like, understand a little bit. [16-year old male with cancer]

Those in favour of the 16-year age limit for adolescent ORA cited a reduced capacity of younger adolescents to manage one's care and their need of parental support. Some parents and HCPs were hesitant about early adolescent ORA as they saw it as a burden for adolescents or perceiving some information in the EHR as harmful, which led several parents to suggest that adolescents should have a parent present when reading the records. One parent stated:

I probably wouldn't have wanted [adolescents'] access that early. There is a conflict, I'm thinking, with the child's right to know and at the same time, whether a child is emotionally equipped to see serious illnesses or prognoses, and take in the information. [father of 15-year old with juvenile arthritis]

Parental access after age 13 was endorsed by most adolescents and almost all parents, viewing it as a necessity in case of serious health issues. Some HCPs worried about infringements on the privacy of adolescents with cancer, given parents' (understandable) interest in their health. Those positive to parents losing access at age 13 focused on needs for adolescent privacy. Most parents recognised the need to conceal sensitive information, yet stressed their rights. Most adolescents did not feel the need to conceal information from their parents, due to an open relationship and parents' prior involvement in their care. Still, some preferred to keep non-treatment information private. While it was stated that any information can be sensitive, some referred to alcohol use:

[By age 15], things start coming up, like, I talk a lot with the doctors about alcohol. I don't know how alcohol affects my medications, and I've had kidney failure, you know, so I've thought it's always good to discuss it with the doctors. And it's not something I want my parents to find out about. [18-year old male with inflammatory bowel disease]

Some HCPs argued that it did not matter whether adolescents had sole access because parents could easily ask the adolescent to log in for them to read. This view was confirmed by a few parents, one asserting that the only benefit of adolescent access was that they logged in for them. One parent stated:

Any protection designed for a child, so that parents or guardians can't read it, is easy for a parent to bypass. So, it only creates a false sense of security. [father of 15-year old with juvenile arthritis]

Participants of all groups noted the potential harm of ORA to some children and adolescents, in cases involving controlling parents or honour-based contexts, both related to parents' access and adolescents, as the parent might access the adolescent's EHR by coercion.

Regulatory change: Adolescents, parents and oncology HCPs provided suggestions for regulatory change. For example, they suggested removing the existing access gap between the ages 13-15 by finding a middle ground in between. Some parents stated that it customises disclosure of sensitive information should be enabled on adolescents' preferences or via technological tagging. Some HCPs were sceptical of ORA regulations based on pre-defined age limits, considering the significance of life events for ORA needs. One HCP mentioned that separate records for HCPs and adolescents/parents may prevent issues related to documentation. All three groups suggested increased education for adolescents, parents, and HCPs about the possibility to extend access and how to apply, and to facilitate the procedure by digitising the application and enabling a combined application to all relevant units. HCPs argued that extended access should require renewals every six months or annually, and that the child should be consulted in this process.

Summary

Adolescents with serious health issues, their parents and oncology HCPs were critical to ORA regulations preventing access to minors' EHRs for adolescents and parents during adolescence. Adolescents who had ORA valued it, yet many lacked awareness about ORA regulations. Some adolescents preferred longer parental ORA yet some adolescents held a desire for privacy, preferences that were not solely dependent on age. Most parents had concerns about early adolescent ORA and advocated for longer parental access, especially for children with serious health issues. Oncology HCPs recognised the inconveniences for families of adolescents with cancer, but perceived risks related to overcautious documentation and its potential implications for EHR quality and patient care. Awareness about options to extend access was generally low.

Discussion

With the thesis aim of exploring experiences of online access to minors' EHRs, the results expanded our knowledge about ORA for minors and parents in several ways. Previously unexplored areas include the Swedish context, use of access control practices, and stakeholder awareness and views on ORA regulations. In this section, I will first discuss the results based on biomedical ethical principles, then address implications for practice and the methods used. Main findings are presented in Figure 10.



Figure 10. An overview of the main findings of the six studies in the thesis.

Ethical Analysis

The discussion builds on classic biomedical ethical principles suggested by Beauchamp and Childress [1]. In the case of patient portals, the paediatric population has been identified as a particularly vulnerable group requiring unique legal and ethical considerations [56]. For example, proxy access (i.e., where one individual is provided access to the EHR of another) leads to confidentiality concerns. Furthermore, the adolescent's developing nature brings about questions pertaining to adolescent autonomy and nonmaleficence. In Paper II, these aspects emerged as key tenets in the debate on paediatric ORA. *Justice* and *truthfulness* were excluded, leaving thesis to focus on the principles of *autonomy*, *nonmaleficence*, *beneficence*, and *confidentiality* in relation to minor and parental ORA. Based on the findings from Papers II-VI, I have identified issues related to each ethical principle, as depicted in Figure 11.

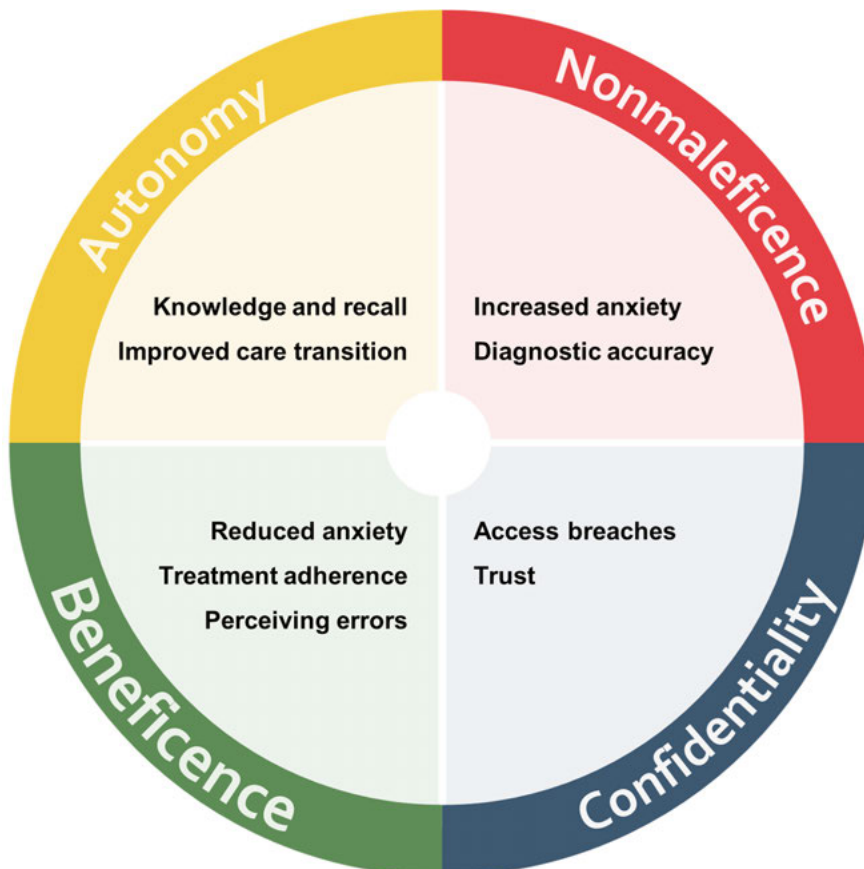


Figure 11. Issues categorised by biomedical ethical principles in relation to ORA in paediatric contexts.

Autonomy

By assisting with increased understanding, knowledge and recall, as well as support of the transition between adolescent and adult care, ORA may enhance child and parental capacity to make informed decisions about medical care. However, such positive impact on autonomy requires that certain conditions like improved understanding of medical information are met.

Knowledge and recall

The findings of this thesis indicated that ORA provides minors and parents with improved recall and knowledge, which may strengthen the individual's capacity to make informed decisions about their own care. As expressed by Swedish adolescents with serious health issues and their parents in Paper V, reading clinical notes and tracking test results enhanced their understanding about the adolescent's health condition. A US observational study found that viewing test results was the most frequently accessed feature among young patients and caregivers [154]. In Paper III, adolescents in Sweden rated all information types highly, and common reasons for accessing the PAEHR included gaining an overview of their medical history and ensuring understanding of what the HCP said. Parents of adolescents with serious health issues interviewed in Paper V reported feeling better equipped in guiding their child and teaching them about their illness. These findings on adolescents' and parents' views support previous US work on adolescents with cancer and blood disorder and their parents [109], as identified in Paper II.

While both adolescents and parents report several benefits from increased knowledge about the adolescent's health, opportunities for increasing adolescent autonomy may be hampered by a lack of interest and capacity among adolescents to read and understand EHRs. Evidence varies on adolescents' interest in patient portals [104,155], and according to Swedish oncology HCPs (Paper VI), interest may depend on type of health issue, where adolescents with chronic conditions such as diabetes may benefit the most from tracking their health. In gastroenterological and psychiatric care, adolescents have showed adequate understanding of parts of the EHR [111,112]. However, in a US study, medical jargon and not feeling like the target group of patient portals was identified as a barrier to adolescent portal use [155].

A risk of assumed autonomy – the idea that the adolescent has the capacity to understand their EHRs and manage their own care – is a mounting responsibility it creates, as has been stated by Stineman [156]: “In broad terms the adult seeks care, the child receives care. The developmentally immature adult in the adult system of care is a victim since he or she is assumed autonomous”. Adolescents, parents, and HCPs in Papers V and VI echoed this concern, stating that ORA might place an excessive burden on adolescents, especially for those battling serious illnesses.

While existing work indicates adequate comprehension among some adolescent patient groups, findings call for further investigation of minors' and parents' understanding of EHRs and minors' interest in accessing patient portals. A Dutch study using validated measures found that adolescents and parents reported increased autonomy from using a specifically designed patient portal [157], yet another found that adults did not report higher autonomy [158], warranting more research using objective outcome measures.

Improved care transition

Access to information about their past and ongoing care may deepen adolescents' understanding for their health and engage them in managing their care as they prepare for adulthood. In the findings of Paper V, adolescents with serious health issues from early childhood noted benefits in being able to go back and learn about experiences they could not remember. Adolescents, parents and HCPs (Papers V-VI) anticipated that ORA would aid adolescents seek future care and support their transition into adult patienthood. This finding was supported by a US study with adolescents with cancer and blood disorder and their parents [109] (Paper II). This potential benefit is underlined by a US study in which adolescents with chronic illness expressed concern about having to bringing the new team "up to speed" on their medical history when transitioning to adult care [159]. The study also revealed that some adolescents felt that their parents are unwilling to "let go" of their caregiving role, after being so involved for a long time.

Observational findings from the case study of adolescents' patient portal use (Paper I) may indicate a potential in ORA in facilitating the care transition from adolescent to adult care. Usage was highest during late adolescence in both countries [103], which aligns with US studies [154]. While most 16-year olds in both Sweden and Finland had accessed the national PAEHR, higher use during late adolescence was shown in Finland, where there is no minimum access age for minors. While other factors like HCP encouragement may be at play, it is possible that early access supports increased use during late adolescence. Furthermore, in an interview study from the US where transition was expected to occur at age 21, adolescents with chronic illness transitioning to adult care suggested that starting the transition process at an earlier age, such as 15 or 16, would be beneficial [159].

So far, preliminary empirical research in this thesis and prior studies indicate an anticipation among stakeholders in that adolescents' transition to adulthood can be supported by reading their EHRs. In this way, ORA could contribute to augmenting developing autonomy. In a systematic review of randomised controlled trials (RCTs) exploring the effect of a transition intervention on the transfer from paediatric to adult care, no study included ORA as part of the intervention [160]. Thus, more research is needed to clarify how the transition is supported and the contexts in which it occurs.

Nonmaleficence

HCPs have a duty to ‘first, do no harm’ [1]. Since harm caused by information is sometimes used as an argument to justify limited disclosure, it is important to analyse whether ORA poses a risk of harm to adolescents and parents. Some possible varieties of harm that may arise from ORA include increased distress and decreased diagnostic accuracy.

Increased Anxiety

Health anxiety is the excessive worry about one’s symptoms or the risk of developing a serious illness. Given their underdeveloped executive functioning [161], higher levels of doubt and low self-esteem [40], and potentially lacking health literacy, adolescents may be more susceptible to health anxiety. In Paper V, parents expressed concern related to adolescents with ORA not being able to understand or cope with the information in the EHR without a parent being present, especially given the severity of their child’s health issues. Such concerns may lead to a preference for the *Parent Orientation* model, where only the parent has ORA [45]. Similarly, HCPs in Paper VI worried that ORA could lead to heightened anxiety among adolescents and parents, particularly due to immediate access to worrisome or confusing information, without a face-to-face explanation from a HCP. These findings align with prior work on parents and HCPs (Paper II) [117,126], and evoke an analogy drawn between the traditionally paternalistic HCP-patient relationship and dynamics of parent-child interaction. Like parents, HCPs have superior knowledge and are given authority to determine their subordinate’s best interest, based on the assumption that they will act with beneficence. Paternalism has been described as “hard beneficence”, where the HCP has been likened to “a loving parent with dependent and often fearful and ignorant children” [162]. Out of concern and a desire to prevent potential distress from ORA, some parents and HCPs advocate for information nondisclosure. This may be seen as a case of epistemic injustice, where adolescents and parents are denied information, potentially hampering their autonomy, reducing their involvement in care, and limiting their ability to partake in decision-making.

Concerns around adult ORA and resulting HCP reluctance are particularly pronounced in mental health, where patients may be increasingly susceptible to anxiety from reading EHRs. This issue may be especially relevant to consider for the adolescent population, given the growing prevalence of mental health issues among young people [35,36]. The severity of mental health issues among adolescents is notable, with increasing rates of self-harm observed in Norway [37] and Asia [38], underlining the need to consider the implications of ORA for this population. Overall, more studies are needed to explore minor patients’ and parents’ experiences of distress and anxiety from accessing the minor patients’ EHRs. It remains to be understood whether the potential for patient anxiety from reading EHRs might be reduced by increased

empathy of language used in the EHR, for example using tools powered by generative artificial intelligence (AI) and large language models (LLM) [163]. These tools have been found to have particular strengths in offering cues and signatures of empathy in documentation [164].

Diagnostic Accuracy

As found in Paper II, HCPs hold a concern about a decreased EHR quality when minors and parents have access to notes. Partly, there is a worry that minors and parents may be deterred from being completely honest with HCPs (parents share the same worry about adolescents). Moreover, HCPs without ORA experience anticipated hesitancy to chart sensitive or potentially worrying information [125,126]. Consistent with these findings, oncology HCPs in Paper VI reported a need for cautious documentation, sometimes communicating externally from the EHR and omitting information. This also accords with a prior study where HCPs described using personal codes to document sensitive information about minors [131]. There are several potential negative consequences from missing or incomplete data in EHRs (e.g., misdiagnosis, poor quality of care, and erroneous research findings), especially in the light of increasing use of AI to analyse patient data.

These findings indicate that ORA may limit HCPs' ability to fully document sensitive information about children in the EHR, out of concern for causing confusion, emotional distress, or damaged relationships between patient, parents, and HCPs. Such concerns may decrease the clinical accuracy of notes and compromise HCP autonomy. The original function of clinical documentation was to serve as an aide-mémoire and communication tool among HCPs, and it is unknown whether parental or minor ORA may devalue the utility of documentation for HCPs. Further research might therefore aim to investigate whether ORA in paediatric settings objectively interferes with records and diagnostic reasoning. Measuring the rate of diagnostic error in paediatric settings is challenging; however, use of patient surveys, retrospective case reviews, and clinical outcome measures could help examine rates of diagnostic accuracy following ORA [165–167].

Beneficence

HCPs have an obligation to promote beneficial health outcomes and wellbeing of patients [1]. The main perceived benefits of ORA on adolescent patients' and parents' wellbeing found in this thesis include reduced anxiety, increased treatment adherence, and error rectification.

Reduced Anxiety

A benefit from ORA reported by adolescents with serious health issues and their parents in Paper V was an increased sense of control. Reduced anxiety was often related to access to laboratory test results, potentially by decreasing

the risk of “scanxiety” – the anxiety associated with waiting for test results [168]. This corroborates prior US findings described in Paper II [109,155]. Oncology HCPs in Paper VI imagined that parents (not adolescents) would experience more control from ORA, which supports earlier work [117,126]. Future research is essential to develop a full picture of the impact, both positive and negative, of ORA on minors’ and parents’ emotional experiences, specifically among minors with serious health issues. The risk of increased anxiety from receiving bad news without face-to-face communication has been described under *Nonmaleficence*.

Treatment Adherence

ORA has potential to improve treatment adherence and increasing compliance with HCP recommendations by for example facilitating appointment reviewing and medication management. Adolescents in Paper V did not express that their own ORA led to benefits related to treatment adherence. However, survey findings from Paper III indicated that around half of adolescents read their EHRs to remember the care plan or to follow the treatment recommendations. Also, in a US interview study published after the publication of the scoping review, adolescents with chronic illness using a patient portal described that reading their EHRs reinforced the importance of taking medications and following HCPs’ recommendations, and enabled scheduling appointments around social activities [155] (Paper II). One Swedish oncology HCP in Paper VI speculated that ORA may increase adolescents’ understanding of why medical procedures were necessary, which may increase compliance. In the US, a psychiatry provider working in an adolescent inpatient setting reported that clinical note sharing helped inpatient counselling sessions and compliance for 8 of 20 patients aged 12 or older [111]. By contrast, a case was described where notifications were sent to adolescents who had gained access to their EHRs without being aware of it, which instead led to missed appointments. Further investigation is needed to explore the factors that affect adolescents’ readiness to manage their own care independently.

Adolescents and parents in Paper V agreed that appointment scheduling and medication management on the patient portal helped parents to manage their child’s care. This is in line with prior observational [45,154,169], qualitative [106], and quantitative survey [115] research conducted in the US (Paper II). US paediatric oncology HCPs have stated that parental ORA can contribute to compliance and reduce no-shows [170].

Only limited research suggests that ORA for minors and parents may contribute positively to beneficence by enhancing treatment adherence. Although observational studies have found appointment and medication management as highly used features among adolescents and parents, effects on treatment adherence and appointment attendance have not been studied. Thus, future studies are needed to ascertain whether and how ORA minor patients’ adherence to treatment and medication, as well as in attending appointments.

Perceiving Errors

All types of EHR information (clinical notes, test results, diagnoses, etc.) can hold errors that may lead to safety hazards, such as medication errors, delays, or missed diagnoses. In a survey study on general practitioners in England, 60% believed that most patients would find significant errors in their EHR [171]. Providing patients with ORA might facilitate identification and rectification of errors, thereby preventing possible harms that may result. In a US study identified in the scoping review [109] (Paper II), adolescents with cancer and blood disorder and parents reported reading the EHR to check its accuracy, which was mirrored in Paper III, where almost four of five adolescents valued the ability to point out errors. However, only one of five suspected inaccuracies. In a study that is not included in this thesis [172], I presented additional findings from the NORDeHEALTH survey on Swedish adolescents' error identification, where one fourth reported having found an error. Of these, less than a third perceived the error to be very serious and a majority reported not notifying anyone of the error. Adolescents may hesitate to notify HCPs of errors or omissions directly, due to fear of repercussions [124] or because of a preference for reporting adverse events via electronic media (there is currently no easy way to report errors in *1177 journal*), as stated by a focus group study with adolescent patients based in the US [173].

It should be noted that the clinical relevance of patient-reported errors remains unknown, as these errors could, for example, pertain to more trivial mistakes including spelling mistakes or have little clinical importance. Further research should examine experiences of error identification from ORA among minors and parents and incorporate an assessment of the errors' clinical significance. In Paper V, parents of adolescents with serious health issues attributed ORA to the ability to prevent misunderstandings related to sensitive types of care, that could cause embarrassment for the adolescent, such as related to sexual health or gender identity. Given adolescents' sensitivity to these topics, preventing such misunderstanding may be vital in maintaining adolescents' trust in healthcare.

Confidentiality and the Patient-HCP Relationship

A trusting relationship between the adolescent and HCP is essential to foster open communication regarding health issues, which by consequence facilitates effective care. The relationship between parent and HCP is also important as such partnership can contribute to improved adolescent health [43]. The main issues related to paediatric ORA identified in this thesis concerned the risk of access breaches and impact of ORA on trust.

Access Breaches

Worry about disclosure of information to parents can affect young patients' willingness to seek care and affect their openness with HCPs. Furthermore, some parents may be deterred from disclosing confidential information if it will be visible in minors' EHRs.

In Paper IV's national survey, Swedish adolescents accessing their records online expressed high perceived security of their EHR and very few reported experiences of non-consensual access. Still, two out of every five respondents wanted to control who could access their EHRs, a desire that was related to better self-reported health. A varying need for privacy was suggested in the scoping review (Paper II), where mainly adolescents without serious illness voiced confidentiality concern while adolescents with cancer and blood disorder stated that there was no information they did not want parents to see [109]. Although Swedish adolescents with serious health issues expressed a similar openness with parents, some stated wanting to conceal information that was unrelated to treatment, a desire that increased with age (Paper V). While most valued parental ORA, in agreement with the *Family Engagement* model [45], one adolescent dealing with mental health issues advocated *Confidentiality* and sole adolescent access from early adolescence.

While adolescents with serious health issues may be more open to parental insight due to prior involvement in their care, all have the right to selective privacy from parents. Parents made a distinction in the importance of privacy between children with and without a serious health issue (Paper V), as the child's health issue increased their reliance on parental support for healthcare management. Parents suggested hiding information related to mental health and sexual health, as their interest concerned information related to treatment of their child's illness. Indeed, these may be particularly sensitive types of care, yet according to adolescents in Papers IV and V, the definition of sensitive information can vary based on the individual's personal context. Therefore, increased flexibility and customisable options appear to be necessary. Paper I demonstrated that in Finland, where parental access depends on minors' consent, 96% of minors assessed to have decision-making capacity chose to disclose information to guardians [103]. In Paper V, however, parents of adolescents with a serious health issue questioned adolescents' ability to know which information would be necessary for them to know.

Parents of adolescents with serious health issues experience unique needs for ORA (Paper V), making loss of access in Sweden as the child turns 13 and complications in receiving extended access frustrating. Similar difficulties in receiving proxy access were identified in a US study where 18 of 24 attempts were successful [174]. In the study, barriers mirrored those reported in Papers V and VI; lack of knowledgeable staff and need for paper forms and signatures. US studies have demonstrated that rather than obtaining proxy access, parents accessed the EHR through their adolescents' portal accounts

[175,176], a finding that was supported in Paper V, where parents of older adolescents reported asking their child to login to manage their care after having lost their own access.

Parents in Paper V worried mainly about third-party threats and appeared to not consider their own access as constituting a potential breach, which supports prior findings [128] (Paper II). Adolescents, parents, and HCPs in Papers V and VI who advocated loss of parental access earlier during adolescence tended to focus on risks pertaining to confidentiality, occasionally referring to cases where the child may be in danger from parental disclosure, such as honour-based contexts, custody battles, and child maltreatment. Some parents in Paper V argued that potential harm to adolescents must be rare and that the majority will benefit from parental ORA. No studies have explored experiences of paediatric ORA for children at risk of maltreatment, yet statistics show that 746 cases of gross violation of peace were reported in Sweden in 2022 [177], and 3,853 reports of child rape (age 0-17) in 2023 [178]. While there is much uncertainty in these numbers, investigation on the subject of ORA in such settings is critically needed.

Another concern stated by parents and HCPs in Papers V and VI was that adolescents may share confidential information on social media. This risk has also been anticipated by US adolescents with ORA experience [155]. Paper III indicated that few adolescents accessed their PAEHR to share documents. This correlates with previous findings of adolescents without ORA not intending to share EHR information [105]. Although most adolescents in Paper V stated that they would not do it themselves, some did not perceive an issue if others wanted to do it. Since almost all Swedish adolescents in middle and high school report daily use of social media [59], further studies are required to assess adolescents' attitude and behaviour related to sharing of EHR information online.

Trust

In healthcare, trust is an essential component to enable communication and foster collaborative decision-making between minors and HCPs, but also between parents and HCPs. The transparency of ORA has potential to affect the trust between adolescent, parent, and HCP. In this thesis, in the Swedish national survey (Paper IV), most adolescent reported that reading their notes improved trust for their HCP. While positive effects on the relationship between minor, parent, and HCP were not mentioned in interviews with adolescents and parents (Paper V), participants felt that ORA enhanced communication, which is in line with previous US research [111]. However, a fifth of adolescents surveyed in Paper III reported reading the records due to uncertainty about having received appropriate care. Furthermore, in a conference study conducted with co-authors [179], a fourth of Swedish adolescents reported feeling offended after reading their EHRs, citing reasons such as mention of family members, perceived lies by HCPs, inappropriate wording, unknown

childhood information, and misgendering (i.e., incorrect gender use). If ORA exacerbates perceptions of having received inappropriate care or creates a feeling of being offended, the patient-HCP relationship is likely to be adversely impacted. Additional research is needed to investigate adolescents' experiences concerning effects of ORA on trust, and to identify if ways to enhance note writing can protect minors' trust in HCPs.

Nor did Swedish oncology HCPs in Paper VI report positive effects on trust, but stated that ORA helped to improve communication. US oncology HCPs have reported that the transparency of ORA strengthened their connection with parents, yet they were concerned that disagreements or perceived inaccuracies could negatively affect the relationship with primarily the parent [180], which was also noted by oncology HCPs in this thesis (Paper VI) and a Norwegian psychiatry HCPs [19]. HCPs in Paper VI also viewed some parents' compulsive checking of the PAEHR during appointments as impairing the parent-HCP dynamic. Conversely, parents in Paper V reported worrying that their questions related to the EHR might be seen as critical to HCPs, which could damage the relationship between them.

There is a risk that ORA may adversely impact the clinical relationship and complicate the relationship between the adolescent patient and their parent. Still, access to minors' EHRs may also increase young patients' and parents' trust in their healthcare provider. It is still unknown under what clinical contexts, and for which patients, ORA can positively and negatively affect trust among minors and parents.

Implications for Practice

In this section, implications for practice are suggested to support ethically sound ORA implementation and use of ORA for minors and parents.

Policy

To inform future policies on paediatric ORA, more evidence is needed. As shown in Paper II and cross-country comparisons, both age-based and more flexible case-by-case approaches lead to issues, respectively. In general, based on the thesis findings, I recommend that policy-makers prioritise adolescent safety and autonomy, support parents caring for ill children, and address HCP privacy concerns. Responsibilities should not be imposed on adolescents who are unwilling or unable to manage their care, and when ORA is implemented, policy should ensure education for minors, parents, and HCPs.

In the process of developing policies, stakeholders should be involved to gather knowledge about needs and concerns. Lack of involvement may lead to reluctance and low motivation to adopt new tools and behaviours. Targeted investigations are warranted, potentially utilising Delphi polls with topic

experts. A previous Delphi study [181] investigating views on ORA for adolescents in mental healthcare among researchers and HCPs, identified agreement on recommendations including that HCPs should be provided with information about formal regulations, and that the sensitive nature of the notes should be discussed with the adolescent. This is especially important since this thesis indicated that perceptions of what constitutes sensitive information can differ for young people, and depend on other factors than gender and age. Furthermore, needs for information concealment differs over time during childhood and adolescence. There is ample room for further work, with recommendations for future topics provided under *Further Directions*.

Education

Adolescents and parents should be educated on PAEHR use and confidentiality (e.g., age of gaining access and reasons for limits; the moment when parents will lose access; possibility to restrict information; children's and adolescents' need for privacy; and procedures for adolescents to gain ORA and for parents to stay involved in the child's care). This is important given adolescents' low awareness about ORA regulations, and adolescents' and parents lack of knowledge about access extensions (Paper V). Very small numbers of applications for extended access (Paper I), disproportionate to region size, indicate variable and lacking information available to minors and parents.

Although adolescents may be digital natives, patient portals are commonly designed for adults rather than adolescents and using digital health services may not be intuitive. Due to lacking confidence, there may also be a fear to do something wrong. Therefore, adolescents should be educated in terms of digital health literacy (e.g., content; navigating the PAEHR; understanding EHR information). While adolescents can be difficult to reach, prior research indicates that useful communication channels include marketing campaigns, social media, conversations during visits, and information in clinics [182]. Educational materials could be created that facilitate parental and minor understanding, possibly employing generative AI tools to tailor content to adolescents, ensuring that they feel addressed. In an effort to increase patient understanding of EHR content, a Dutch study developed and tested an algorithm that enabled patient-friendly clarifications of diagnoses in the PAEHR using Systematized Nomenclature of Medicine – Clinical Terms (SNOMED CT) [183], an international terminology system for clinical documentation. Results indicated that most portal users used the feature and rated the clarifications as good quality. Further exploration of such tools integrated in PAEHRs is warranted to facilitate patients' health literacy and understanding.

Considering their extensive lack of knowledge (Papers V-VI), Swedish HCPs should be educated on PAEHRs (e.g., use; updates; privacy functionality; release expectations; and information visibility for children, adolescents, and parents). In a US survey, only 1 of 5 physicians had received training

about minor confidentiality in the EHR [184]. Furthermore, HCPs expressed concerns about increased workload and a need for caution when writing clinical notes. Suggested solutions to these issues include additional training for HCPs on writing clinical notes that patients, including adolescents and parents, have access to [19]. Common tips are avoiding medical jargon, labelling of emotions and subjective or offensive language [125], using templates for potentially stigmatising topics [185], and spell-checking [134]. However, avoiding medical jargon may compromise EHR quality. Another solution lies in the integration of generative AI tools to assist with note writing (further detailed under *Portal Functionality*).

Dialogue

Limited encouragement from HCPs for adolescents to access their PAEHR, as identified in Paper III, is consistent with prior literature [186]. As early ORA may lead to higher use later in adolescence (Paper I), it would be beneficial if parents, HCPs, and the healthcare system supported adolescents in reading their records. Since HCPs worry about increased minor and parent anxiety, decreased documentation quality, and a greater workload [94,187], HCPs may be reluctant to promote ORA. Other potential disincentives pertain to a low knowledge and confidentiality concerns [25,130,142,188]. Interviews indicated that adolescents, parents, and HCPs are unaware of some of the benefits and risks experienced by one another (Papers V-VI), such as that parents did not foresee any positive emotional impact on adolescents. Dialogue between the parties could enhance HCPs' (and parents') understanding about ORA for adolescents and mitigate concerns. To avoid confusion and further enhance transparency, HCPs should communicate with adolescents and parents regarding note sharing, communication, and timing of release.

As erring is human, adolescents and parents need to be informed about the risk of errors in the EHR and encouraged to report them. Providing assurance that there is no risk of retribution has the potential to strengthen the partnership between adolescent, parent, and HCPs, and the sense of being a team that in collaboration works towards EHR accuracy.

A barrier to patient-HCP conversations about ORA is that, as stated by parents and oncology HCPs (Papers V-VI), the focus of visits is providing care and not discussing the EHR. Parents described feeling anxious about bringing up the topic of applying for extended access during an appointment, knowing that ORA was not a priority for HCPs and fearing it might cause annoyance. Therefore, written materials could be helpful to enhance parental and minor understanding about ORA and its benefits and risks. For example, a guide for adults reading their EHRs [189] could be adapted to minors and parents. While more evidence is still needed, increased education about autonomy is essential to ensure parents and HCPs understand how ORA can support, but also potentially undermine autonomy.

Furthermore, to enhance ORA implementation, EHR vendors and patient portal makers should also communicate with HCPs and researchers to stay updated with needs and areas for improvement.

Portal Functionality

EHR vendors and patient portal developers should design functionality that preserves minors' and parents' confidentiality, such as the ability to mark any type of information in the EHR as confidential for HCPs and preferably also minors and parents (e.g., family history), as noted in Paper VI and II [28,49,147,149]. Findings of Paper IV underline the need for flexibility of patient portals to grant or restrict access based on preference and age of any adolescent patient. Desire for confidentiality appeared to depend on individual preferences and type of care received, rather than age or gender. Patient portal designers also need to enable sharing of part of a clinical note (granular sharing), such as when related to child maltreatment. This is necessary to prevent potential harm to children, for example in the case of parents of children admitted for suspected nonaccidental trauma. There needs to be safeguarding functions that facilitate immediate limitation of EHR access for emergency cases.

Attempts have been made to enable portal functionality that aid HCPs in protecting adolescents' EHRs. Kaufman et al. [190] developed a confidential shared teen sexual EHR section for managing teen sexual history, where HCPs could mark notes as "sensitive" in case of concern about harm, observing documentation of sexual activity in 72% of notes. The idea was that if sensitive notes are stored separately, most notes can be shared with proxy users. In the Netherlands, researchers developed a patient portal where adolescents can decide to conceal information from their parents [157]. Researchers and HCPs have suggested customisable controls of information display for both parents and adolescents [28], emphasised the need for HCPs to be able to label information as confidential [132,144,146], and for enabling adolescents to restrict parental access [141,147].

Portal functionality is also to ensure access control practices work effectively. If a parent perceives their adolescent incapable or unwilling to manage their own healthcare, they may consider it part of their parental responsibility to find a workaround [175], such as by accessing the adolescent's account, if possible (Paper V). Even if the adolescent consents to this, EHR security is compromised, necessitating increased measures of security.

The procedure of extending access, implemented in Sweden to allow adolescent and parental ORA between the ages 13-15 under special circumstances, was regarded as inadequately implemented, due to lack of information and difficult procedures (Papers V-VI). Considering the stressful situation of minors with serious health issues and their parents, the application process

should be facilitated, such as by digitising application forms and enabling adolescents and parents to fill them out and submit online.

EHR vendors or patient portal developers should aim to support HCPs in clinical documentation, such as through AI-powered tools using LLMs. These tools could assist for example to increase the empathy of notes as perceived by patients and HCPs [163], and for transcription of patient encounters. AI-assisted technologies may contribute to reducing the workload on HCPs, allow larger focus on the patient, and enable increased customisation to adolescents' needs. Generative AI or other tools could also help to increase minors' and parents' comprehension, such as through automatic translation of abbreviations, medical glossaries, and educational links, such as investigated in a Dutch study [183]. Furthermore, given research suggesting that young patients and parents may contribute to rectification of EHR errors, patient portals may also benefit from developing features that enable patients to report of errors that they find in the records online and their severity.

Methodological Considerations

In this section, I will discuss the rationale for methods used, strengths and weaknesses, and their potential impact on the findings. The thesis research included a case study, a scoping review, two survey studies, and two mixed-methods studies.

Some limitations of this thesis apply to all six studies. First, the criteria defining adolescents differ throughout the thesis (13-20 in Paper II, 15-19 in Papers III-IV, and 13-18 in Papers V-VI). These necessary differences derived from varying methodology and study aims: The global scope of Paper II considered the variation of age limits applied across contexts, where only a small fraction of studies included minors. To maximise the input from the adolescent population, 19 to 20-year olds were included if participants were predominantly younger than 18. Papers III-VI were based on Sweden, where adolescents receive ORA at age 16, and can apply for access from age 13. Due to ethical legislation in Sweden [101] and the scope of the NORDeHEALTH survey, we could only include adolescents aged 15 or over in Papers III and IV, which may have reduced potential recruitment. This aligns with the United Nations (UN) definition, which designates 15 as the lower age of adolescence [191]. Eventually, only two cases occurred of excluding respondents for being aged 14 or younger. As the Paper V survey was set up on a smaller scale, demand of parental consent for minors aged 13 or 14 could be included.

Second, given observed differences between expectations of ORA before actual use, and experiences after using ORA [18,94], it is important to distinguish stakeholders' views prior to, opposed to post-implementation of ORA. In Paper V, adolescents and parents with experience of accessing their records were intended for inclusion. Nevertheless, some study participants had not

accessed their records and instead shared their perceptions of what it would be like to have ORA. In agreement with co-authors, I decided to include the adolescents who had not accessed the records and one parent who had only read their adolescent's paper-based records, given recruitment difficulties and the explicit aim of investigating views on ORA regulations.

Third, the adolescents differed in terms of health across the studies: in Papers I to IV, health status was not an inclusion criterion, while in Paper V, participants had a variety of serious health diagnoses. Paper VI focused specifically on HCPs working with children and adolescents with cancer. There may be differences in views on ORA based on health status, as suggested by HCPs in Paper VI. Notwithstanding, the overall aim was to explore the broad experiences of ORA of minors. To better understand the unique needs of age groups and patients with specific health issues, more research is needed.

Case Study (Paper I)

Paper I consisted of a case study that aimed to describe and compare minors' and guardian proxy users' PAEHR usage in Sweden and Finland, and to investigate the use of country-specific access control practices. In case studies, the researcher collects detailed information over a certain period to provide an in-depth analysis of a case [78]. During data collection, I faced disparities in data availability that limited the potential of cross-country comparison. For example, due to the lack of detail in the Finnish data, guardian access by minor's age could only be studied for Sweden. Additional challenges in accessing information on minors' and guardians' PAEHR use included limited time of contact persons to provide the requested data and technical constraints of the system to retrieve the information. To facilitate efforts to compare adoption of health IT systems such as PAEHRs, standardisation across contexts enabling retrieval of similar data is necessary. These issues also underscore the need for dialogue between researchers and portal providers.

Another limitation is that some of the observed adolescent PAEHR usage might include guardians accessing their children's accounts, particularly in the case of younger adolescents who are more likely to allow guardian access [105]. Several parents of older adolescents in Paper V (who had lost their own access) stated that their child would log in for them to read and previous US work using natural language processing (NLP) methods have identified notable parental use of adolescents' PAEHRs [175]. Moreover, the study did not examine applications for blocked access in Sweden, while Finnish data showed that very few minors opted to deny disclosure of a prescription note to parents. Given that other types of information, like notes on mental or behavioural 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. Furthermore, despite

the identified differences in ORA 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 the role and scope of ORA across international contexts. An important contextual difference from prior studies is that the opt-out systems applied by the Nordic countries contrast with opt-in systems used in many other countries, where patients need to actively enrol or sign up.

Scoping Review (Paper II)

Paper II was a scoping review following the Arksey & O'Malley [82] framework, that aimed to identify, categorise, and summarise knowledge about various stakeholders' views, use, and experiences of EHR access for children, adolescents, and parents. Compared to the only previously conducted review that focused on adolescents and parents and included 11 studies [42], our scoping review included any stakeholder type and included 74 studies. However, by restricting studies to those published in English, important papers written in other languages may have been missed. There may also have been an information bias, as 92% of the included studies were conducted in the US. Among the identified studies, some merged adolescents with young adults or parent proxies, which complicated the analysis of specific groups. A quality assessment of the included studies was not performed due to the extent of the data and the scoping review approach.

Data analysis was complicated by the fact that not all included studies made an explicit distinction between positive and negative views or experiences, thus some cases were coded as such by the authors. Furthermore, several expert viewpoints provided recommendations for the future based on concerns about PAEHRs, that were coded under concerns. While all authors were included in data analysis, focusing on different stakeholder groups, I was involved in analysis of all groups. All authors were junior or senior researchers in health informatics, where senior authors had extensive experience of qualitative research and conducting literature reviews.

Stakeholder consultations strengthened our findings and ensure their relevance. However, inviting the stakeholders to a more active participation earlier on, or to provide input throughout the process could have enabled more integration of their findings into the study.

Surveys and Mixed Methods (Papers III-VI)

Papers III and IV utilised surveys to explore adolescents' experiences, such as encouragement to use PAEHRs, information and function utility, and views on security and privacy. In Papers V and VI, surveys were part of the mixed-

methods approach examining adolescents', parents', and HCPs' views, awareness, and perceived benefits and risks with respect to ORA regulations.

The study setting is a key factor that may limit the findings' generalisability to other contexts. Papers III-VI were conducted in Sweden, a country with distinct characteristics that likely shaped the outcomes, making it important to consider these specific circumstances. First, Sweden is among the most digitised countries in the world regarding Internet accessibility [192], where citizens depend on digital services for many aspects of everyday life. Second, the national patient portal has been available to citizens for a decade, creating expectations of online information availability. Third, Sweden is a developed nation, which means trust in the healthcare system is likely higher compared to developing countries [193]. Fourth, Sweden's universal healthcare coverage differs from systems in countries like the US, which rely on private insurance and where HCP views on ORA are often influenced by fear of litigation. These aspects likely affect the external validity of the studies and generalisability of the findings, therefore, similar investigations in other environments that differ from these aspects may yield different results.

Beyond these contextual factors, study design aspects complicate the validation of the findings. First, self-reported survey data come with unknown response biases. For example, those who want to participate may have very negative experiences. There was also a risk of positively biased results in Papers III and IV, as the NORDeHEALTH survey was available on the national patient portal and decisions to respond may have been affected by competence and skills to use the service. However, given that we aimed to reach actual users and few adolescents are difficult to reach, other means of recruitment may have been less successful. Surveys in Papers III-VI were created by the authors and thus, were not standardised tools; however, testing with participant groups who provided feedback was performed to ensure that items were relevant and clearly formulated [93].

Sample sizes may also limit the findings' generalisability. Although the sample size of 218 participants in Papers III and IV was adequate for statistical analyses, there may have been significant variations among the participants. Also, the survey sample sizes in Papers V and VI were small, especially for adolescents (N=31) and parents (N=57), which resulted in the merge of findings for publication. While parents represented a range of education levels, residential area types, and income levels, nearly all had Swedish as primary language. Since socioeconomic factors [194,195], such as language [196,197], drive disparities in paediatric ORA adoption, future work should include minors and parents from diverse language backgrounds to gain a wider range of perspectives.

Interviews (Papers V-VI)

Papers V and VI were mixed-methods studies that included semi-structured interviews in addition to surveys, requiring further methodological consideration. While credibility can be strengthened by engagement with participants over time, participants in Paper V and VI were interviewed only on one occasion. However, method triangulation through combining multiple methods is a well-established means for strengthening the conclusions about the findings [93,97]. In these papers, surveys quantitatively examined views, experiences, and awareness of ORA, and interviews helped to uncover participants' underlying reasoning behind their views [198]. Thus, survey findings did not inform the interviews but were used as a separate source of data. Data triangulation of multiple informant groups (adolescents, parents, and HCPs) was used for a comprehensive understanding.

Interview sample sizes ranged between 8-17, and most adolescent interview participants were in late adolescence. The lower number of adolescent participants recruited (N=8) may be due to that younger individuals are less afflicted by health conditions, or they may be less involved in their own care. In my experience communicating with adolescents who registered interest to participate, some appeared preoccupied and to lack confidence in research settings. Nevertheless, I conducted all interviews and perceived that data were saturated, as no new insights were emerging.

Since recruitment was slow (about 1 year for HCPs and 1.5 years for adolescent and parents), changes to external factors may have influenced participants' attitudes. However, the national regulatory framework for ORA was the same throughout the time of the study, and major changes to the national PAEHR accessibility did not occur. Although the Covid-19 pandemic was a more prominent issue during the beginning of data collection, participants' responses did not appear affected by this circumstance in their views on ORA. When combining surveys and interviews, it is worth noting that interview participants may be more impacted by social desirability bias than survey respondents, due to the direct interaction with the researcher. Also, those who agreed to participate in interviews may have held stronger beliefs about ORA, or have had unique experiences related to ORA, than those who only responded to the survey. Still, a mixed-methods comparison found that qualitative findings reflected quantitative results well, and a series of Mann-Whitney tests showed no significant difference in views on ORA regulations between those who partook in interviews and those who did not.

Throughout, I strove to be transparent about study procedures, providing material including surveys and interview guides in original and translated versions, and using standardised tools to report qualitative research such as the COREQ checklist [92]. My main supervisor and I conducted the thematic data analysis, consulting with senior researcher co-authors as needed and discussing the data coding.

Pre-understanding has been noted as a threat to the validity of qualitative research, and concerns the researcher's preconceptions, beliefs, values, and assumptions that may affect the study and findings. Disclosing the researcher's pre-understanding contributes to transparent research [93,97]. I am a PhD student in health informatics examining ORA and the sole researcher responsible for data collection. Conducting all interviews allowed me to engage myself in each group's perspective. Although I am a patient user of the Swedish PAEHR *1177 journal*, I did not have ORA as an adolescent. I do not have any children, and lack clinical work experience in healthcare, but for some education in clinical mental healthcare. Thus, I did not belong to any of the studied groups, which may have fostered an open mindset.

Theoretical Framework

This thesis drew on the principles of biomedical ethics introduced by Beauchamp and Childress [1], to analyse the findings related to stakeholders' experiences of ORA. Another possibility would have been to apply a technical implementation framework like the United Theory of Acceptance and Use of Technology (UTAUT) [199], which is designed to explain users' technology usage and adoption. The COM-B model (Capability, Opportunity, Motivation, and Behaviour) [200] could have been useful to better understand adolescents', parents', and HCPs' behaviour associated with paediatric ORA. While these are powerful tools for understanding behaviour and technology adoption, I perceived the topic of paediatric ORA as having unique layers that could not be overlooked. Given that confidentiality concerns pose a major barrier to its implementation, there is ultimately a moral question of to what degree the practice is beneficial or harmful. As such, the principal concerns aligned with the ethical framework suggested by Beauchamp and Childress [1], emphasising autonomy, non-maleficence, beneficence, and confidentiality. Also, UTAUT and COM-B focus on user behaviour, while this thesis includes the perspectives of HCPs, who, while not end users of the PAEHRs like minors and parents, are a central part in the ORA equation and have expressed persistent concerns about patient and caregiver access to minors' EHRs.

Future Directions

This thesis encompassed six studies examining experiences of online access to minors' health records. The importance of our work is underlined by its involvement in the Swedish government's investigation of electronic access to children's healthcare information conducted in 2023 [71]; in the investigation, parts of the scoping review in Paper II were translated to be used as evidence, and I provided input to the lawyer appointed by the Ministry of Social Affairs. Still, paediatric ORA is a nascent research area with abundant room for further exploration. Despite favourable findings of benefits from patient and proxy access to EHRs for minors and parents, critical questions remain that I have been unable to address within this thesis.

An increased sense of safety from ORA was reported by minors and parents (Papers II and V). However, particularly parents and HCPs worried about confusing or worrisome information causing minors distress. Additional research using validated measures is required to assess adolescents' and parents' emotional experiences. Given that health anxiety may be exacerbated by low levels of understanding, future studies should explore minors' and parents' comprehension of EHRs and the educational potential of ORA. Furthermore, EHR accuracy may be improved by enabling minors and parents to contribute to error correction, yet the clinical relevance of patient-reported errors needs to be assessed. This investigation is especially important given that an increasing use of speech detection technologies for EHR documentation may lead to an increase in errors.

To avoid negative reactions from parents, HCPs reported a need to be cautious and vague in their documentation which may jeopardise the quality of EHRs and increase HCP work burden. More studies are therefore needed to explore how HCP training in writing EHRs and increased patient guidance can reduce anxiety in minors and parents when reading EHRs. I also anticipate ongoing efforts in the coming years to improve our understanding of how generative AI tools can support HCP with clinical documentation, such as by conveying empathy in text [201]. HCPs play a key role in ORA and their concerns about the record as a work tool must be considered. Therefore, efforts should be made to reduce the administrative workload of EHR documentation and ORA, allowing HCPs to concentrate more on patient care.

Findings suggest that ORA might increase minors' and parents' trust with their healthcare provider, by being transparent about clinical work. However, ORA may impact and complicate the patient-parent relationship. For example, one 15-year old in Paper V who had received mental health care expressed more desire for privacy compared to participants who had received care for other serious health issues. Future research should examine when ORA affects trust positively or negatively among minors and parents.

Although ORA can be beneficial for many families, it also carries the risk of exposing vulnerable children and adolescents to potential harm, deterring

them from seeking care. Parental access endangering the safety of the child was not specifically addressed in this thesis and needs further exploration. Little research has focused on ORA for minors experiencing domestic violence, abuse or maltreatment, and no studies have addressed minors' and parents' experiences, or examined the topic of safeguarding EHRs from parental access in cases of child maltreatment.

In Figure 12, I have sorted the topics related to minor and parental ORA that merit further work, based on the biomedical ethical principles discussed in this thesis: *autonomy*, *nonmaleficence*, *beneficence*, and *confidentiality*.

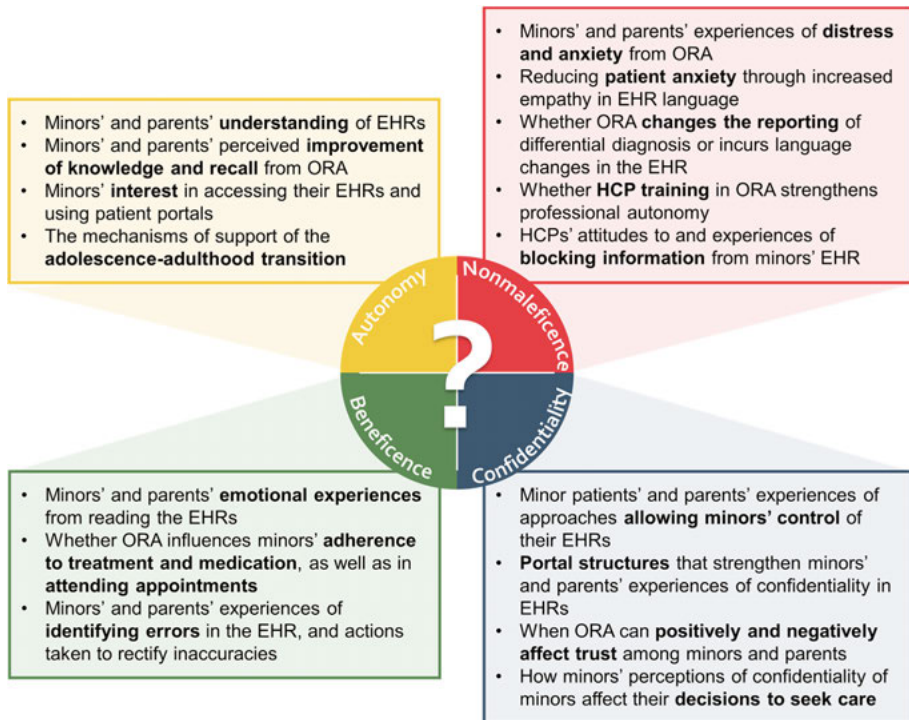


Figure 12. Topics for future research related to biomedical ethical principles.

As observed in Papers I and II, a plethora of solutions for providing ORA to minors' EHRs have been applied across countries and institutions. To develop a better understanding of minors', parents' and HCPs' views and experiences, further studies should continue to explore approaches internationally, involving minors and parents of different socioeconomic backgrounds. Future research should also evaluate minors' and parents' experiences in different clinical contexts and settings, including adolescents receiving care pertaining to sexual health, reproductivity, and gender identity. Delphi polls using purposive sampling could be used to assess experts' opinions [181,202].

Conclusion

Paediatric ORA remains a developing and uncertain area within digital health implementation, but is increasingly emerging as a topic of active debate. My overall aim with this thesis was to contribute more focused research on this challenging question by exploring stakeholder experiences of online access to minors' EHRs.

What was known on the topic before my PhD thesis?

- Patient ORA is being implemented in more than 20 countries, and adult patients report benefits including enhanced recall and engagement. Approaches to paediatric ORA differ globally.
- As digital natives, adolescents have high expectations of digital services. While some adolescents hesitate to share confidential information with HCPs if concerned about parental disclosure, there is a lack of evidence on the topic of their experiences with ORA.
- HCPs report concerns about the changing role of EHRs, patients' reactions to reading their own EHRs, and protecting patient confidentiality in cases of proxy access. However, no research has examined Swedish HCPs' perspectives on ORA regulations.
- National PAEHR systems have been in place in the Nordic countries since 2010s. In Swedish news media, parents have voiced alarm regarding the decision to restrict parental proxy access when the child turns 13. Views and experiences of minors, parents, or paediatric HCPs in Sweden have not yet been examined.

As the first Swedish exploration on these issues, this research employed observational and empirical methods grounded in a biomedical ethical framework [1]. My thesis broadens our understanding of ORA for both minors and parents, offering insights from a non-US context while incorporating adolescents' perspectives. The key contributions of this work are summarised below.

What has my PhD thesis added to our knowledge?

- About half of Swedish 16-year olds have accessed the national PAEHR, and early access may lead to higher use during late adolescence.
- Most prior work on paediatric ORA has been US-based and adolescents' experiences have received scant attention, warranting studies exploring different approaches to access to minors' EHRs.
- Swedish adolescents expressed a desire to manage access to their EHRs. What is considered as sensitive information can differ based on health status, age, gender, and personal factors, highlighting the importance of studying approaches that allow more adolescent control.
- A disconnect was identified, with adolescents and parents stating optimism, while HCPs voiced concerns about EHR documentation and effects on quality. Such concerns may lead to limited encouragement for reading PAEHRs, potentially hindering adolescent and parental usage. Education and open dialogue among stakeholders could enhance understanding and alleviate concerns.
- Swedish adolescents, parents, and oncology HCPs were critical to ORA restrictions for ages 13-15, noting the challenges in tailoring access to meet the needs of adolescents with complex health conditions. These practices may not adequately address the nuanced needs of this group, calling for more flexible, individualised approaches.
- Significant uncertainty remains surrounding ORA for minors and parents. There is a pressing need for studies on children at risk of harm as well as the application of generative AI in clinical documentation, and how paediatric patients, their parents, and HCPs might use these tools.

This thesis constitutes an early empirical effort to delineate the ethical complexities of ORA in paediatric settings, underscoring the delicate balance required between respecting autonomy and safeguarding privacy. While ORA holds potential to engage young patients in their care and support those with additional healthcare needs, uncertainties about its actual benefits and potential risks warrant further research. Education and communication are vital for ORA to strengthen the adolescent-parent-HCPs partnership. ORA advancement in paediatric care will require HCPs to reconsider the role of clinical documentation as a novel communication tool. What is now needed is research that explores the experiences of ORA across various contexts, approaches, and countries to inform guidance on its implementation. Future work should aim to deepen understanding and contribute to the development of best practices for ORA in paediatric contexts on a global scale.

Sammanfattning på svenska

Idag får allt fler patienter världen över tillgång till sina journaler via patientportaler på nätet, där de kan läsa anteckningar från vårdbesök, provsvar, remisser, diagnoser och annan vårdrelaterad information. Vuxna patienter har rapporterat flera fördelar med att kunna läsa sin journal, såsom förbättrat minne av information från vårdbesök, en ökad känsla av trygghet och större delaktighet i sin vård. Vårdpersonalen har å andra sidan uttryckt oro över att patienter tar del av sin journal via nätet, då detta kan begränsa journalens användbarhet som arbetsverktyg, på grund av potentiella reaktioner från patienter och bristande skydd av känslig information. De negativa effekterna har dock varit mindre än förväntat.

Att ge någon annan person, såsom föräldrar, tillgång till en patients journal kan vara positivt när patienten inte är förmögen att ta hand om sin vård. Under tidig barndom är detta ofta oproblematiskt, men när barnet växer upp och blir tonåring kan frågor kring känslig information uppstå. Oro för föräldrars insyn kan få att individen att undvika vård eller vara mindre öppen med vårdpersonal. Även föräldrar kan undanhålla viktig hälsoinformation, som exempelvis genetiska sjukdomar, för att skydda barnet. Detta kan försvåra för vårdpersonal vid dokumentation och leda till ofullständig journalinformation. För att skydda barn och ungdomars integritet finns därför särskilda regelverk för journaltillgång, som varierar mellan olika länder.

I Sverige har *1177 journal* varit tillgänglig för alla invånare sedan ett decennium. Barn under 16 år har inte själva tillgång till sin journal, men barnets förälder (här samma som vårdnadshavare) har automatisk tillgång till barnets journal fram till att barnet fyller 13 år, varpå varken barn eller förälder har tillgång till barnets journal, tills barnet fyller 16 och själv kan ta del av sin journal. Föräldrar kan under denna tid ansöka om att få förlängd tillgång till barnets journal, och även barnet kan ansöka om att få tidigare tillgång till sin journal. Denna brist på tillgång har kritiserats i svenska medier, framförallt av föräldrar till svårt sjuka barn. Inga forskningsstudier har dock undersökt hur systemet upplevs av ungdomar, föräldrar eller vårdpersonal, eller belyst journaltillgång för ungdomar och föräldrar ur ett etiskt perspektiv.

Huvudsyftet med avhandlingen har varit att undersöka olika intressenters (ungdomars, föräldrars och vårdpersonals) tillgång till barn och ungdomars journal via nätet. I avhandlingen ingår sex artiklar. Den första studien var en fallstudie som utforskade i vilken grad barn, ungdomar och föräldrar i Sverige

och Finland loggade in i journalen och använde de specifika kontrollfunktionerna för ungas och föräldrars tillgång. Den andra artikeln var en internationell litteraturoversikt som summerade forskning om åsikter, användning och upplevelser bland barn, ungdomar, vårdnadshavare, vårdpersonal och andra intressenter. I den tredje och fjärde artikeln användes resultaten från en nationell enkätstudie för att undersöka upplevelser hos ungdomar i Sverige som läste sin journal. Den femte och sjätte artikeln var kombinationsstudier, också i en svensk kontext, som genom enkäter och intervjuer studerade hur Journalen och regelverket kring åldersgränser upplevdes av 1) ungdomar med allvarliga hälsoproblem och deras vårdnadshavare, samt 2) vårdpersonal som arbetade med barn och ungdomar med cancer.

Fallstudien visade att en mindre andel av ungdomar använde sin journal i Sverige än i Finland, där man inte infört någon undre åldersgräns. Antalet ansökningar om utökad tillgång för ungdomar och föräldrar i Sverige var få. I litteraturoversikten framgick det att nästan all tidigare forskning hade genomförts i USA och att inga studier hade utförts i Sverige. Få studier hade tittat på barn och ungdomars erfarenheter, varav majoriteten gällde unga med kroniska sjukdomar. Enkätstudierna visade att uppmuntran från vårdpersonal kan öka ungdomars benägenhet att oftare logga in i sin journal, och att informationen i *1177 journal* upplevdes som mycket användbar. Vidare tyckte ungdomar att *1177 journal* höll en hög en säkerhetsnivå, och att tillgång till den ökade deras tillit till vården. Samtidigt önskade många att kunna kontrollera vem som kunde läsa deras journal. Psykisk ohälsa var det ämne som flest tyckte var känsligt, men synen på vad som är känsligt kan variera från person till person. Kombinationsstudierna visade att ungdomar med allvarliga hälsoproblem, föräldrar och vårdpersonal var kritiska till regelverkets avbrott i tillgång under tonåren, även om vårdpersonalen var mindre samstämmiga i sin kritik. Ungdomar som läste sin journal upplevde det som värdefullt, medan föräldrar ansåg att deras egen åtkomst var nödvändig, med oro för ungdomars förmåga att hantera informationen. Vårdpersonalen var bekymrad över att föräldrars tillgång skulle leda till en ökad försiktighet i dokumentationen, vilket skulle kunna påverka journalkvaliteten och patientsäkerheten negativt. Kunskapen om möjligheterna för att ge ungdomar och föräldrar tillgång vid särskilda omständigheter för de som är 13–15 år var generellt låg.

Sammanfattningsvis bidrar denna avhandling med nya insikter om journaltillgång via nätet för ungdomar och föräldrar i Sverige. Även om tillgång till sin journal kan öka ungdomars engagemang i sin vård, kvarstår osäkerhet kring de potentiella effekter och riskerna, och mer forskning krävs. Tillgång till journalen via nätet har potential att bli ett effektivt verktyg för att förbättra ungdomars hälsa. För att förverkliga denna möjlighet behövs ökad utbildning och bättre stöd för vårdpersonal i klinisk dokumentation, samt tydligare och mer tillgänglig information och initiativ som främjar en öppen dialog mellan ungdomar, föräldrar och vårdpersonal.

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References

- [1] Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. New York, NY: Oxford University Press; 2019.
- [2] Fricker M. *Epistemic Injustice*. New York: Oxford University Press; 2007.
- [3] Bourgeois F, Lowe E, Wachenheim D. OpenNotes: Sharing Visit Notes With Patients and Families. *Pediatr Nurs* 2018;44:45–8.
- [4] Allen A. Genetic Privacy: Emerging Concepts and Values. In: Rothstein MA, editor. *Genet. Secrets Prot. Priv. Confidentiality Genet. Era*, New Haven, CT: Yale University Press; 1997, p. 31–59.
- [5] Record. Merriam-Webster Dict n.d. <https://www.merriam-webster.com/dictionary/record> (accessed October 26, 2024).
- [6] Journal. Merriam-Webster Dict n.d. <https://www.merriam-webster.com/dictionary/journal> (accessed October 26, 2024).
- [7] Walker J, Leveille S, Bell S, Chimowitz H, Dong Z, Elmore JG, et al. OpenNotes After 7 Years: Patient Experiences With Ongoing Access to Their Clinicians' Outpatient Visit Notes. *J Med Internet Res* 2019;21:e13876. <https://doi.org/10.2196/13876>.
- [8] Hägglund M, Kharko A, Bärkås A, Blease C, Cajander Å, DesRoches C, et al. NORDeHEALTH – Learning from the Nordic Experiences of Patient Online Record Access. *J Med Internet Res* 2023;25:e47573. <https://doi.org/10.2196/47573>.
- [9] Lorkowski J, Pokorski M. Medical Records: A Historical Narrative. *Biomedicines* 2022;10:2594. <https://doi.org/10.3390/biomedicines10102594>.
- [10] Müller K. *Från läkarens egna minnesanteckningar till vårdapparatens kommunikationsmedium*. Bachelor's thesis. Lund University, 2018.
- [11] Wendel L. När läkare blev skyldiga att föra patientjournal. En studie av introduktionen av 1963 års läkarinstruktion. *Ark Samh Och Forsk* 2019;6–42.
- [12] *Arkiv inom hälso- och sjukvård*. Stockholm: Kommunikationsdepartementet; 1968.
- [13] Aaslestad P. *The Patient as Text: the Role of the Narrator in Psychiatric Notes, 1890-1990*. 1st ed. London: CRC Press; 2009.
- [14] Shenkin BN, Warner DC. Giving the Patient His Medical Record: A Proposal to Improve the System. *N Engl J Med* 1973;289:688–92. <https://doi.org/10.1056/NEJM197309272891311>.
- [15] Riksdagsförvaltningen. Patientjournallag (1985:562). Vol. 562. 1985.
- [16] Bruno MA, Petsavage-Thomas JM, Mohr MJ, Bell SK, Brown SD. The “Open Letter”: Radiologists' Reports in the Era of Patient Web Portals. *J Am Coll Radiol* 2014;11:863–7. <https://doi.org/10.1016/j.jacr.2014.03.014>.
- [17] Petersson L, Erlingsdóttir G. Open Notes in Swedish Psychiatric Care (Part 1): Survey Among Psychiatric Care Professionals. *JMIR Ment Health* 2018;5:e11. <https://doi.org/10.2196/mental.9140>.

- [18] Petersson L, Erlingsdóttir G. Open Notes in Swedish Psychiatric Care (Part 2): Survey Among Psychiatric Care Professionals. *JMIR Ment Health* 2018;5:e1052. <https://doi.org/10.2196/10521>.
- [19] Nielsen MS, Steinsbekk A, Nøst TH. Views on patient portal use for adolescents in mental health care - a qualitative study. *BMC Health Serv Res* 2023;23:132. <https://doi.org/10.1186/s12913-023-09156-6>.
- [20] Stillman M. Death by Patient Portal. *JAMA* 2023;330:223–4. <https://doi.org/10.1001/jama.2023.11629>.
- [21] Blease C, Cohen IG, Hoffman S. Sharing Clinical Notes: Potential Medical-Legal Benefits and Risks. *JAMA* 2022;327:717. <https://doi.org/10.1001/jama.2021.23179>.
- [22] Moll J, Rexhepi H, Cajander Å, Grünloh C, Huvila I, Hägglund M, et al. Patients' Experiences of Accessing Their Electronic Health Records: National Patient Survey in Sweden. *J Med Internet Res* 2018;20:e9492. <https://doi.org/10.2196/jmir.9492>.
- [23] Esch T, Mejilla R, Anselmo M, Podtschaske B, Delbanco T, Walker J. Engaging patients through open notes: an evaluation using mixed methods. *BMJ Open* 2016;6:e010034. <https://doi.org/10.1136/bmjopen-2015-010034>.
- [24] Rexhepi H, Åhlfeldt R-M, Cajander Å, Huvila I. Cancer patients' attitudes and experiences of online access to their electronic medical records: A qualitative study. *Health Informatics J* 2018;24:115–24. <https://doi.org/10.1177/1460458216658778>.
- [25] Beaton L, Williams I, Sanci L. Exploring adolescent and clinician perspectives on Australia's national digital health record, My Health Record. *Aust J Prim Health* 2021;27:102–8. <https://doi.org/10.1071/PY20169>.
- [26] Skinner H, Biscope S, Poland B, Goldberg E. How Adolescents Use Technology for Health Information: Implications for Health Professionals from Focus Group Studies. *J Med Internet Res* 2003;5:e32. <https://doi.org/10.2196/jmir.5.4.e32>.
- [27] Ford CA. Foregone Health Care Among Adolescents. *JAMA* 1999;282:2227. <https://doi.org/10.1001/jama.282.23.2227>.
- [28] Anoshiravani A, Gaskin GL, Groshek MR, Kuelbs C, Longhurst CA. Special Requirements for Electronic Medical Records in Adolescent Medicine. *J Adolescent Health* 2012;51:409–14. <https://doi.org/10.1016/j.jadohealth.2012.08.003>.
- [29] Ancker JS, Sharko M, Hong M, Mitchell H, Wilcox L. Should parents see their teen's medical record? Asking about the effect on adolescent–doctor communication changes attitudes. *J Am Med Inform Assoc* 2018;25:1593–9. <https://doi.org/10.1093/jamia/ocy120>.
- [30] Bourgeois FC, DesRoches CM, Bell SK. Ethical Challenges Raised by Open-Notes for Pediatric and Adolescent Patients. *Pediatrics* 2018;141:e20172745. <https://doi.org/10.1542/peds.2017-2745>.
- [31] Palfrey J, Gasser U. *Born Digital: Understanding the First Generation of Digital Natives*. New York: Basic Books; 2011.
- [32] Russo K. Assessment and Treatment of Adolescents With Chronic Medical Conditions. *J Health Serv Psychol* 2022;48:69–78. <https://doi.org/10.1007/s42843-022-00059-4>.
- [33] Hälsa hos skolbarn (resultat Skolbarns hälsövanor 2021/2022). *Folkhälsomyndigheten*; 2023.
- [34] Cancer hos barn – Vanliga cancersjukdomar hos barn. Cancerfonden n.d. <https://www.cancerfonden.se/om-cancer/cancersjukdomar/cancer-hos-barn> (accessed October 3, 2024).

- [35] AAP-AACAP-CHA Declaration of a National Emergency in Child and Adolescent Mental Health. *Am Acad Pediatr* 2021. <https://www.aap.org/en/advocacy/child-and-adolescent-healthy-mental-development/aap-aacap-cha-declaration-of-a-national-emergency-in-child-and-adolescent-mental-health/> (accessed October 25, 2024).
- [36] Förekomst av psykisk ohälsa bland barn och unga vuxna. Socialstyrelsen; 2024.
- [37] Tørmoen AJ, Myhre M, Walby FA, Grøholt B, Rossow I. Change in prevalence of self-harm from 2002 to 2018 among Norwegian adolescents. *Eur J Public Health* 2020;30:688–92. <https://doi.org/10.1093/eurpub/ckaa042>.
- [38] Liu W, Hu Z, Liu Z, Zhang F, Ding Y, Shui Y, et al. Age- and sex-dependent increase in self-harm among adolescents with mental health problems in East China during COVID-19 related society-wide isolation. *Front Public Health* 2023;11:1129123. <https://doi.org/10.3389/fpubh.2023.1129123>.
- [39] Hein IM, Troost PW, Lindeboom R, Benninga MA, Zwaan CM, Van Goudoever JB, et al. Accuracy of the MacArthur Competence Assessment Tool for Clinical Research (MacCAT-CR) for Measuring Children’s Competence to Consent to Clinical Research. *JAMA Pediatr* 2014;168:1147. <https://doi.org/10.1001/jamapediatrics.2014.1694>.
- [40] Orth U, Robins RW. The Development of Self-Esteem. *Curr Dir Psychol Sci* 2014;23:381–7. <https://doi.org/10.1177/0963721414547414>.
- [41] Grenfeldt K, Parkdahl M. Ett otroligt antiklimax: Psykologers erfarenhet av patienters tillgång till journalen. Master's thesis. University of Gothenburg, 2018.
- [42] Bush RA, Connelly CD, Fuller M, Pérez A. Implementation of the Integrated Electronic Patient Portal in the Pediatric Population: A Systematic Review. *Telemed J E Health* 2016;22:144–52. <https://doi.org/10.1089/tmj.2015.0033>.
- [43] Ford CA, Davenport AF, Meier A, McRee A-L. Partnerships Between Parents and Health Care Professionals to Improve Adolescent Health. *J Adolesc Health* 2011;49:53–7. <https://doi.org/10.1016/j.jadohealth.2010.10.004>.
- [44] Britto MT, Hesse EA, Kamdar OJ, Munafo JK. Parents’ Perceptions of a Patient Portal for Managing Their Child’s Chronic Illness. *J Pediatr* 2013;163:280–281.e2. <https://doi.org/10.1016/j.jpeds.2013.02.041>.
- [45] Thompson LA, Martinko T, Budd P, Mercado R, Schentrup AM. Meaningful use of a confidential adolescent patient portal. *J Adolesc Health* 2016;58:134–40. <https://doi.org/10.1016/j.jadohealth.2015.10.015>.
- [46] Howard S. Patients’ access to medical records around the world. *BMJ* 2024;q1481. <https://doi.org/10.1136/bmj.q1481>.
- [47] Essén A, Scandurra I, Gerrits R, Humphrey G, Johansen MA, Kierkegaard P, et al. Patient access to electronic health records: Differences across ten countries. *Health Policy Technol* 2018;7:44–56. <https://doi.org/10.1016/j.hlpt.2017.11.003>.
- [48] Scandurra I, Pettersson M, Eklund B, Lyttkens L. Analysis of the Updated Swedish Regulatory Framework of the Patient Accessible Electronic Health Record in Relation to Usage Experience. *MEDINFO 2017 Precis Healthc Inform* 2017:798–802. <https://doi.org/10.3233/978-1-61499-830-3-798>.
- [49] Wong D, Morgan-Lynch S. Patient portals and young people: addressing the privacy dilemma of providing access to health information. *J Prim Health Care* 2017;9:240. <https://doi.org/10.1071/HC17037>.
- [50] Hagström J, Scandurra I, Moll J, Blease C, Haage B, Hörhammer I, et al. Minor and Parental Access to Electronic Health Records: Differences Across Four

- Countries. *Stud Health Technol Inform* 2022;294:495–9. <https://doi.org/10.3233/SHTI220508>.
- [51] GP Online Services Guidance - Children and Young People 2023.
- [52] A European Health Data Space for people and science. *Eur Comm* 2022. https://ec.europa.eu/commission/presscorner/detail/en/ip_22_2711 (accessed November 7, 2022).
- [53] Walker J, Meltsner M, Delbanco T. US experience with doctors and patients sharing clinical notes. *BMJ* 2015:g7785. <https://doi.org/10.1136/bmj.g7785>.
- [54] Schapiro NA, Mihaly LK. The 21st Century Cures Act and Challenges to Adolescent Confidentiality. *J Pediatr Health Care* 2021;35:439–42. <https://doi.org/10.1016/j.pedhc.2021.03.005>.
- [55] Sisk BA, Antes AL, Bereitschaft C, Enloe M, Bourgeois F, DuBois J. Challenges to Developing and Implementing Policies for Adolescent Online Portal Access. *Pediatrics* 2023:e2023061213. <https://doi.org/10.1542/peds.2023-061213>.
- [56] Mehta S, Jamieson T, Ackery AD. Helping clinicians and patients navigate electronic patient portals: ethical and legal principles. *Can Med Assoc J* 2019;191:E1100–4. <https://doi.org/10.1503/cmaj.190413>.
- [57] Gillon R. Defending the four principles approach as a good basis for good medical practice and therefore for good medical ethics. *J Med Ethics* 2015;41:111–6. <https://doi.org/10.1136/medethics-2014-102282>.
- [58] Gillon R. Ethics needs principles—four can encompass the rest—and respect for autonomy should be “first among equals.” *J Med Ethics* 2003;29:307–12. <https://doi.org/10.1136/jme.29.5.307>.
- [59] Svenskarna och internet 2024. Internetstiftelsen. <https://svenskarnaochinternet.se/rapporter/svenskarna-och-internet-2024/> (accessed September 30, 2024).
- [60] Svenskarna och internet 2015. Internetstiftelsen. <https://svenskarnaochinternet.se/rapporter/svenskarna-och-internet-2015/> (accessed August 4, 2022).
- [61] Svenskarna och internet 2023. Internetstiftelsen. <https://svenskarnaochinternet.se/rapporter/svenskarna-och-internet-2023/> (accessed September 30, 2024).
- [62] Häggglund M, Scandurra I. Patients’ Online Access to Electronic Health Records: Current Status and Experiences from the Implementation in Sweden. *Stud Health Technol Inform* 2017;245:723–7.
- [63] Statistik för Ineras tjänster [Statistics for Inera’s services]. Inera AB n.d. <https://www.inera.se/tjanster/statistik-for-ineras-tjanster/> (accessed August 25, 2023).
- [64] Bärkås A, Scandurra I, Rexhepi H, Blease C, Cajander Å, Häggglund M. Patients’ Access to Their Psychiatric Notes: Current Policies and Practices in Sweden. *Int J Environ Res Public Health* 2021;18:9140. <https://doi.org/10.3390/ijerph18179140>.
- [65] Scandurra I, Lyttkens L, Eklund B. Implications of Swedish National Regulatory Framework of the Patient Accessible Electronic Health Record. *Stud Health Technol Inform* 2016;228:695–9.
- [66] Nationella rekommendationer inför publicering av patientjournal via nätet om barnsjukvård. Inera AB; 2017.
- [67] Fick inte se sin cancersjukes journal på nätet – regeringen lovar ändring. *Ekot* 2023.
- [68] Föräldrar blockade från Vilmers vårdkontakter “Besök missas.” P4 Malmöhus 2022.

- [69] Nya åldersgränser för tjänster på 1177.se. Inera 2022. <https://www.inera.se/utveckling/genomforda-projekt-och-utredningar/nya-aldersgranser-for-tjanster-pa-1177.se/> (accessed October 31, 2022).
- [70] Åldersgränser i 1177- tjänster: Utredningsrapport och barnkonsekvensanalys. Inera AB; 2022.
- [71] Regeringskansliet. Elektronisk tillgång till barns uppgifter inom hälso- och sjukvården och tandvården. Regeringskansliet 2023. <https://www.regeringen.se/rattsliga-dokument/departementsserien-och-promemorior/2023/09/ds-202326/> (accessed June 18, 2024).
- [72] Extent W, Should G, Information R, Handledare MS, Singer A. Barns rätt till självbestämmande inom hälso- och sjukvård Children’s Right to Self-Determination Within Healthcare 2018.
- [73] Riksdagsförvaltningen. Patientlag (2014:821). Vol. 821. 2014.
- [74] Riksdagsförvaltningen. Föräldrabalken (1949:381). Vol. 381. 1949.
- [75] Riksdagsförvaltningen. Patientsäkerhetslagen (2010:659). Vol. 659. 2010.
- [76] Riksdagsförvaltningen. Offentlighets- och sekretesslagen (2009:400). Vol. 400. 2009.
- [77] Hägglund M. Nordic countries lead new initiative on patient access to EHRs. *TheBMJopinion* 2021. <https://blogs.bmj.com/bmj/2021/05/18/maria-hagglund-nordic-countries-lead-new-initiative-on-patient-access-to-ehrs/> (accessed January 16, 2022).
- [78] Yin RK. *Case study research : design and methods*. London: SAGE; 2014.
- [79] Befolkningsstatistik. Stat Cent 2022. <https://www.scb.se/hitta-statistik/statistik-efter-amne/befolkning/befolkningens-sammansattning/befolkningsstatistik/> (accessed March 7, 2023).
- [80] Befolkningsstruktur. Statistikcentralen 2023. <https://stat.fi/sv/statistik/vaerak> (accessed December 5, 2023).
- [81] My Kanta Pages. KantaFi 2022. <https://www.kanta.fi/en/my-kanta-pages> (accessed November 23, 2022).
- [82] Arksey H, O’Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;8:19–32. <https://doi.org/10.1080/1364557032000119616>.
- [83] Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* 2009;6:e1000097. <https://doi.org/10.1371/journal.pmed.1000097>.
- [84] Hagström J, Blease C, Haage B, Scandurra I, Hansson S, Hägglund M. Use of and Experiences With Online Access to Electronic Health Records for Parents, Children, and Adolescents: Protocol for a Scoping Review. *JMIR Res Protoc* 2022;11:e36158. <https://doi.org/10.2196/36158>.
- [85] Ouzzani M, Hammady H, Fedorowicz Z, Elmagarmid A. Rayyan—a web and mobile app for systematic reviews. *Syst Rev* 2016 51 2016;5:1–10. <https://doi.org/10.1186/s13643-016-0384-4>.
- [86] Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101. <https://doi.org/10.1191/1478088706qp063oa>.
- [87] Schwarz J, Bärkås A, Blease C, Collins L, Hägglund M, Markham S, et al. Sharing Clinical Notes and Electronic Health Records With People Affected by Mental Health Conditions: Scoping Review. *JMIR Ment Health* 2021;8:e34170. <https://doi.org/10.2196/34170>.
- [88] Hägglund M, Kharko A, Hagström J, Bärkås A, Blease C, Cajander Å, et al. The NORDeHEALTH 2022 Patient Survey: Cross-Sectional Study of National

- Patient Portal Users in Norway, Sweden, Finland, and Estonia. *J Med Internet Res* 2023;25:e47573. <https://doi.org/10.2196/47573>.
- [89] Eysenbach G. Improving the Quality of Web Surveys: The Checklist for Reporting Results of Internet E-Surveys (CHERRIES). *J Med Internet Res* 2004;6:e34. <https://doi.org/10.2196/jmir.6.3.e34>.
- [90] Creswell JW, Creswell JD. *Research design: qualitative, quantitative, and mixed methods approaches*. Los Angeles: SAGE; 2018.
- [91] Zanaboni P, Kummervold PE, Sørensen T, Johansen MA. Patient use and experience with online access to electronic health records in Norway: Results from an online survey. *J Med Internet Res* 2020;22. <https://doi.org/10.2196/16144>.
- [92] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349–57. <https://doi.org/10.1093/intqhc/mzm042>.
- [93] Creswell JW, Poth CN. *Qualitative inquiry & research design: choosing among five approaches*. 3rd ed. Thousand Oaks: Sage Publications; 2007.
- [94] Hagström J, Blease C, Haage B, Scandurra I, Hansson S, Hägglund M. Views, Use, and Experiences of Web-Based Access to Pediatric Electronic Health Records for Children, Adolescents, and Parents: Scoping Review. *J Med Internet Res* 2022;24:e40328. <https://doi.org/10.2196/40328>.
- [95] Price A, Clarke M, Staniszewska S, Chu L, Tembo D, Kirkpatrick M, et al. Patient and Public Involvement in research: A journey to co-production. *Patient Educ Couns* 2022;105:1041–7. <https://doi.org/10.1016/j.pec.2021.07.021>.
- [96] Riggare S. E-patients hold key to the future of healthcare. *BMJ* 2018;k846. <https://doi.org/10.1136/bmj.k846>.
- [97] Patton MQ. *Qualitative research & evaluation methods*. London: SAGE; 2002.
- [98] Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15:1277–88. <https://doi.org/10.1177/1049732305276687>.
- [99] Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004;24:105–12. <https://doi.org/10.1016/j.nedt.2003.10.001>.
- [100] World Medical Association. World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects. *J Am Med Assoc* 2013;310:2191–4. <https://doi.org/10.1001/jama.2013.281053>.
- [101] Riksdagsförvaltningen. Lag (2003:460) om etikprövning av forskning som avser människor. Vol. 460. 2003.
- [102] Saunders B, Kitzinger J, Kitzinger C. Anonymising interview data: challenges and compromise in practice. *Qual Res* 2015;15:616–32. <https://doi.org/10.1177/1468794114550439>.
- [103] Hagström J, Hägglund M, Holmroos M, Lähteenmäki P, Hörhammer I. Minors' and guardian access to and use of a national patient portal: A retrospective comparative case study of Sweden and Finland. *Int J Med Inf* 2024;105465. <https://doi.org/10.1016/j.ijmedinf.2024.105465>.
- [104] Miklin DJ, Vangara SS, Delamater AM, Goodman KW. Understanding of and Barriers to Electronic Health Record Patient Portal Access in a Culturally Diverse Pediatric Population. *JMIR Med Inform* 2019;7:e11570. <https://doi.org/10.2196/11570>.
- [105] Frazer C, Ratchford F, Roch J. Enabling Adolescent Electronic Access to Personal Health Information. *Stud Health Technol Inform* 2017;234:115–9.
- [106] Bergman DA, Brown NL, Wilson S. Teen Use of a Patient Portal: A Qualitative Study of Parent and Teen Attitudes. *Perspect Health Inf Manag* 2008;5:13.

- [107] Ramsey A, Lanzo E, Huston-Paterson H, Tomaszewski K, Trent M. Increasing Patient Portal Usage: Preliminary Outcomes From the MyChart Genius Project. *J Adolesc Health* 2018;62:29–35. <https://doi.org/10.1016/j.jadohealth.2017.08.029>.
- [108] Ransom NR. A teen’s perspective: Adolescent access to their own electronic medical records. *Int J Adolesc Med Health* 2016;28:123–4. <https://doi.org/10.1515/ijamh-2015-0081>.
- [109] Hong MK, Wilcox L, Feustel C, Wasileski-Masker K, Olson TA, Simoneaux SF. Adolescent and Caregiver use of a Tethered Personal Health Record System. *AMIA Annu Symp Proc AMIA Symp* 2016;2016:628–37.
- [110] Carlson JL, Goldstein R, Buhr T, Buhr N. Teenager, parent, and clinician perspectives on the electronic health record. *Pediatrics* 2020;145. <https://doi.org/10.1542/peds.2019-0193>.
- [111] Dohil I, Cruz R, Sweet H, Huang JS. Sharing Notes With Adolescents and Young Adults Admitted to an Inpatient Psychiatry Unit. *J Am Acad Child Adolesc Psychiatry* 2021;60. <https://doi.org/10.1016/j.jaac.2020.09.016>.
- [112] Huang JS, Yueh R, Ma S, Cruz R, Bauman L, Choi LJ. Adolescents’ and Young Adults’ Satisfaction with and Understanding of Medical Notes from a Pediatric Gastroenterology Practice: A Cross-Sectional Cohort Study. *J Pediatr* 2019;215:264–6. <https://doi.org/10.1016/j.jpeds.2019.06.052>.
- [113] Calman N, Pfister HR, Lesnewski R, Hauser D, Shroff N. Electronic Access to Adolescents’ Health Records: Legal, Policy, and Practice Implications. vol. 22. 2014.
- [114] Britto MT, Jimison HB, Munafo JK, Wissman J, Rogers ML, Hersh W. Usability Testing Finds Problems for Novice Users of Pediatric Portals. *J Am Med Inform Assoc* 2009;16:660–9. <https://doi.org/10.1197/jamia.M3154>.
- [115] Bell SK, Folcarelli P, Fossa A, Gerard M, Harper M, Leveille S, et al. Tackling Ambulatory Safety Risks Through Patient Engagement: What 10,000 Patients and Families Say About Safety-Related Knowledge, Behaviors, and Attitudes After Reading Visit Notes. *J Patient Saf* 2021;17:e791–9. <https://doi.org/10.1097/PTS.0000000000000494>.
- [116] Kelly MM, Collier RJ, Hoonakker PLT, Nacht CL, Dean SM. Provider Experiences With Offering Families Bedside Health Record Access Across a Children’s Hospital. *Hosp Pediatr* 2020;10:1002–5. <https://doi.org/10.1542/hpeds.2020-0044>.
- [117] Zellmer BM, Nacht CL, Collier RJ, Hoonakker PLT, Smith CA, Sklansky DJ, et al. BedsideNotes: Sharing Physicians’ Notes With Parents During Hospitalization. *Hosp Pediatr* 2021;11:503–8. <https://doi.org/10.1542/hpeds.2020-005447>.
- [118] Kelly MM, Thurber AS, Collier RJ, Khan A, Dean SM, Smith W, et al. Parent Perceptions of Real-time Access to Their Hospitalized Child’s Medical Records Using an Inpatient Portal: A Qualitative Study. *Hosp Pediatr* 2019;9:273. <https://doi.org/10.1542/HPEDS.2018-0166>.
- [119] Sarabu C, Lee T, Hogan A, Pageler N. The Value of OpenNotes for Pediatric Patients, Their Families and Impact on the Patient–Physician Relationship. *Appl Clin Inform* 2021;12:076–81. <https://doi.org/10.1055/s-0040-1721781>.
- [120] Schultz CL, Alderfer MA. Are online patient portals meeting test result preferences of caregivers of children with cancer? A qualitative exploration. *Pediatr Blood Cancer* 2018;65. <https://doi.org/10.1002/PBC.27306>.
- [121] Asan O, Scanlon MC, Crotty B, Holden RJ, Flynn KE. Parental Perceptions of Displayed Patient Data in a PICU: An Example of Unintentional

- Empowerment. *Pediatr Crit Care Med* 2019;20:435–41. <https://doi.org/10.1097/PCC.0000000000001895>.
- [122] Byczkowski TL, Munafo JK, Britto MT. Family perceptions of the usability and value of chronic disease web-based patient portals. *Health Inf J* 2014;20:151–62. <https://doi.org/10.1177/1460458213489054>.
- [123] Kelly MM, Hoonakker PLT, Dean SM. Using an inpatient portal to engage families in pediatric hospital care. *J Am Med Inform Assoc* 2017;24:153–61. <https://doi.org/10.1093/jamia/ocw070>.
- [124] Lam BD, Bourgeois F, Dong ZJ, Bell SK. Speaking up about patient-perceived serious visit note errors: Patient and family experiences and recommendations. *J Am Med Inform Assoc* 2021;28:685–94. <https://doi.org/10.1093/jamia/ocaa293>.
- [125] Kelly MM, Smith CA, Hoonakker PLT, Nacht CL, Dean SM, Sklansky DJ, et al. Stakeholder Perspectives in Anticipation of Sharing Physicians' Notes With Parents of Hospitalized Children. *Acad Pediatr* 2021;21:259–64. <https://doi.org/10.1016/j.acap.2020.11.018>.
- [126] Chung RK, Kim UO, Basir MA. Differing perspectives on parent access to their child's electronic medical record during neonatal intensive care hospitalization: a pilot study. *J Matern Fetal Neonatal Med* 2018;31:1078–84. <https://doi.org/10.1080/14767058.2017.1306853>.
- [127] Smith CA, Collier RJ, Dean SM, Sklansky D, Hoonakker PLT, Smith W, et al. Parent Perspectives on Pediatric Inpatient OpenNotes. *AMIA Annu Symp Proc AMIA Symp* 2019;2019:812–9.
- [128] Gaskin GL, Bruce J, Anoshiravani A. Understanding Parent Perspectives Concerning Adolescents' Online Access to Personal Health Information. *J Particip Med* 2016;8.
- [129] Janssen A, Keep M, Selvadurai H, Kench A, Hunt S, Simonds S, et al. Factors that influence use of a patient portal by health professionals. *Int J Environ Res Public Health* 2021;18:1–14. <https://doi.org/10.3390/IJERPH18041877>.
- [130] Goldstein RL, Anoshiravani A, Svetaz MV, Carlson JL. Providers' Perspectives on Adolescent Confidentiality and the Electronic Health Record: A State of Transition. *J Adolesc Health* 2020;66:296–300. <https://doi.org/10.1016/j.jadohealth.2019.09.020>.
- [131] Stablein T, Loud KJ, DiCapua C, Anthony DL. The Catch to Confidentiality: The Use of Electronic Health Records in Adolescent Health Care. *J Adolesc Health* 2018;62:577–82. <https://doi.org/10.1016/j.jadohealth.2017.11.296>.
- [132] Sharko M, Wilcox L, Hong MK, Ancker JS. 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* 2018;25:1008–17. <https://doi.org/10.1093/jamia/ocy042>.
- [133] Weinstock M. Q&A: Gina Altieri. *Mod Healthc* 2018;48:0032.
- [134] Lee JA, Miller SD, Mezzoff EA, Screws J, Sauer C, Huang JS. The 21st Century CURES Act in Pediatric Gastroenterology: Problems, Solutions, and Preliminary Guidance. *J Pediatr Gastroenterol Nutr* 2021;72:700–3. <https://doi.org/10.1097/MPG.0000000000003117>.
- [135] Spooner SA. Special Requirements of Electronic Health Record Systems in Pediatrics. *Pediatrics* 2007;119:631–7. <https://doi.org/10.1542/PEDS.2006-3527>.
- [136] Gracy D, Weisman J, Grant R, Pruitt J, Brito A. Content Barriers to Pediatric Uptake of Electronic Health Records. *Adv Pediatr* 2012;59:159–81. <https://doi.org/10.1016/j.yapd.2012.04.004>.

- [137] Bourgeois FC, Taylor PL, Emans SJ, Nigrin DJ, Mandl KD. Whose Personal Control? Creating Private, Personally Controlled Health Records for Pediatric and Adolescent Patients. *J Am Med Inform Assoc* 2008;15:737–43. <https://doi.org/10.1197/jamia.M2865>.
- [138] Sittig DF, Singh H. Legal, ethical, and financial dilemmas in electronic health record adoption and use. *Pediatrics* 2011;127:e1042-1047. <https://doi.org/10.1542/peds.2010-2184>.
- [139] Berlan ED, Bravender T. Confidentiality, consent, and caring for the adolescent patient. *Curr Opin Pediatr* 2009;21:450–6. <https://doi.org/10.1097/MOP.0b013e32832ce009>.
- [140] Swartz MK. Protecting the Privacy Rights of Adolescents. *J Pediatr Health Care* 2013;27:161. <https://doi.org/10.1016/j.pedhc.2012.11.007>.
- [141] Bayer R, Santelli J, Klitzman R. New Challenges for Electronic Health Records: Confidentiality and Access to Sensitive Health Information About Parents and Adolescents. *JAMA* 2015;313:29. <https://doi.org/10.1001/jama.2014.15391>.
- [142] Nielsen BA. Confidentiality and electronic health records: Keeping up with advances in technology and expectations for access. *Clin Pract Pediatr Psychol* 2015;3:175–8. <https://doi.org/10.1037/cpp0000096>.
- [143] Taylor JF, Williams RL, Blythe MJ. Healthcare reform, EHRs, and adolescent confidentiality. *Contemp OBGYN* 2015.
- [144] Kendrick EJ, Benson C. Patient Portals in Child and Adolescent Psychiatry. *Child Adolesc Psychiatr Clin N Am* 2017;26:43–54. <https://doi.org/10.1016/j.chc.2016.07.005>.
- [145] Confidentiality in Adolescent Health Care: ACOG Committee Opinion, Number 803. *Obstet Gynecol* 2020;135:e171–7. <https://doi.org/10.1097/AOG.0000000000003770>.
- [146] Williams RL, Taylor JF. Four steps to preserving adolescent confidentiality in an electronic health environment. *Curr Opin Obstet Gynecol* 2016;28:393–8. <https://doi.org/10.1097/GCO.0000000000000305>.
- [147] Gray SH, Pasternak RH, Gooding HC, Woodward K, Hawkins K, Sawyer S, et al. Recommendations for Electronic Health Record Use for Delivery of Adolescent Health Care. *J Adolesc Health* 2014;54:487–90. <https://doi.org/10.1016/j.jadohealth.2014.01.011>.
- [148] Jasik CB. Unlocking the Potential of the Patient Portal for Adolescent Health. *J Adolesc Health* 2016;58:123–4. <https://doi.org/10.1016/j.jadohealth.2015.12.003>.
- [149] Taylor P, Bourgeois FC, Mandl KD. Access controls for a pediatric personally controlled health record. *AMIA Annu Symp Proc AMIA Symp* 2007:1131.
- [150] Green-Shook S. Parental Proxy Access via Web Portals: Ensuring Compliance and Quality Documentation. *J AHIMA* 2009;80:60–1.
- [151] Sherek PD, Gray E. Case study: managing pediatric health information in a patient portal. *J AHIMA* 2014;85:46–7.
- [152] Hagström J, Blease C, Scandurra I, Moll J, Cajander Å, Rexhepi H, et al. Adolescents' reasons for accessing their health records online, perceived usefulness and experienced provider encouragement: a national survey in Sweden. *BMJ Paediatr Open* 2024;8:e002258. <https://doi.org/10.1136/bmjpo-2023-002258>.
- [153] Hagström J, Åhlfeldt R-M, Blease C, Cajander Å, Rexhepi H, Moll J, et al. Security and Privacy of Online Record Access: A Survey of Adolescents' Views and Experiences in Sweden. *J Adolesc Health* 2024;75:730–6. <https://doi.org/10.1016/j.jadohealth.2023.12.027>.

- [154] Steitz BD, Cronin RM, Davis SE, Yan E, Jackson GP. Long-term patterns of patient portal use for pediatric patients at an academic medical center. *Appl Clin Inform* 2017;8:779–93. <https://doi.org/10.4338/ACI-2017-01-RA-0005>.
- [155] Sisk BA, Antes AL, Bereitschaft C, Bourgeois F, DuBois JM. Providing Adolescents with Access to Online Patient Portals: Interviews with Parent-Adolescent Dyads. *J Pediatr* 2024;270:114015. <https://doi.org/10.1016/j.jpeds.2024.114015>.
- [156] Koop CE, Bronheim SM, Stineman M, Schidlow DV, McManus P, Millar H, et al. Growing Up and Getting Medical Care: Youth with Special Health Care Needs. In: Magrab PR, Millar HEC, editors. *Summ. Conf. Proc.*, Jekyll Island, Georgia: Georgetown University Child Development Center; 1989.
- [157] Benjamins J, De Vet E, Jordaan G, Haveman-Nies A. Effect of using client-accessible youth health records on experienced autonomy among parents and adolescents in preventive child healthcare and youth care: A mixed methods intervention study. *J Child Health Care* 2023;13674935231177782. <https://doi.org/10.1177/13674935231177782>.
- [158] Thielmann RR, Hoving C, Cals JW, Crutzen R. Patient online access to medical records in general practice: Perceived effects after one year follow-up. *Patient Educ Couns* 2024;125:108309. <https://doi.org/10.1016/j.pec.2024.108309>.
- [159] Tuchman LK, Slap GB, Britto MT. Transition to adult care: experiences and expectations of adolescents with a chronic illness. *Child Care Health Dev* 2008;34:557–63. <https://doi.org/10.1111/j.1365-2214.2008.00844.x>.
- [160] Chu PY, Maslow GR, von Isenburg M, Chung RJ. Systematic review of the impact of transition interventions for adolescents with chronic illness on transfer from pediatric to adult healthcare. *J Pediatr Nurs* 2015;30:e19–27. <https://doi.org/10.1016/j.pedn.2015.05.022>.
- [161] Xie S, Zhang X, Cheng W, Yang Z. Adolescent anxiety disorders and the developing brain: comparing neuroimaging findings in adolescents and adults. *Gen Psychiatry* 2021;34:e100411. <https://doi.org/10.1136/gpsych-2020-100411>.
- [162] Hellin T. The physician-patient relationship: recent developments and changes. *Haemoph Off J World Fed Hemoph* 2002;8:450–4. <https://doi.org/10.1046/j.1365-2516.2002.00636.x>.
- [163] Blease C, Torous J, McMillan B, Hägglund M, Mandl KD. Generative Language Models and Open Notes: Exploring the Promise and Limitations. *JMIR Med Educ* 2024;10:e51183. <https://doi.org/10.2196/51183>.
- [164] Ayers JW, Poliak A, Dredze M, Leas EC, Zhu Z, Kelley JB, et al. Comparing Physician and Artificial Intelligence Chatbot Responses to Patient Questions Posted to a Public Social Media Forum. *JAMA Intern Med* 2023;183:589–96. <https://doi.org/10.1001/jamainternmed.2023.1838>.
- [165] Zwaan L, Singh H. The challenges in defining and measuring diagnostic error. *Diagnosis* 2015;2:97–103. <https://doi.org/10.1515/dx-2014-0069>.
- [166] Graber ML. The incidence of diagnostic error in medicine. *BMJ Qual Saf* 2013;22:ii21–7. <https://doi.org/10.1136/bmjqs-2012-001615>.
- [167] Blease CR, O’Neill SF, Torous J, DesRoches CM, Hägglund M. Patient Access to Mental Health Notes: Motivating Evidence-Informed Ethical Guidelines. *J Nerv Ment Dis* 2021;209:265–9. <https://doi.org/10.1097/NMD.0000000000001303>.
- [168] Feiler B. Scanzxiety. Fear of a postcancer ritual. *Time* 2011;177:56.

- [169] Tom JO, Mangione-Smith R, Solomon C, Grossman DC. Integrated Personal Health Record Use: Association With Parent-Reported Care Experiences. *Pediatrics* 2012;130:e183–90. <https://doi.org/10.1542/PEDS.2011-1786>.
- [170] Sisk BA, Bereitschaft C, Enloe M, Schulz G, Mack J, DuBois J. Oncology Clinicians' Perspectives on Online Patient Portal Use in Pediatric and Adolescent Cancer. *JCO Clin Cancer Inform* 2023:e2300124. <https://doi.org/10.1200/CCI.23.00124>.
- [171] Blease C, Kharko A, Dong Z, Jones RB, Davidge G, Hägglund M, et al. Experiences and opinions of general practitioners with patient online record access: an online survey in England. *BMJ Open* 2024;14:e078158. <https://doi.org/10.1136/bmjopen-2023-078158>.
- [172] Hagström J, Blease C, Kharko A, Scandurra I, Hägglund M. Adolescents Identifying Errors and Omissions in Their Electronic Health Records: A National Survey. *Stud Health Technol Inform* 2023;302:242–6. <https://doi.org/10.3233/SHTI230111>.
- [173] Sawhney PN, Davis LS, Daraiseh NM, Belle L, Walsh KE. Barriers and Facilitators of Adverse Event Reporting by Adolescent Patients and Their Families. *J Patient Saf* 2020;16:232–7. <https://doi.org/10.1097/PTS.0000000000000290>.
- [174] Wachenheim D, Hurwitz I, Dukhanin V, Wolff J, DesRoches CM. Shared Access to Adults' Patient Portals: A Secret Shopper Exercise. *Appl Clin Inform* 2024;a-2370-2220. <https://doi.org/10.1055/a-2370-2220>.
- [175] Ip W, Yang S, Parker J, Powell A, Xie J, Morse K, et al. Assessment of Prevalence of Adolescent Patient Portal Account Access by Guardians. *JAMA Netw Open* 2021;4:1–9. <https://doi.org/10.1001/jamanetworkopen.2021.24733>.
- [176] Xie J, Hogan A, McPherson T, Pageler N, Lee TC, Carlson J. Creating a Guardrail System to Ensure Appropriate Activation of Adolescent Portal Accounts. *Appl Clin Inform* 2023;a-2015-0964. <https://doi.org/10.1055/a-2015-0964>.
- [177] Holmberg S. Grov fridskränkning mot barn. Stockholm: Brottsförebyggande rådet; 2023.
- [178] Fjelkegård L, Franke Björkman K, Patel E. Utnyttjande av barn genom köp av sexuell handling. Stockholm: Brottsförebyggande rådet; 2022.
- [179] Hagström J, Blease C, Moll J, Rexhepi H, Scandurra I, Hägglund M. Adolescents' and Young Adults' Experiences of Offense from Reading Their Health Records Online. In: Bichel-Findlay J, Otero P, Scott P, Huesing E, editors. *Stud. Health Technol. Inform.*, vol. 310, Sydney, Australia: IOS Press; 2024, p. 1422–3. <https://doi.org/10.3233/SHTI231225>.
- [180] Alpert JM, Morris BB, Thomson MD, Matin K, Geyer CE, Brown RF. Open-Notes in oncology: oncologists' perceptions and a baseline of the content and style of their clinician notes. *Transl Behav Med* 2019;9:347–56. <https://doi.org/10.1093/tbm/iby029>.
- [181] Nielsen MS, Steinsbekk A, Nøst TH. Development of Recommendations for the Digital Sharing of Notes With Adolescents in Mental Health Care: Delphi Study. *JMIR Ment Health* 2024;11:e57965–e57965. <https://doi.org/10.2196/57965>.
- [182] Sisk BA, Antes AL, Bereitschaft C, Enloe M, Lin S, Srinivas M, et al. Engaging Adolescents in Using Online Patient Portals. *JAMA Netw Open* 2023;6:e2330483. <https://doi.org/10.1001/jamanetworkopen.2023.30483>.
- [183] Van Mens HJT, Hannen GEG, Nienhuis R, Bolt RJ, De Keizer NF, Cornet R. Evaluation of Patient-Friendly Diagnosis Clarifications in a Hospital Patient

- Portal. *Appl Clin Inform* 2023;14:455–64. <https://doi.org/10.1055/a-2067-5310>.
- [184] Goldstein RL, Mermelstein SJ, Sisk BA, Carlson JL. 152. Managing Adolescent Confidentiality in the Electronic Health Record Post Implementation of the 21st Century Cures Act Final Rule: A Survey of Providers. *J Adolesc Health* 2023;72:S86. <https://doi.org/10.1016/j.jadohealth.2022.11.174>.
- [185] Fernández L, Fossa A, Dong Z, Delbanco T, Elmore J, Fitzgerald P, et al. Words Matter: What Do Patients Find Judgmental or Offensive in Outpatient Notes? *J Gen Intern Med* 2021;36:2571–8. <https://doi.org/10.1007/s11606-020-06432-7>.
- [186] DesRoches CM, Leveille S, Bell SK, Dong ZJ, Elmore JG, Fernandez L, et al. The Views and Experiences of Clinicians Sharing Medical Record Notes With Patients. *JAMA Netw Open* 2020;3:e201753. <https://doi.org/10.1001/jamanetworkopen.2020.1753>.
- [187] Grünloh C, Myreteg G, Cajander Å, Rexhepi H. “Why Do They Need to Check Me?” Patient Participation Through eHealth and the Doctor-Patient Relationship: Qualitative Study. *J Med Internet Res* 2018;20:e8444. <https://doi.org/10.2196/JMIR.8444>.
- [188] Park K, Park MD, Longhurst CA. Patient and Family Access to Electronic Health Records: A Key Ingredient for a Pediatric Learning Health System. *J Particip Med* 2015;7:e2.
- [189] Blease C, McMillan B, Salmi L, Davidge G, Delbanco T. Adapting to transparent medical records: international experience with “open notes.” *BMJ* 2022:e069861. <https://doi.org/10.1136/bmj-2021-069861>.
- [190] Kaufman A, Rungvivatjarus T, Pierce H, Chong A, Kuelbs CL. Improving Sexual History Documentation in Teenagers. *Hosp Pediatr* 2024;14:455–62. <https://doi.org/10.1542/hpeds.2023-007144>.
- [191] Definition of Youth. United Nations Department of Economic and Social Affairs (UNDESA); 2013.
- [192] Sweden in the Digital Economy and Society Index | Shaping Europe’s digital future n.d. <https://digital-strategy.ec.europa.eu/en/policies/desi-sweden> (accessed October 8, 2024).
- [193] Peters D, Youssef FF. Public trust in the healthcare system in a developing country. *Int J Health Plann Manage* 2016;31:227–41. <https://doi.org/10.1002/hpm.2280>.
- [194] Ketterer T, West DW, Sanders VP, Hossain J, Kondo MC, Sharif I. Correlates of Patient Portal Enrollment and Activation in Primary Care Pediatrics. *Acad Pediatr* 2013;13:264–71. <https://doi.org/10.1016/j.acap.2013.02.002>.
- [195] LeLaurin JH, Nguyen OT, Thompson LA, Hall J, Bian J, Cho HD, et al. Disparities in Pediatric Patient Portal Activation and Feature Use. *JAMIA Open* 2021;4:ooab086. <https://doi.org/10.1093/jamiaopen/ooab086>.
- [196] Schultz CL, McCahan SM, Lewis AM, Bunnell HT, Alderfer MA. Online patient portal use by caregivers in pediatric oncology: Are we widening socio-demographic disparities? *Pediatr Blood Cancer* 2021;68:e29373. <https://doi.org/10.1002/pbc.29373>.
- [197] Solebo AL, Horvat-Gitsels L, Twomey C, Wagner SK, Rahi JS. Socioeconomic and demographic patterning of family uptake of a paediatric electronic patient portal innovation. *PLOS Digit Health* 2024;3:e0000496. <https://doi.org/10.1371/journal.pdig.0000496>.
- [198] Brinkmann S, Kvale S. *InterViews: learning the craft of qualitative research interviewing*. 3rd ed. Los Angeles: Sage Publications; 2015.

- [199] Venkatesh V, Morris MG, Davis GB, Davis FD. User Acceptance of Information Technology: Toward a Unified View. *MIS Q* 2003;27:425–78. <https://doi.org/10.2307/30036540>.
- [200] Michie S, Van Stralen MM, West R. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implement Sci* 2011;6:42. <https://doi.org/10.1186/1748-5908-6-42>.
- [201] Kharko A, McMillan B, Hagström J, Muli I, Davidge G, Hägglund M, et al. Generative artificial intelligence writing open notes: A mixed methods assessment of the functionality of GPT 3.5 and GPT 4.0. *Digit Health* 2024;10:20552076241291384. <https://doi.org/10.1177/20552076241291384>.
- [202] Blease C, Kharko A, Hägglund M, O’Neill S, Wachenheim D, Salmi L, et al. The benefits and harms of open notes in mental health: A Delphi survey of international experts. *PLOS ONE* 2021;16:e0258056. <https://doi.org/10.1371/journal.pone.0258056>.

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