Patients' Access to Their Mental Health Records

Understanding Policy, Access, and Patient Experiences

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Abstract
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ORA is the concept of patients' access to clinical information, which has become more widespread worldwide. When patients are provided online record access (ORA) to their health records, concerns have been raised by healthcare professionals, especially when it comes to patients with mental health diagnoses. In the general population, positive aspects appear to outweigh the negative, yet limited research has so far explored the impact of ORA in mental healthcare.

The overall aim of this thesis was to explore how patients experience ORA in mental healthcare through four studies: 1) a literature review aimed to explore the current literature on the experiences of ORA among mental healthcare patients, care partners, and healthcare professionals, 2) a document analysis combined with key stakeholder email interviews that aimed to explore to what extent ORA in mental healthcare has been implemented in Sweden including national and local policy regulations, 3) an online patient survey study aimed to understand mental healthcare patients' experiences with ORA in Sweden, Estonia, Finland, and Norway, and 4) an online patient survey study aimed to understand if and how patients with mental health conditions experiences of ORA differs from patients in other healthcare settings.

More patients reported positive experiences with ORA in mental healthcare than negative experiences. Common benefits of ORA included, among others, a greater sense of control over their care, improved understanding of their mental health diagnosis, and better adherence to appointments. Despite patients' predominant positive experiences, only 17 out of 21 regions in Sweden offered ORA in mental healthcare in 2021. Additionally, many patients experienced errors and omissions and felt offended by the content of their health records. Mental healthcare patients experienced this at a higher rate than patients in other healthcare settings.

In conclusion, mental healthcare patients have higher rates of negative experiences of ORA compared to patients in other healthcare settings. However, patients' experiences of ORA are still predominantly positive among both patient groups. Yet, in 2021, only 17 regions offered patients ORA in mental healthcare. Denying mental healthcare patients ORA to protect them from negative experiences could instead increase stigma in this patient group.

Keywords: Mental health, Psychiatry, Online Record Access, Patient-Accessible Electronic Health Records, Open notes, Patient experiences

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List of Papers

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

I. Schwarz, J*., **Bärkås, A***., Blease, C., Collins, L., Hägglund, M., Markham, S., Hochwarter, S. (2021) Sharing Clinical Notes and Electronic Health Records with People Affected by Mental Health Conditions: Scoping Review. *JMIR Mental Health*. 8(12):e34170.

II. **Bärkås, A**., Scandurra, I., Rexhepi, H., Blease, C., Cajander, Å., Hägglund, M. (2021) Patients' Access to Their Psychiatric Notes: Current Policies and Practices in Sweden. *International Journal of Environmental Research and Public Health*, 18(17):940.

III. Fagerlund, A.J*., **Bärkås, A***., Kharko, A., Blease, C., Hagström, J., Huvila, I., Hörhammer, I., Kane, B., Kristiansen, E., Kujala, S., Moll, J., Rexhepi, H., Scandurra, I., Simola, S., Soone, H., Wang, B., Åhlfeldt, R.M., Hägglund, M., Johansen, M.A. (2023). Experiences from patients in mental healthcare accessing their electronic health records: results from a cross-national survey in Estonia, Finland, Norway and Sweden. (Submitted to *BMC Psychiatry*).

IV. **Bärkås, A**., Kharko, A., Blease, C., Cajander, Å., Fagerlund, A.J., Huvila, I., Johansen, M.A., Kane, B., Kujala, S., Moll, J., Rexhepi, H., Scandurra, I., Wang, B., Hägglund, M. (2023) Errors, Omissions and Offenses in the Health Record of Mental Health Care Patients: Results from a Nationwide Survey in Sweden. *Journal of Medical Internet Research*. 25:e47841.

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Additional Work

In addition to the work presented in this thesis, contribution was made to following papers during the PhD studies:

- **Bärkås, A.**, Kharko, A., Åhlfeldt, RM., Hägglund, M. (2024) Patients' Experiences of Demanded Access to Online Health Records. *Studies in Health Technology and Informatics*. 310:1424-1425. [Conference].
- 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. *International Journal of Medical Informatics*. 181:105302.
- **Bärkås, A.**, Kharko, A., Åhlfeldt, RM., Hägglund, M. (2023) Patients' Experiences of Unwanted Access to Their Online Health Records. *Studies in Health Technology and Informatics*. 302:356-357. [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. *Journal of Medical Internet Research*. 25:e47573.
- Wang, B., Kristiansen, E., Fagerlund, A.J., Zanaboni, P., Hägglund, M., **Bärkås, A.**, et al. (2023) Users' Experiences with Online Access to Electronic Health Records in Mental and Somatic Health Care: Cross-Sectional Study. *Journal of Medical Internet Research*. 25:e47840.
- 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. *Journal of Medical Internet Research*. 25:e45974.
- **Bärkås, A.**, Hägglund, M., Moll, J., Cajander, Å., Rexhepi, H., et al. (2022) Patients' Access to Their Psychiatric Records: A Comparison of Four Countries. *Studies in Health Technology and Informatics*. 294:510-514. [Conference].
- Hägglund, M., Kharko, A., **Bärkås, A.**, Blease, C.., Cajander, Å., DesRoches, C., et al. (Preprint) NORDeHEALTH – Learning from the Nordic Experiences of Patient Online Record Access. *JMIR Preprints*. 2023;49084.
- Moll, J., Scandurra, I., **Bärkås, A.**, Blease, C., Hägglund, M., Hörhammer, I., et al. (Preprint) A Socio-Technical analysis of Patients' Access to Electronic Health Records (PAEHR) in four European countries: Method Development and Cross-Country Comparison of Contextual Factors. *JMIR Preprints*. 2023;55752.

Contents

Abbreviations

AMI	Any Mental Illness
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, 4th Edition
EHDS	European Health Data Space
EHR	Electronic Health Record
EU	European Union
HCP	Healthcare Professional
ICD-11	International Classification of Diseases 11th Revision
ISO	International Organization for Standardization
NRF	National Regulatory Framework
OCD	Obsessive Compulsive Disorder
ORA	Online Records Access
PAEHR	Patient-Accessible Electronic Health Record
PTSD	Post-Traumatic Stress Disorder
SMI	Serious Mental Illness
US	United States
VA	U.S. Department of Veterans Affairs
WHO	World Health Organization

Key Concepts

Error	In this thesis, Error is defined as inaccuracies in the content of the EHR reported by patients. **Note:** Error should not be confused with 'Medical Error', which is defined as "an act of commission or omission that substantively increases the risk of a medical adverse event, and can result from the failure of planned action to be completed as intended" [1].
Omission	In this thesis, Omission is defined as the absence of information in the EHR reported by patients. **Note:** Omission should not be confused with 'Error of Omission', which is defined as "a medical error resulting in an inappropriate increased risk of disease-related adverse event(s) resulting from receiving too little treatment (underuse), and includes delays in diagnosis, and failure to provide indicated treatments" [1].
Offense	"The feeling of offense is a negative emotion felt when an action or omission of someone, with whom we have a relevant affective relationship, causes a blow to our image" [2].
Online Record Access (ORA)	"ORA has been used as a 'solution-neutral' concept to describe the phenomenon of patients' online record access. ORA can be implemented through a tethered PAEHR or any other technical solution that gives patients online record access" [3].
Open notes	"Open notes has been used to describe the phenomenon of patients' online access to free-text notes written by clinicians in the EHR. Open notes can be seen as a key part of ORA" [3].
Patient-Accessible Electronic Health Record (PAEHR)	"The term PAEHR is describing a solution that gives patients online access to their EHR" [3].
Patient Experiences	In this thesis, patients' experiences of interacting with their PAEHR are explored; hence, they are users of a technical solution. User experiences are defined as "Users' perceptions

and responses include the users' emotions, beliefs, preferences, perceptions, comfort, behaviors, and accomplishments that occur before, during and after use. These experiences are influenced by the user's internal and physical state resulting from prior experiences, attitudes, skills, abilities and personality; from the context of use" (ISO 9241-210:2019) [4].

Positive experience In this thesis, a positive experience is defined as feeling a positive emotion: "an emotional reaction designed to express a positive affect, such as happiness when one attains a goal, relief when danger has been avoided, or contentment when one is satisfied with the present state of affairs" [5], where an emotion is defined as: "complex reaction pattern, involving experiential, behavioral, and physiological elements, by which an individual attempts to deal with a personally significant matter or event" [6].

Negative experience In this thesis, a negative experience is defined as feeling a negative emotion: "an unpleasant, often disruptive, emotional reaction designed to express a negative affect, and it is not conducive to progress toward obtaining one's goal" [6].

Introduction

Patients' Online Record Access (ORA) is increasingly implemented worldwide [3,8,9]. ORA is a concept that describes the phenomenon of patients' access to their clinical information online and is independent of any specific solution or platform [3]. ORA is often provided through Patient-Accessible Electronic Health Records (PAEHR), which can be described as web-based platforms allowing patients to view their Electronic Health Records (EHR) [3,8,9]. There are generally many indications of positive aspects of ORA, but also much concern, especially within mental healthcare. However, this has been a relatively unexplored area, hence the importance of this thesis, which aims to explore how patients experience ORA in mental healthcare.

Internationally, the implementation of ORA has become more widespread, but it has yet to become universally standard. In Europe, countries like Sweden [8], Norway [10], Finland [11], and Estonia [12] have rolled out nationwide PAEHRs, serving most of their population. In Sweden, the PAEHR Journalen allows citizens to log in via a secure solution, offering them ORA to their clinical information, such as notes, lab results, medications, diagnoses, and referrals [13]. More recently, the European Commission has introduced the European Health Data Space (EHDS) initiative. This scheme aims to give all EU citizens access to their EHRs, in line with the EU's digital strategy for 2030 [14]. Meanwhile, the OpenNotes initiative started in the US in 2010, advocating for clearer patient access to their medical records [15]. As of April 5, 2021, the 21st Century Cures Act, a US federal legislation, requires all healthcare providers to offer patients online access to their full EHR, encompassing test results and clinical notes [16]. Giving patients access to their EHRs has been debated in nearly all nations that have adopted ORA, with mental healthcare access being especially controversial.

In this thesis, the first two studies explore current knowledge about patients' and other stakeholders' experiences with ORA in mental healthcare (Study I) and to what extent ORA in mental healthcare has been implemented in Sweden (Study II). These studies set the stage for and provide important input to the remaining two studies that explore patients' experiences of ORA in mental healthcare in Sweden, Estonia, Finland, and Norway through an online patient survey; Study III explores mental healthcare patients experiences with ORA in the four countries, and Study IV compares mental healthcare patients' experiences of ORA with patients in other healthcare settings, with focus on Sweden. Through qualitative and quantitative studies, this doctoral thesis aims

to contribute a deeper understanding of patients' experiences with ORA in mental healthcare by addressing the existing knowledge gap. Additionally, this thesis seeks to provide guidance to policymakers for care on equal terms with new insights on this controversial topic. Care on equal terms includes patients' right to information and participation in their care, which is highly relevant to ORA in mental healthcare. The following research questions are addressed:

1. What is currently known internationally about the experiences of ORA in mental healthcare? *(Study I)*
2. To what extent are Swedish patients offered access to their records from mental healthcare? *(Study II)*
3. What are mental healthcare patients' experiences with ORA in Sweden, Estonia, Finland, and Norway? *(Study III)*
4. Are patients with mental health conditions more likely than non-mental healthcare patients to find errors and omissions and to feel offended when reading their records? *(Study IV)*

Mental Health

About 970 million individuals were living with a mental health condition in 2019 globally. This number can be translated to one in every eight individuals globally, in which the most common mental health conditions were anxiety and depression [17]. According to the International Classification of Diseases 11th Revision (ICD-11), "mental, behavioral and neurodevelopmental conditions are syndromes characterized by clinically significant disturbance in an individual's cognition, emotional regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes that underlie mental and behavioral functioning" [18]. Mental health conditions include, among others, mental, neurological, and substance use disorders, suicide risk, and associated psychosocial, cognitive, and intellectual disabilities, as an umbrella term [19].

Individuals living with a mental health condition are described to often suffer from impairment of functioning in everyday life and significant stress [17,18]. According to the US-based National Institute of Mental Health, mental illness includes mental health conditions that are diagnosable according to the 4th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) [20]. Mental health conditions can vary in severity and can be included in two categories of mental illness: Any Mental Illness (AMI) and Serious Mental Illness (SMI). AMI is defined as a "mental, behavioral, or emotional disorder, which can vary in impact, ranging from no impairment to mild, moderate, and even severe impairment" [20]. SMI, on the other hand, is defined as "mental, behavioral, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more

major life activities, with the burden of mental illness particularly concentrated among those who experience disability due to SMI" [20]. The U.S. Department of Veterans Affairs (VA), identifies several mental health diagnoses under SMI, including Major Depression, Schizophrenia Spectrum Disorder, Bipolar Disorder, Obsessive Compulsive Disorder (OCD), Panic Disorder, Post-Traumatic Stress Disorder (PTSD), and Borderline Personality Disorder [21].

Mental Healthcare in Sweden

Sweden has a decentralized healthcare system consisting of 21 autonomous regions, with private healthcare providers operating across multiple regions. The governance of Swedish healthcare is underpinned by the Swedish Healthcare Act (2017:30) and the Swedish Patient Act (2014:821). Both emphasize the significance of offering equal care to every citizen.

The context of psychiatric care in Sweden is viewed holistically and includes outpatient care, inpatient care, and psychotherapy. Moreover, it encompasses a diverse team of professionals, including physicians, nurses, nursing assistants, psychologists, physical therapists, occupational therapists, medical secretaries, and social workers [22,23]. An individual can receive psychiatric care from primary care centers, psychiatric outpatient clinics, and psychiatric inpatient clinics at hospitals. Psychiatric care in Sweden consists of three main healthcare settings: Pediatrics and Adolescent Psychiatry, Adult Psychiatry, and Forensic care.

If an individual under 18 requires mental healthcare, the individual or their caregiver can seek the necessary care. Primary care centers or youth clinics can assist with mild to moderate mental health conditions, including sleep problems, mild to moderate anxiety, or depression. Severe or acute mental health conditions, such as self-harming behavior, eating disorders, or severe anxiety or depression, are treated at specialized pediatric and adolescent psychiatry clinics [24].

For individuals over the age of 18 in need of mental healthcare, primary care is the first point of contact, offering care for mild mental health conditions such as crisis support, counseling, and psychological treatment. If specialist psychiatric care is required, such as for depression, anxiety, addiction issues, eating disorders, suicidal ideation, or trauma- and stress-related issues due to war, a referral will be made to a specialist psychiatric outpatient clinic for further assessment and treatment [25]. Some adults may require psychiatric inpatient care, either voluntarily or involuntarily. Initial assessment by a physician is necessary, typically at a primary care center, emergency department, or psychiatric outpatient clinic. This assessment is required even for voluntary inpatient care, often due to the risk of self-harm, psychotic symptoms, or insufficient outpatient psychiatric care. Individuals suffering from SMI who re-

quire 24-hour psychiatric care but resist it may be subject to involuntary psychiatric care under the Act on Compulsory Psychiatric Care (1991:1128) or the Act on Forensic Psychiatric Care (1991:1129) [26].

In cases where an individual commits a criminal act under the influence of a serious mental disorder, they will not be sentenced to prison but to forensic psychiatric care. The determination of whether the individual had a serious mental disorder during the criminal act is made through a forensic psychiatric examination conducted by the National Board of Forensic Medicine to determine the sentence in a criminal case [27].

Implementation of ORA in Sweden

In 1997, the Uppsala Region aimed to provide patients access to their health records by initiating the EU project SUSTAINS. However, five years later, a pilot study of a PAEHR was developed but was subsequently shut down by the Swedish Data Inspection Board due to legal issues. The decision to close the PAEHR was discussed, leading to the resolution of the legal issues in 2008 with the introduction of the Swedish Patient Data Act (2008:355) [13]. This act mandates, among other things, that healthcare providers must document patients' clinical data in the EHR and ensure patients' privacy and security when sharing the EHR with them. Most importantly, the act does not require or force healthcare providers to share health records online with patients; it only allows it [28].

Apart from legal issues, the process of providing patients access to their EHR faced resistance from the Swedish Medical Association, which sought to delay the introduction of the PAEHR due to concerns that it would impede healthcare providers' work as patients may not understand the content and may ask questions [29]. However, by 2012, approximately 300,000 patients in Region Uppsala had access to the PAEHR. Since 2015, the Swedish national eHealth organization (Inera AB) has been responsible for the maintenance and development of the PAEHR, named Journalen (1177.se) [13].

Inera has, in collaboration with the Swedish Association of Local Authorities and Regions, comprising all 21 regions, introduced the Swedish National Regulatory Framework (NRF). The NRF ensures that every citizen has equal digital access to their health information regardless of where they live or receive care [30,31]. Inera emphasizes that all regions have adopted the NRF, suggesting that every Swedish citizen should have access to their entire health records.

By 2016 [8,13], 17 regions had integrated with Journalen to provide citizens with ORA to their clinical information, and by 2017, this number increased to 19 regions [32]. Today, all 21 Swedish regions offer citizens ORA to their clinical information in Journalen, including clinical notes, lab results, diagnoses, referrals, and medications. However, the information available in

Journalen may vary depending on the region where the patient receives care, as each of the 21 regions has distinct policy documents regarding patient ORA. However, offering patients access to their clinical notes from psychiatric care remains controversial. A study from 2018 indicated that only two of the 21 regions provided patients access to notes from psychiatric clinics at that time [8].

The NORDeHEALTH Research Project

The studies in this doctoral thesis project are performed within the NORDe-HEALTH research project (www.nordehealth.eu), funded by NordForsk. The project has partners from Sweden, Norway, Finland, Estonia, and the USA and aims to identify the challenges and opportunities in digitalizing health services, especially when national portals are implemented to give patients online access to their EHRs. The overall project does not focus on mental health exclusively.

The contribution of this thesis to the project is to comprehend the experiences of mental healthcare patients with ORA. An integral aspect of the NORDeHEALTH project has been conducting a socio-technical analysis of PAEHR implementation across different countries aimed at developing a comprehensive, collaborative method suitable for cross-country socio-technical analysis [33]. This thesis has included an analysis of the extent to which patients have access to their mental health records in Sweden, including policy regulations and frameworks, as this serves as an important starting point for future research.

Significance

Mental health conditions affect millions globally, with anxiety and depression ranking among the leading causes of illness according to the WHO [17]. Despite the prevalence of these conditions, patients may face challenges in managing their health, including medication adherence [17,34]. In this context, ORA has emerged as a potentially empowering tool; however, there are challenges to improving standards of documentation while respecting patients and optimizing clinical benefits [35]. The unique complexities of shared mental health notes raise concerns about their impact on patients' well-being [22]. The existing literature has yet to fully address these complexities, leaving a knowledge gap in the understanding of how patients experience ORA in mental healthcare settings.

This thesis aims to fill this knowledge gap by providing new insights into the challenges and benefits of patients accessing their mental health records online. Specifically, this thesis seeks to explore whether patients perceive ORA as beneficial or harmful and whether ORA is equally shared with mental healthcare patients. By addressing these questions, this thesis seeks to provide guidance to policymakers for care on equal terms and guidance in policies and practices surrounding ORA in mental healthcare. Additionally, this thesis aims to offer insights to other countries planning to implement ORA, as Sweden and the included countries in the NORDeHEALTH project are at the forefront of ORA implementation.

Aims

The overall aim of the doctoral thesis was to explore how ORA in mental healthcare is experienced by patients. The four studies´ specific aims were:

    I.   To explore the current literature on the effects of ORA among patients, care partners, and HCPs.

    II.   To explore Swedish national and local policy regulations regarding patients' ORA in mental healthcare and describe to what extent patients are provided ORA in mental healthcare.

    III.   To understand mental healthcare patients' experiences with ORA in Sweden, Estonia, Finland, and Norway.

    IV.   To understand if and how patients with mental health conditions experiences of ORA differs from patients in other healthcare settings.

Methods

This section will describe the methods of the four included studies. The studies included different methodological approaches, see Table 1.

Table 1. Overview of the included studies methodological approaches.

	Study I	**Study II**	**Study III**	**Study IV**
Design	Literature review	Qualitative	Quantitative	Quantitative
Data acquisition	Systematic scoping review of current evidence	Web-based gathering of policy and regulatory documents; email interviews	Online patient survey with responses from Sweden, Estonia, Finland, Norway	Online patient survey with responses from Sweden only
Participants	Not applicable	Key stakeholders from Swedish regions and private healthcare providers	Users of the national patient portal in each country	Users of the national patient portal in Sweden
Analysis	Thematic analysis	Document analysis	Descriptive, comparative statistics	Descriptive, summative, comparative statistics

Study I

The aim was to explore the current literature on the effects of ORA among patients, care partners, and HCPs, to understand what is currently known internationally about the experiences of ORA in mental healthcare.

Design

A systematic scoping review [36,37] was undertaken due to the exploratory nature of the research question and the absence of existing systematic reviews

in the research area. This method aims to explore evidence in relatively new fields of research, allowing for the exploration of broader topics where various study designs may be applicable, especially in areas that are broad and poorly defined [36]. To the best of the researchers' knowledge, this study represents the first systematic scoping review collating existing research on ORA with people with mental health conditions. While a systematic review typically focuses on a specific research question using a narrow range of quality-assessed studies [36], the broader scope of this research area made a systematic scoping review the most appropriate method.

Data Collection

The study involved a thorough literature search in six electronic databases based on the key concepts 1) EHR, 2) sharing EHR with patients, and 3) mental health – all based on the research question "What is known from the existing literature about sharing EHRs or clinical notes with people affected by a mental health condition." Table 2 presents the inclusion and exclusion criteria of the included studies.

Mixed Method Appraisal Tool (MMAT) was utilized to evaluate the quality of the included studies. The evaluation with MMAT focuses on the methods. It includes criteria such as the appropriateness and rigor of methods, management of confounding factors, reduction of selection bias, and acknowledgment of study limitations. MMAT is tailored for systematic reviews covering qualitative, quantitative, and mixed-method studies [38,39]. The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) Extension for Scoping Reviews checklist was used to report the findings and ensure reproducibility and traceability [40].

Table 2. Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
- Studies in English	- Grey data (Websites, tweets, and blogs)
- No restriction on the type of study	- Paper-based sharing of patient files
- Studies containing original empirical data	- Pediatric and adolescent healthcare settings
- Studies on patients affected by a mental health condition (>18 years)	
- Studies on care partners or family members of people affected by mental health condition	
- Studies on HCPs	
- Studies on policy stakeholders	
- All healthcare settings	
- No location restrictions	

Data Analysis

A thematic analysis [41] was independently conducted on the included studies (n=31) by two researchers. This analysis aimed to identify key themes within the compiled material, and the findings of Study I were organized accordingly.

First, the results from the included studies were compiled and analyzed by reading each of the included studies' results. The included studies were compiled in a Word document. Then, the material was categorized and sorted for common themes that emerged during the analysis, such as "patients' positive experiences". These themes were then further categorized and coded using color schemes to organize the text based on the frequency of specific experiences. Identified themes included Patients' positive experiences, Patients' negative experiences, HCPs' experiences, Experiences of care partners, and Views of policy stakeholders.

Study II

The aim was to explore Swedish national and local policy regulations regarding patients' ORA in mental health and describe to what extent patients are provided ORA to mental healthcare records. The study was conducted to describe ORA in Swedish mental healthcare.

Design

A qualitative approach with sequential data collection, divided into three steps, was utilized for Study II. First, a document analysis [42] was conducted on the regions and private healthcare providers' web pages on information and policies regarding ORA in psychiatric care, utilizing thematic analysis of the collected material. Second, the material was compiled according to the themes, followed by (third step) key stakeholder email interviews based on the collected material and emerging themes.

Participants

The study involved key stakeholders from the Swedish regions (n=21) and private healthcare providers (n=3). Recruitment of included participants was conducted through a closed eService, utilized by healthcare providers to exchange experiences and coordinate implementation of ORA in their respective organizations.

Data Collection

A sequential data collection process began with an analysis of policies regarding patients' access to their health records in psychiatric care, using information obtained from the web pages of the 21 regions and three private healthcare providers. The findings were collected in an Excel document to gain an overview of the findings and to categorize the findings for analysis. The next step was to conduct key stakeholder email interviews with representatives from each region and private healthcare providers to validate and supplement the web-based findings. The email interviews included structured and semi-structured questions, with the possibility of providing attached documents and the opportunity to explore answers to questions they could not immediately respond to.

Data Analysis

The qualitative analysis involved categorizing and interpreting the collected data, focusing on the regional implementations of ORA to psychiatric notes in the PAEHR. The categories analyzed were 1) which regions and private care providers share psychiatric notes and in which psychiatric care settings, 2) are notes shared with patients in outpatient and inpatient psychiatric care, 3) are both signed and unsigned notes shared, and 4) are the notes shared with immediate or delayed access.

The email interview provided further detail to the analysis, and enabled completing the results with information that was missing in the analyzed policy materials.

The NORDeHEALTH Patient Survey

An online patient survey (the NORDeHEALTH patient survey [3]) was distributed nationwide in the respective national PAEHR in Sweden, Estonia, Finland, and Norway as part of the international research project NORDeHEALTH, see Figure 1 for an overview of the survey items.

Participants of Study III and Study IV were users of the national patient portals in the four included countries (Sweden: 1177 Journalen, Estonia: Digilugu, Finland: My Kanta, Norway: Pasientsjournal) who logged in to their accounts during the available duration of the patient survey. The survey remained accessible to users for three weeks in Sweden, Finland, and Norway. In Estonia, the survey was open for nine weeks due to the lower number of responses affected by the lower population. Eligibility criteria included participants aged 15 years or above in Sweden, Estonia, and Finland, those aged 16 or above in Norway, and those who spoke the national languages in which the survey was conducted. Participation was voluntary. In total, 29,334 patient

users responded: 13,008 (44.35%) responses in Sweden, 2104 (7.17%) in Estonia, 4719 (16.07%) in Finland, and 9508 (32.40%) in Norway [3].

The survey consisted of single- and multiple-choice questions and Likert scale ratings, totaling 45 questions (38 closed-ended and seven open-ended). Figure 1 presents the thematic sections of the survey questions.

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. ... Betters communication between me and HCPs

Note: For accurate wording, see Multimedia Appendix 2 & 3
HCP - healthcare professional, *HR* - health record,
MDT - multidisciplinary meeting, *ORA* - online records access

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

Figure 1. Overview of the survey items (adapted from [3]).

Study III

The aim was to understand mental healthcare patients' experiences with ORA in Sweden, Estonia, Finland, and Norway.

Design

Study III focused on the survey responses from patients with mental healthcare experiences in Sweden, Estonia, Finland, and Norway from the NORDeHEALTH Patient Survey.

Participants

In total, 29,334 patient users responded, and only those who responded that they had received mental healthcare (N=6157) on the survey question "Have you been in contact with a healthcare professional in the last two years for any of the following?" were included. Answer options were "mental health", "cancer", "other health problems", and "no care, no treatment". Those who did not check the box for "mental health" (n=23,177) were excluded. The remaining participants included those who responded to "mental health" as a solitary response or together with "cancer" and/or "other health problems", as this was a multiple-choice question. The number of included participants in this study was 3131 (50.85%) in Sweden, 334 (5.42%) in Estonia, 693 (11.26%) in Finland, and 1999 (32.47%) in Norway, based on the total of included participants (N=6157). Table 3 provides an overview of the types of care the participants indicated receiving treatment for, to indicate the co-existence of other care needs among the population.

Table 3. Included participants per country based on the question "Have you been in contact with a healthcare professional in the last two years for any of the following?"

Answer option	Sweden n=3131, n(%)	Estonia n=334, n(%)	Finland n=693, n(%)	Norway n=1999, n(%)
Mental health	3131 (100)	334 (100)	693 (100)	1999 (100)
Cancer	174 (5.56)	16 (4.79)	39 (5.63)	144 (5.70)
Other health problems	2441 (77.96)	273 (81.74)	628 (90.62)	1561 (78.09)

Note: Due to the question being a multiple-choice, the total will not add up to 100%.

Data Collection

Data was collected anonymously and through convenience sampling through the survey distributed independently in each country's national patient portal, which authenticated users could access via a survey link. The survey remained

accessible to users for three weeks in Sweden, Finland, and Norway. In Estonia, the survey was open for nine weeks due to the lower number of responses affected by the lower population.

The close-ended questions were only mandatory in Sweden and Norway and optional in Estonia and Finland due to technical differences between the survey systems. This study focused only on the close-ended questions from six of the survey's seven thematic sections: 1) sociodemographic information, 2) experience with healthcare, 3) experience with ORA through the patient portal, 4) reasons for using the patient portal, 5) errors, omissions, and offenses, and 6) security and privacy.

Data Analysis

A quantitative analysis was conducted from the collected data, which were summarized by each country. Due to optional questions in two countries, the data was calculated based on accessible and missing data, using descriptive statistics with counts and percentages. The software JASP (v. 0.17.1; University of Amsterdam) was used for the analysis.

Study IV

The aim was to understand if and how patients with mental health conditions experiences of ORA differs from patients in other healthcare settings, focusing on patients' experiences of errors, omissions, and offenses in Swedish mental healthcare.

Design

Study IV focused on the Swedish survey responses only from the NORDeHEALTH Patient Survey, comparing the responses from participants with mental healthcare experiences to those in other healthcare settings.

Participants

In total, 13,008 patient users responded to the Swedish survey. In order to compare experiences of ORA between patients with and without experience of mental health care, in study IV, the participants were divided into groups (see Table 4). The groups were made based on the survey question "Have you been in contact with a healthcare professional in the last two years for any of the following?" with answer options: "mental health," "cancer," "other health problems," and "no care or treatment." The question was multiple-choice, meaning several answer options could be chosen. Participants who responded "no care or treatment" were excluded; hence, 12,334 participants remained.

The mental healthcare group (MHC) included all the participants who responded "mental health" as a solitary response or together with "cancer" and/or "other health problems." The non-mental healthcare group (non-MHC) included participants who responded "cancer" and/or "other health problems".

Table 4. Group definition based on the question "Have you been in contact with a healthcare professional in the last two years for any of the following?"

Answer option	MHC (n=3131), n (%)	non-MHC (n=9203), n (%)
Mental health	3131 (100)	Not applicable
Cancer	174 (5.56)	1530 (16.63)
Other health problems	2441 (77.96)	8605 (93.5)
No care or treatment (n=674)	Excluded	Excluded

Note: Due to the question being a multiple-choice, the total will not add up to 100%.

Data Collection

Data were collected as convenience sampling through a nationwide survey distributed in the national patient portal 1177 and its PAEHR section Journalen. In order to ensure that only authenticated PAEHR users participated in the survey, a notification of the survey link became visible upon logging into their accounts. Participation remained anonymous, as there was no connection between user accounts and the survey link. No specific quotas were set for age, gender, or other sociodemographic characteristics. The survey remained accessible to users for three weeks and was built using Webropol (Webropol Sverige AB).

The close-ended questions were mandatory to answer. This study focused only on the close-ended questions from five of the survey's seven thematic sections: 1) sociodemographic information, 2) experience with healthcare, 3) experience with ORA through the patient portal, 4) reasons for using the patient portal, and 5) errors, omissions, and offenses.

Data Analysis

A quantitative analysis was conducted from the collected data. The study's primary aim was divided into two sub-aims. Descriptive statistics were calculated for sub-aim 1) "to explore how participant characteristics and interaction with the national PAEHR differed between patients who received mental healthcare and those who have not." Descriptive statistics were used to describe and understand the characteristics of the collected dataset. Summative statistics were calculated for sub-aim 2) "to compare the rate of errors, omissions, and offenses between patients who have received mental healthcare and those who have not." Summative statistics were used to provide overall conclusions based on the findings.

Stratified random sampling with proportional allocation [43] was conducted to further explore disparities in the rates of perceived errors, omissions, and offenses between the groups. Subsamples of the MHC and non-MHC groups were created and matched by age and gender, with each stratum determined by the MHC group. The gender "other" was omitted from both subsamples (n=76) from the stratified analysis since it was not possible to match the numbers between the groups for stratification. To summarize the results, descriptive statistics were utilized.

Group comparisons for single-choice questions were conducted utilizing the Pearson chi-square test, with statistical significance set at P<.05 throughout the study analysis. The software JASP (v. 0.16.2; University of Amsterdam) was used for the analysis.

Ethical Considerations

Ethical approval within the NORDeHEALTH project was granted by the Swedish Ethical Review Authority (EPN 2021/05229), for Study III and IV in this doctoral thesis project. Additionally, Study III had ethical approval in Estonia, Finland, and Norway. In Estonia ethical approval was granted to the Taltech University by the Research Ethics Committee of National Institute of Health Development in Estonia (Protocol #31, Approval #977), in Finland to Aalto University by the Aalto University Research Ethics Committee (Approval #D/957/03.04/2020). In Norway, according to the Norwegian Act on Medical and Health Research §2 and §4, the study did not require approval from the regional ethics committee, but the data handling procedure was approved by the Data Protection Officer of the University Hospital of North Norway (Approval #02799). According to Swedish legislation, Study I and II did not require ethical approval as no sensitive personal data were analyzed. Nonetheless, ethical guidelines with informed consent were followed in Study II where data was collected from key stakeholders.

This project adheres to the ethical principles outlined in the Declaration of Helsinki for medical research involving human subjects. These principles ensure the protection of participants' rights and integrity, as well as the ethical and respectful conduct of research. The Declaration mandates requirements for obtaining informed consent and upholding participants' integrity [44]. The collected data are handled according to the Swedish Patient Data Act (2008:355) and General Data Protection Regulation (EU2016/679) stored on Uppsala University servers. The data are presented in the studies as anonymous data.

The NORDeHEALTH Patient Survey was designed within the NORDeHEALTH Research Project. We discussed whether to collect personal data and include questions about the respondents' specific mental health diagnoses, to enable a comparison between patients with different severity of mental

health problems. However, we decided to make the survey completely anonymous, and to not ask for a specific mental health diagnosis. The rationale for anonymizing the survey and reducing the sensitivity of the questions, the likelihood of obtaining as many rich responses related to experiences of using the PAEHRs as possible increased.

Results

In this section, the results of the thesis are presented. In Study I, we aimed to explore the current literature on the effects of ORA among patients, care partners, and HCPs, and therefore conducted a literature review to describe the current international evidence of patients' experiences with ORA in mental healthcare. In Study II, we aimed to explore Swedish national and local policy regulations regarding patients' ORA in mental healthcare and describe to what extent patients are provided ORA in mental healthcare, and therefore conducted a qualitative document analysis with key stakeholder email interviews to describe ORA in Swedish mental healthcare. In Study III, we aimed to understand mental healthcare patients' experiences with ORA in Sweden, Estonia, Finland, and Norway, and therefore conducted the NORDeHEALTH patient survey to describe patients' experiences with ORA in mental healthcare in Sweden, Estonia, Finland, and Norway. In Study IV, we aimed to understand if and how patients with mental health conditions experiences of ORA differs from patients in other healthcare settings, and therefore further analyzed the Swedish responses to the NORDeHEALTH patient survey focusing on patients' experiences of errors, omissions, and offenses.

International Evidence of Experiences with ORA in Mental Healthcare

The literature review (Study I) resulted in a total of N=31 included studies out of N=1034 identified during the search. Most of these studies employed a qualitative design (n=10, 32%), followed by surveys (n=9, 29%). Geographically, over half of the studies were conducted in the US (n=18, 58%), followed by Sweden (n=5, 16%) and Canada (n=3, 10%). Approximately an equal number of studies included patient participants (55%) and HCPs (53%), with none of the patient studies conducted in Sweden, see Table 5.

The MMAT assessment assigned a score between 1 and 5 to each study, with 5 representing the highest quality (100% compliance with MMAT criteria) and 1 indicating the lowest (20%). One paper with a score of 1 was excluded due to low quality. The majority of included studies received top scores according to MMAT criteria.

Table 5. Characteristics of included studies (N=31).

Characteristics	Total, n (%)	Studies [reference number]
Study Design		
Qualitative	10 (32)	[45–54]
Survey	9 (29)	[10,22,23,55–60]
Mixed Method	4 (13)	[61–64]
Descriptive	2 (6)	[65,66]
Cohort	2 (6)	[67,68]
Intervention	4 (13)	[69–72]
Randomized Controlled Trial	1 (3)	[72]
Country		
Australia	1 (3)	[52]
Canada	3 (10)	[56,62,70]
Netherlands	1 (3)	[51]
Norway	1 (3)	[10]
Sweden	5 (16)	[22,23,49,54,64]
United Kingdom	2 (6)	[50,63]
United States	18 (58)	[45–48,53,55,57–61,65–69,71,72]
Study Participants		
Patients	17 (55)	[45,50,51,55,56,58–61,63,65–70,72]
HCPs	16 (53)	[10,22,23,46–49,51,52,57,62,64–66,69,71]
Care Partners	1 (3)	[56]
Policy Stakeholders	2 (6)	[53,54]
MMAT-score		
5	23 (74)	[10,22,23,45–54,57,59–62, 65–68,70]
4	3 (10)	[55,58,71]
3	4 (13)	[63,64,69,72]
2	1 (3)	[56]
1	-	*Excluded due to low score*

Note: individual papers can be assigned to the various sub-parameters at the same time, hence, the percentages will not add up to 100%.

Positive Experiences among Patients and HCPs

According to findings from Study I, most patients with mental health conditions noted positive experiences with ORA in mental healthcare. Many of the patients reported to feel more sense of control over their care (sense of control defined as "the belief individuals maintain about the extent to which they can shape the course of their own outcomes" [73]) when reading their notes in mental healthcare [55,58,61,69]. ORA in mental healthcare provided increased feelings of validation [61] (validation as being heard and understood) and contributed to a greater understanding of the potential side effects of their medications and remembering to take their medications [58,59,68,69]. Most

patients have noted that ORA contributed to a better understanding of their mental health [58,69] and increased awareness of their diagnosis [56]. In addition, they remembered their mental healthcare plan better [69] and were better prepared for their scheduled visits [58,61]. The odds of attending scheduled appointments increased when patients were offered ORA [70].

Improved transparency [61] (transparency defined as "openness in relating to other people" [74]) and increased trust in their clinicians [45,55,61] were reported as positive outcomes by some patients. Further, findings indicate that perceived benefits noted by some patients in mental healthcare were the opportunity to control if the appointment description was correct [46,56,61,69] and to ensure no errors occurred in the notes [56,61,69]. The findings also indicate that no barriers (barriers defined as "mental, emotional, or behavioral limitations in individuals" [75]) exist for most patients with mental health conditions about their ability to use a PAEHR [72]. In addition, the findings also indicate that severe mental diagnoses, such as Schizophrenia spectrum disorder and Bipolar disorder, coupled with variables of older age and higher number of mental health visits, were associated with trust in their clinician, improved patient activation, and efficacy (efficacy defined as "competence in behavioral performance with reference to a person's perception of their performance capabilities" [76]) in healthcare interactions when reading their PAEHR [67].

Some of the HCPs reported experiencing benefits with ORA in mental healthcare. Some of the noted benefits were that HCPs believed ORA would help strengthen the patient-provider relationship [47,48,51], increase transparency [47,62], improve patients' participation in care [47,51,57,69], and increase patients' feelings of trust [23,47] in their HCP.

Negative Experiences among Patients and HCPs

Less patients reported negative experiences with ORA in mental healthcare compared to positive experiences. Findings indicate that some patients felt judged, labeled [46,61], stressed, worried [55,58,61,69], and upset when reading the notes [55]. Offense and disrespect were other feelings reported caused by the tone of the notes [45]. Some patients felt upset when experiencing diminished their problems [55], and others reported starting to question the therapy itself and the nature of documentation [69].

When discovering diagnoses in the notes that were never discussed during any visits, patients felt confused, blindsided, and worried that inaccuracies in the notes could affect their treatment [45,46]. A lack of congruence between what the note said and the patients' recollection of an appointment made some patients feel upset and worried [45,61,69]. Incongruences in general in the notes contributed to experiencing low transparency, lack of respect, and decreased trust in their clinicians [45,46]. Concerns about security issues and the

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need to maintain confidentiality with ORA in mental healthcare were empha-
sized as vital by some of the patients [50,58,61,69].

Experienced risks with ORA in mental healthcare were more commonly
reported by HCPs compared to experienced benefits. Commonly reported
risks included concerns that ORA in mental healthcare would increase their
workload [22,23,48,49,51,52,57,62] and that patients would feel offended or
confused [22,57] or worry more [22,23,57] when reading the clinical notes.
Some HCPs raised concerns that patients would disagree with the content of
the notes [22,57] and the diagnosis [57] or that patients would feel stigmatized
by the clinical assessments written in the notes [47,69]. Additionally, some
HCPs reported becoming less detailed and candid when documenting the
notes [22,23,46,48,49,57,62,69], expressing concerns about patients' potential
lack of understanding of medical terminology, leading to misunderstandings
and misinterpretations [22,23,48,49,51,69]. Other HCPs raised concerns about
anonymity and privacy, worrying that patient ORA could impact patient safety
[22,23,48,49,51,57,62,64].

Care Partners and Policy Stakeholders

Family members and friends, i.e., care partners, of patients with mental health
conditions were included in one study [56]. The care partners expressed inter-
est in supporting their family members or friends by accessing their health
records to help renew medications, schedule appointments, and receive edu-
cational materials, among other reasons.

Views of policy stakeholders and experts on ORA in mental healthcare
were included in two studies [53,54], with one of the included studies being
Study II in this thesis [54]. The other study [53] involved experts on ORA,
who emphasized the importance of educating HCPs on documentation prac-
tices in mental healthcare and highlighted the importance of accurate and
truthful notes.

Summary

Among patients and HCPs, both positive and negative experiences and expec-
tations with ORA in mental healthcare were reported. However, most of the
studies were conducted in the US, and studies involving patients are often
qualitative or small-scale pilot studies. There are few Swedish studies involv-
ing HCPs in mental healthcare [22,23] and limited research involving patients.
When ORA was originally implemented in Sweden, access to records from
psychiatric care was often excluded [8] and the extent to which patients actu-
ally have had access to their mental health records have remained unclear.
Therefore, Study II will describe Swedish national and local policy regulations
regarding patients' ORA in mental healthcare and assess the extent to which
patients are provided ORA in this context.

ORA in Swedish Mental Healthcare

To further understand the context of ORA in Swedish mental healthcare, Study II included a document analysis of the regions and private healthcare providers' web pages for information and policies regarding ORA in psychiatric care, followed by key stakeholder interviews.

Swedish patients are offered ORA in mental healthcare in 17 of the 21 regions in adult psychiatry, see Table 6. Regarding psychiatric care for pediatrics and adolescents, 15 regions offered ORA to patients, and seven regions offered ORA to patients in forensic psychiatric care. All regions that offered ORA in mental healthcare (n=17) shared clinical notes with patients in both outpatient and inpatient mental healthcare.

In Swedish healthcare, the clinical information in an EHR needs to be validated by the responsible HCP. Information that is validated is often referred to as "signed", and not validated clinical information "unsigned". This is especially important in cases where HCP dictate clinical notes that are later transcribed by administrative staff and entered into the record. All regions (n=17) shared signed and unsigned mental healthcare notes with patients in the PAEHR.

11 regions offered patients immediate access to the notes after their visits. Four regions offered immediate access to signed notes, and one offered immediate access to notes from outpatient care. Some regions did not offer immediate access since they had a respite, where two regions had a 14-day respite until the patients could read their notes (regardless of whether they were signed or not), four regions had a 14-day respite to unsigned notes only, and one region had a 28-day respite.

Private healthcare providers can offer patients healthcare across multiple regions in Sweden. Three private healthcare providers were included in the study because they were the only ones who either shared clinical information with patients in the PAEHR or were in the process of implementing patient access to the PAEHR at the time of conducting Study II. Two providers shared clinical mental health notes, while one had not yet implemented shared notes in the PAEHR. None of the private healthcare providers carried forensic care, only adult psychiatric care and psychiatric care for pediatrics and adolescents. The two who offered ORA in the PAEHR shared mental health notes from outpatient care, and both shared signed notes. Only one shared notes from inpatient care since the other did not carry any inpatient care. One gave immediate access to the mental health notes, while the other had a 14-day respite.

Table 6. Presentation of how the regions and private healthcare providers offer access to mental healthcare in the PAEHR, where **1** is adult psychiatry; **2** pediatrics and adolescents psychiatry; **3** forensic psychiatry; **4** outpatient; **5** inpatient; **6** signed notes; **7** unsigned notes; **8** immediate access; **9** immediate access signed notes only; **10** immediate access outpatient only; **11** respite *14* days; **12** respite *14* days unsigned notes only; **13** respite *28* days inpatient only.

Regions	1	2	3	4	5	6	7	8	9	10	11	12	13
Blekinge	X	X	n/a	X	X	X	X	X	–	–	–	–	–
Dalarna	X	X	X	X	X	X	X	X	–	–	–	–	–
Gotland	X	X	n/a	X	X	X	X	X	–	–	–	–	–
Gävleborg	X	X	X	X	X	X	X	–	–	–	X	–	–
Halland	–	–	–	–	–	–	–	–	–	–	–	–	–
Jämtland-Härjedalen	–	–	–	–	–	–	–	–	–	–	–	–	–
Jönköping	X	X	–	X	X	X	X	X	–	–	–	–	–
Kalmar	X	X	X	X	X	X	X	X	–	–	–	–	–
Kronoberg	X	X	–	X	X	X	X	–	X	–	–	X	–
Norrbotten	X	X	X	X	X	X	X	X	–	–	–	–	–
Skåne	X	X	X	X	X	X	X	–	–	X	–	–	X
Stockholm	X	–	–	X	X	X	X	X	–	–	–	–	–
Sörmland	–	–	–	–	–	–	–	–	–	–	–	–	–
Uppsala	X	X	–	X	X	X	X	–	X	–	–	X	–
Värmland	X	X	X	X	X	X	X	X	–	–	–	–	–
Västerbotten	–	–	–	–	–	–	–	–	–	–	–	–	–
Västernorrland	X	X	–	X	X	X	X	X	–	–	–	–	–
Västmanland	X	X	–	X	X	X	X	X	–	–	–	–	–
Västra Götaland	X	–	X	X	X	X	X	–	X	–	–	X	–
Örebro	X	X	–	X	X	X	X	X	–	–	–	–	–
Östergötland	X	X	–	X	X	X	X	–	X	–	–	X	–
Capio *(private)*	X	X	n/a	X	X	X	X	–	–	–	X	–	–
KRY *(private)*	x/–	x/–	n/a	X	n/a	X	–	X	–	–	–	–	–
MinDoktor *(private)*	–	–	n/a	–	–	–	–	–	–	–	–	–	–

Note: The data represents the status of when conducting the study in 2021, which may be different in 2024.
X = the response "Yes".
– = the response "No".
x/– = represents both Yes and No, in this case, since KRY was following each region's specifications.
n/a = not applicable.

Policy and Regulations

Regarding policy documents and regulations, most regions confirmed that they agreed to the NRF (the Swedish National Regulatory Framework that ensures every citizen equal digital access to their health information regardless of where in Sweden they live and receive care), and all regions except one had their own Digital Agenda or Development Strategy. According to the NRF,

all Swedish citizens aged 16 or older should have access to their health data in the Swedish PAEHR Journalen. This aligns with the digital agendas or strategies where the regions highlight how patients should be offered access to their health records online. Since nothing specific could be found in these policy documents about ORA in psychiatric care, the key stakeholders confirmed in the email interviews how some information is hidden from patients in psychiatric care. Information hidden from patients is "violence in close relationships", "early hypotheses", "concerns about child abuse", and "compulsory care".

Summary

To summarize Study II, clinical notes from adult psychiatry were shared by 17 regions, notes from pediatrics and adolescents by 15 regions, and notes from forensic care by seven regions. Additionally, two of the three private healthcare providers implemented patient access to mental healthcare notes in the PAEHR. Clinical notes were shared from outpatient and inpatient care across all regions, irrespective of psychiatric setting. Most regions confirmed their adherence to the NRF, ensuring every citizen's equal digital access to clinical information. Another study [77] found that all NORDeHEALTH countries shared similar clinical content with patients in mental healthcare. Study III delves into patients' experiences with ORA in mental healthcare across these countries.

Patients Experiences with ORA in Mental Healthcare in Sweden, Estonia, Finland, and Norway

An analysis of the responses from participants with self-reported mental healthcare experience in the NORDeHEALTH patient survey was conducted, to understand patients' experiences with ORA in mental healthcare in Sweden, Estonia, Finland, and Norway.

In all four countries, about half of the respondents reported having had "a very positive experience" with the PAEHR, and about a third have had "a very negative experience", see Table 7.

Most respondents reported increased trust in their HCP and improved communication between themselves and their HCP when accessing their PAEHR (about 70% agreed in both statements in Sweden, Estonia, and Norway, and about 85% in Finland).

Table 7. The occurrence of positive and negative experiences.

	Sweden n=3131, n(%)	Estonia n=334, n(%)	Finland n=693, n(%)	Norway n=1999, n(%)	All countries N=6157, N(%)
Had a very positive experience with the health record. [a]					
Yes	1309 (41.81)	200 (59.88)	276 (40.17)	986 (49.32)	2771 (45.01)
Missing data	-	0	6	-	6
Had a very negative experience with the health record. [a]					
Yes	999 (31.91)	79 (25.57)	202 (29.66)	524 (26.21)	1804 (29.48)
Missing data	-	25	12	-	37

Note: Percentages were calculated per national sample and for all countries in total. In Estonia and Finland, answering all questions was not mandatory for submission, hence missing data. All questions in Norway and Sweden were mandatory, hence no missing data.

[a] Calculations include only data from 'Yes'-responses, and therefore, do not add up to 100%.

Errors, Omissions and Offense

Reports of errors or omissions encountered in the PAEHR were similar between the countries; however, there were some differences, see Table 8. In Sweden, Finland, and Norway, about half of the respondents reported having found an error in their PAEHR, while only one in five did so in Estonia. Reported omissions ranged from 28% (n=78) in Estonia to 35% (n=1089) in Sweden, with a median of 35% (n=2164) overall. The experience of ever having felt offended by the content in the PAEHR varied between the countries, with Estonia (n=61, 18%) and Finland (n=175, 25%) reporting the lowest rates. Sweden (n=1183, 38%) and Norway (n=724, 36%) reported the highest rates. About half of the Swedish and Norwegian respondents rated the most important identified error as "very important", while "somewhat important" received the highest ratings from Estonia (n=39, 57%) and Finland (n=127, 40%). Similarly, nearly half of the respondents in Estonia and Finland, and almost half of those in Norway, reported the most serious identified omission as "somewhat serious". In contrast, most respondents in Sweden (n=622, 57%) rated the most serious omission as "very serious". Most respondents in all countries indicated that they "did nothing" when they found an error or omission.

Privacy and Security

When asked if "family, friends, or another have demanded access to their health records", only a very small proportion indicated having that experience in all countries (3% as a median overall). A small proportion of respondents in all countries indicated they had experienced "someone seeing their health record that they did not want to share" (11% as a median overall). Finland had

Table 8. Rates of errors, omissions, and offenses per country and for all countries.

	Sweden n=3131, n(%)	Estonia n=334, n(%)	Finland n=693, n(%)	Norway n=1999, n(%)	All countries N=6157, N(%)
ERRORS: Have you found anything that was wrong in your EHR (not misspellings/typographical)?					
Yes	1586 (50.65)	71 (21.26)	319 (46.23)	971 (48.57)	2947 (47.89)
No	904 (28.87)	182 (54.49)	251 (36.38)	635 (31.77)	1972 (32.04)
Don't know	641 (20.47)	81 (24.25)	120 (17.39)	393 (19.66)	1235 (20.07)
Missing data	-	0	3	-	3
How important was the worst mistake for you? [a]					
	n = 1586	n = 69	n = 316	n = 971	N = 2942
Very	795 (50.13)	13 (18.84)	37 (11.71)	433 (44.59)	1278 (43.44)
Somewhat	586 (36.52)	39 (56.52)	127 (40.19)	409 (42.12)	1161 (39.44)
Not at all	148 (9.33)	16 (23.19)	112 (35.44)	90 (9.27)	366 (12.44)
Not sure	57 (3.59)	40 (12.66)	40 (12.66)	39 (4.02)	137 (4.66)
OMISSIONS: Have you found anything you thought was missing from your EHR?					
Yes	1089 (34.78)	78 (28.16)	243 (35.17)	754 (37.72)	2164 (35.49)
No	1059 (33.82)	116 (41.88)	235 (34.01)	621 (31.07)	2031 (33.31)
Don't know	983 (31.40)	83 (29.96)	213 (30.82)	624 (31.22)	1903 (31.21)
Missing data	-	57	2	-	59
How serious was the most important missing information for you? [b]					
	n = 1089	n = 77	n = 242	n = 754	N = 2164
Very	622 (57.12)	16 (20.78)	23 (9.50)	262 (34.75)	923 (42.69)
Somewhat	372 (34.16)	42 (54.55)	89 (36.78)	352 (46.68)	855 (39.55)
Not at all	20 (1.84)	10 (12.99)	76 (31.40)	46 (6.1)	152 (7.03)
Not sure	75 (6.89)	9 (11.69)	54 (22.31)	94 (12.47)	232 (10.73)
Did you do any of the following when you found a mistake or missing info in your EHR? [c]					
	n = 1918	n = 104	n = 377	n = 1252	N = 3651
Did nothing	792 (41.29)	68 (65.38)	147 (38.99)	689 (55.03)	1696 (46.45)
Phoned HCP	357 (18.61)	13 (12.50)	67 (17.77)	147 (11.74)	584 (15.99)
Informed at next visit	499 (26.02)	12 (11.54)	122 (32.36)	310 (24.76)	943 (25.83)
Other	270 (14.08)	11 (10.58)	41 (10.88)	106 (8.47)	428 (11.72)
OFFENSE: Have you ever felt offended by something you read?					
Yes	1183 (37.78)	61 (18.32)	175 (25.25)	724 (36.22)	2143 (34.81)
No	1948 (62.22)	272 (81.68)	518 (74.75)	1275 (63.78)	4013 (65.19)
Missing data	-	1	0	-	1

Note: Percentages were calculated per national sample and for all countries. In Estonia and Finland, answering all questions was not mandatory, hence missing data. All questions in Norway and Sweden were mandatory, hence no missing data.
[a] The statistics include only data from respondents who answered "Yes" to ERRORS in the survey.
[b] The statistics include only data from respondents who answered "Yes" to OMISSIONS in the survey.
[c] The statistics include only data from respondents who answered "Yes" to ERRORS and OMISSIONS.

the highest numbers among those who responded "Yes" to both questions, while Sweden had the lowest. Most respondents indicated that they "trust that only authorized healthcare professionals are accessing their health records", with similar numbers indicating that they believe "their health record generally maintains a high level of security".

Summary

Study III provided an overview of mental healthcare patients' experiences with ORA but did not compare them with those of patients in other healthcare settings. Therefore, Study IV conducted such a comparison, focusing on errors, omissions, and offenses.

Patients Experiences of Errors, Omissions and Offenses in Swedish Mental Healthcare

To understand if patients with mental health conditions are more likely than patients in other healthcare settings to experience errors, omissions, and offense, a comparison between the two patient groups was conducted by analysis of the Swedish data from the NORDeHEALTH patient survey.

Findings from Study IV indicate that patients have a predominantly positive experience of their health records, irrespective of the healthcare setting. However, a significant difference was observed between mental healthcare patients (MHC group) and those with non-mental healthcare (non-MHC group) regarding negative experiences. Approximately one-third (n=999, 32%) of the MHC group reported a very negative experience, compared to the non-MHC group (2386, 26%), as shown in Table 9.

Table 9. The occurrence of positive and negative experiences with the health record.

Survey item	MHC [a] (n=3131), n (%)	non-MHC [b] (n=9203), n (%)	P value [c]
Had a very positive experience	1309 (41.81)	4075 (44.28)	.02
Had a very negative experience	999 (31.91)	2386 (25.93)	<.001

[a] MHC: mental healthcare

[b] non-MHC: non-mental healthcare

[c] Derived from a chi-square test comparing MHC and non-MHC subsamples on a given variable.

The findings also indicate that the MHC group experienced errors, omissions, and offensive content in their EHR more than the non-MHC group, see Table 10. About a third of the MHC group reported missing content in their EHR, and half reported finding an error. More than a third of the MHC group reported feeling offended by something they read in their EHR. However, the

majority responded that they had not been offended, but a larger proportion from MHC had been offended. A statistically significant association between

Table 10. Rates of errors, omissions, and offenses between the groups.

Survey item	MHC [a] (n=3131), n (%)	non-MHC [b] (n=9203), n (%)	P value [c]
ERRORS: Have you found anything that was wrong in your EHR (not mis-spellings/typographical)?			<.001
Yes	1586 (50.65)	3311 (35.98)	
No	904 (28.87)	4253 (46.21)	
Do not know/remember	641 (20.47)	1639 (17.81)	
If yes, how important was the worst mistake? [d]			<.001
Very important	795 (50.13)	1366 (41.26)	
Somewhat important	586 (36.95)	1332 (40.23)	
Not at all important	148 (9.33)	508 (15.34)	
Not sure	57 (3.59)	105 (3.17)	
OMISSIONS: Have you found anything you thought was missing from your EHR?			<.001
Yes	1089 (34.78)	2427 (26.37)	
No	1059 (33.82)	4418 (48.01)	
Do not know/remember	983 (31.40)	2358 (25.62)	
If yes, how serious was the most important missing info for you? [e]			.47
Very serious	622 (57.12)	1329 (54.76)	
Somewhat serious	372 (34.16)	895 (36.88)	
Not at all serious	20 (1.84)	46 (1.90)	
Not sure	75 (6.89)	157 (6.47)	
Did you do any of the following when you found a mistake or missing info in your EHR? [f]			.08
Did nothing	792 (41.29)	1838 (42.17)	
Contacted care unit by phone	357 (18.61)	837 (19.20)	
Informed HCP at next visit	499 (26.02)	1010 (23.17)	
Something else	270 (14.08)	674 (15.46)	
OFFENSE: Have you ever felt offended by something you read?			<.001
Yes	1183 (37.78)	1616 (17.56)	
No	1948 (62.22)	7587 (82.44)	

[a] MHC: mental healthcare

[b] non-MHC: non-mental healthcare

[c] Derived from a chi-square test comparing MHC and non-MHC subsamples on a given variable.

[d] Question responded to by the "yes" of errors, the total n is 1586 (MHC) and 3311 (non-MHC).

[e] Question responded to by the "yes" of omissions, the total n is 1089 (MHC) and 2427 (non-MHC).

[f] Question responded to by the "yes" of errors & omissions, total n is 1918 (MHC) and 4359 (non-MHC).

group belonging and identified errors, omissions, and feeling offended was found, indicating that MHC respondents experienced more errors, omissions, and feeling offended than non-MHC respondents.

When rating how important the identified error was, half of the MHC group responded "Very important", and more than half rated the most serious omission as "Very serious". Most reported doing nothing when finding an error or missing information in their EHR.

Stratified Analysis

Additional analysis of errors, omissions, and offenses was conducted to further explore disparities between the groups' rates of errors, omissions, and offenses. Stratified random sampling with proportional allocation was used where the MHC and non-MHC groups were matched in the distribution of age and gender. However, the gender "other" was omitted from both subsamples (n=76) from the stratified analysis since it was not possible to match the numbers between the groups for stratification. The findings indicated that errors, omissions, and offenses were more common among respondents in the MHC group than in the non-MHC group. The difference in rates between the groups was statistically significant, see Table 11.

Summary

Study IV provided a comparison between patients with mental healthcare experiences and patients in other healthcare settings regarding experiences of ORA. The findings indicated that patients in mental healthcare experienced higher rates of errors, omissions, and feeling offended by the content of their clinical information.

Table 11. Rates of errors, omissions, and offenses in the stratified subsamples.

Survey item	MHC [a] (n=3131), n (%)	non-MHC [b] (n=9203), n (%)	*P* value [c]
Participant Characteristics			
Gender			>.99
Woman	2254 (77.32)	2254 (77.32)	
Man	661 (22.68)	661 (22.68)	
Age (years)			>.99
15-19	72 (2.47)	72 (2.47)	
20-24	147 (5.04)	147 (5.04)	
25-34	759 (26.04)	759 (26.04)	
35-44	647 (22.20)	647 (22.20)	
45-54	634 (21.75)	634 (21.75)	
55-64	465 (15.95)	465 (15.95)	
65-74	141 (4.84)	141 (4.84)	
75-84	48 (1.65)	48 (1.65)	
>85	2 (0.07)	2 (0.07)	
Errors, Omissions, and Offenses			
Error rate			<.001
Yes	1471 (50.46)	1067 (36.60)	
No	858 (29.43)	1230 (42.20)	
Don't know/remember	586 (20.10)	618 (21.20)	
Omission rate			<.001
Yes	1017 (34.89)	829 (28.44)	
No	1000 (34.31)	1309 (44.91)	
Don't know/remember	898 (30.81)	777 (26.66)	
Offense rate			<.001
Yes	1084 (37.19)	621 (21.30)	
No	1831 (62.81)	2294 (78.70)	

[a] MHC: mental healthcare

[b] non-MHC: non-mental healthcare

[c] Derived from chi-square test comparing MHC and non-MHC subsamples on a given variable.

Discussion

In this section, the findings of the thesis will be discussed. In Study I, we aimed to explore the current literature on the effects of ORA among patients, care partners, and HCPs, and our results indicate more patients reporting positive experiences with ORA in mental healthcare than negative experiences. In Study II, we aimed to explore Swedish national and local policy regulations regarding patients' ORA in mental healthcare and describe to what extent patients are provided ORA in mental healthcare. Findings indicated that most of the regions offer patients ORA in mental healthcare, however, with some disparities. In Study III, we aimed to understand mental healthcare patients' experiences with ORA in Sweden, Estonia, Finland, and Norway, and found indications of high rates of errors, omissions, and offenses from patients in all four countries, albeit with some differences. In Study IV, we aimed to understand if and how patients with mental health conditions experienced ORA differently from patients in other healthcare settings, with findings indicating higher rates of errors, omissions, and offenses reported by patients with mental healthcare experiences compared to patients in other healthcare settings.

Main Findings

The overarching aim of this doctoral thesis was to explore how patients experience ORA in mental healthcare. Initially, an exploration was conducted to investigate the international evidence of patients' experiences with ORA in mental healthcare (Study I). The main findings indicated that most patients in previous studies reported experiencing benefits from accessing their health records from mental healthcare. In contrast, a smaller number of patients reported negative experiences. Reported benefits include feeling in control of their care [55,58,61,69], increased understanding of their mental health diagnosis [56,58,69] and potential medication side effects [58,59,68,69], enhanced trust in their clinician [45,55,61], and better recall of their scheduled appointments [58,61]. Some of the reported negative experiences included feeling judged, labeled [46,61], offended [45], stressed, worried [55,58,61,69] and upset [55] by the content of their clinical notes, as well as discovering diagnoses that had never been discussed or mentioned [45,46].

Despite the Nordic countries, including Sweden, having well-established national PAEHR systems, few studies were found in Study I addressing ORA in mental healthcare from these countries. The majority originated in the US. In Sweden, four studies were found on HCPs expectations and experiences of ORA in mental healthcare [22,23,49,64], along with one study from Norway focusing on HCPs experiences [10], highlighting HCPs concerns. Because of that, it became imperative to explore patients' experiences of ORA in mental healthcare in the Nordic countries, and especially focusing on Sweden. In order to do so, it was however important to first understand to what extent patients have access to their health records from mental healthcare, which was explored in Study II.

The main findings revealed that 17 out of 21 regions in Sweden offered patients access to their PAEHR in mental healthcare. Among these regions, all 17 provided access to clinical information from adult psychiatry, 15 from pediatrics and adolescent psychiatry, and seven from forensic care. The most common approach was to provide immediate access to all information without any waiting period. Moreover, all regions aimed to provide all patients over 16 with access to all their clinical information in the PAEHR. These were the results in 2021, unlike the results of a study from 2018 (based on a Swedish survey from 2016), where only two regions offered ORA in mental healthcare [8]. Another study analyzed free-text responses from the same survey (2016) and found that some respondents had explicitly commented on the blocking of ORA in mental healthcare, where one said: "I would use Journalen (i.e. the PAEHR) more if the whole record was included. The fact that the psychiatric notes are not included makes me feel discriminated and fragmented as a person. Body and mind affect each other, and somatic care needs to consider what happens in psychiatry and vice versa" [78].

To deepen the understanding of patients' experiences with ORA in mental healthcare in the Nordic countries, a survey study was conducted to gain an overview of patients' experiences of PAEHR in mental healthcare in Sweden, Estonia, Finland, and Norway (Study III). Patients in these countries are given access to similar clinical information from mental healthcare in each country's PAEHR [77]. The main findings were that patient experiences were mainly similar between the countries, with minor differences. For instance, increased trust and improved communication were reported to a larger extent in Finland (85%) than in the other countries (about 70%). About half of the respondents reported identifying an error in Sweden, Finland, and Norway, and about a third an omission. However, only a fifth had identified an error or omission in Estonia. The most common response in all countries was to leave the error or omission and do nothing to correct them, such as contacting the responsible HCP. Throughout the reported errors, omissions, and offenses, Swedish respondents were at the top with the highest numbers, which also regarded rated importance and seriousness.

Learning from the results of the third overview study, especially Sweden being at the top of identified errors, omissions, and offenses, it was important to delve deeper and further explore Swedish patients' experiences of PAEHR in mental healthcare (Study IV). The main findings were that patients in mental healthcare reported errors, omissions, and offenses to a greater extent than patients in other healthcare settings. Similar observations were documented in a Norwegian patient survey study [79]. Additionally, a Swedish patient survey study (based on a survey from 2016) indicated that patients with mental health diagnoses found ORA useful for verifying the accuracy of the clinical content [80]. Furthermore, due to the mental healthcare group in Study IV consisting of more women and younger patients than the non-mental healthcare group, it was important to explore further whether the higher rates of errors, omissions, and offenses remained in the mental healthcare group when creating stratified subsamples. Notably, the same results remained consistent even after both samples were matched by the distribution of age and gender.

Positive Experiences with ORA in Mental Healthcare

More study participants from Study III and Study IV noted positive experiences of ORA than negative. In other words, positive experiences were more commonly reported than negative in all countries (Study III) and in both patient groups (Study IV). Additionally, most patients in Study I, the literature review, also noted more positive experiences than negative. However, this thesis has not further explored the reasons behind these findings. Instead, focus has been on identifying the patient-reported benefits of ORA, which include, among others, an increased sense of control of their care [55,58,61,69], more control of their medications [58,59,68,69], increased understanding of their mental health [58,69] and diagnosis [56], increased feelings of validation [61], and increased trust in their clinician [45,55,61] when reading the health records from mental healthcare.

Empowerment

One could discuss whether ORA in mental healthcare facilitates patient "empowerment", given the abundance of positive experiences. According to WHO, the definition of "empowerment" is "a process through which people gain greater control over decisions and actions affecting their health", and "a process in which patients understand their role, and are given the knowledge and skills by their healthcare provider…" [81]. This definition includes four key components: the patient's understanding of their role, acquisition of sufficient knowledge to cooperate with the HCP, patient skills, and the presence of a facilitating environment [81]. As mentioned, many patients have reported experiences of increased understanding of their mental health and increased

feelings of trust in their clinician with ORA, among other experiences. These experiences may align with key components such as "acquisition of sufficient knowledge to cooperate with the healthcare provider" and "patient skills", which may enhance the patient's understanding of their role. This understanding could, in turn, allow patients to be more active in their care and enable them to participate more effectively in decision-making by allowing them to communicate more efficiently with their HCPs. In essence, ORA in mental healthcare may potentially enhance patient empowerment [45,61,82].

Person-Centered Care

Another discussion arising from these findings is whether ORA in mental healthcare facilitates person-centered care. According to WHO, patient-centered care is defined as "putting the comprehensive needs of people, not only diseases, at the center of health systems and engaging and empowering people to have a more active role in their health" [83]. This holistic approach includes aspects such as family involvement, prevention, and context, with four key attributes: individualization, respectfulness, empowerment, and holistic care [84]. While ORA itself is not synonymous with person-centered care, allowing patients to access their medical records may have the potential to enhance person-centered care by improving communication, fostering better patient-HCP relationships, and empowering patients to participate in their care. However, this potential depends on how the technology is utilized by both patients and HCPs. HCPs must acknowledge and embrace patients' access to their records, adopting new approaches prioritizing person-centered care. Therefore, ORA could be viewed as a tool for person-centered care and an important tool for HCPs to work person-centered. The technology itself will not change the experience of the medical focus if HCPs continue to view individuals solely through the lens of their diagnosis. Technology rarely alters norms and values; ultimately, it is human actions and attitudes that may change healthcare practices.

Negative Experiences with ORA in Mental Healthcare

The findings of this thesis include that many patients reported experiencing errors, omissions, and feelings of offense when reading their health records. Common negative experiences reported by patients in Study I included feeling labeled, judged [46,61] stressed, worried [55,58,61,69], and upset when reading the notes [55]. It raises the question of whether these experiences, coupled with the prevalence of errors, omissions, and feelings of offense, are influenced by biased and stereotypical labeling of diagnoses within the content of the health records. There is a need to explore further the types of errors, omissions, and offenses noted by patients in Study III and IV.

Biases and Stigmas

Biases among HCPs are described to stem from stigmatization of mental health problems or mental illness [85]. Bias could be defined as "implicit associations (unconscious, uncontrollable, or arational processes) may influence our judgment resulting in bias" [86]. In addition, the definition of stigmatization (stigma) is "the negative social attitude attached to a characteristic of an individual that may be regarded as mental, physical, or social deficiency – a stigma implies social disapproval and can lead to unfair discrimination against and exclusion of the individual" [87].

A study from the United Kingdom noted that patients in mental healthcare often report being met with negative attitudes among HCPs [88]. Patients with addiction disorders seem to be particularly vulnerable as they have reported being met with generally a negative attitude among HCPs, such as less empathy and decreased personal engagement, and that the HCPs, in general, make the visits shorter [88]. However, the survey studies in this thesis did not include information about the specific mental health diagnoses of the respondents due to ethical considerations. Nevertheless, it remains unclear whether biases and stigmatizations among HCPs affect how they document clinical notes shared with patients, potentially leading to feelings of offense or labeling. It is also worth considering that patients today have an increased understanding of stigmatized and negative wording [88], which may be attributed to today's society being a more aware society (i.e. "the ability to take the perspective of and empathize with others, including those from diverse backgrounds" [89]). One could discuss whether this could be a reason for them easier noticing errors, omissions, or feeling offended, leading to negative experiences when reading the clinical notes [88].

Stereotypical Threats

The definition of stereotypical threats are "an individual's expectation that negative stereotypes about their member group will adversely influence others' judgements of their performance and that a poor performance will reflect badly on the member group" [90]. In Study IV, respondents who identified themselves as "other" were the smallest gender group, with the largest proportion among the mental healthcare respondents. Although their preferred gender label is unknown, a study indicates that LGBTIQ+ individuals with mental health issues are more vulnerable to stereotypical threats, such as (reported by the study) fear of physicians, fear of communicating with physicians, and seeking mental healthcare, leading to delayed help-seeking due to experienced barriers like internalized homophobia [91]. Another study found that transgender individuals are particularly vulnerable and may experience harm when reading their clinical notes [92]. According to a report from the US-based Public Religion Research Institute, young adults in the US identify as LGBTIQ+ at higher rates than other age groups [93], with similar trends

observed in Sweden [94]. In Study IV, the proportion of younger respondents was larger in the mental healthcare group than in the non-mental healthcare group. This raises questions about whether individuals in mental healthcare are more susceptible to harm, stigmatization, and stereotypical threats than those in other healthcare settings. Alternatively, it may reflect societal shifts towards increased transparency and digitalization in healthcare, providing patients with rapid online access to their clinical information, which comes with the benefit of being more informed about themselves, possibly making it easier to notice errors and omissions. These societal shifts also may contribute to increased awareness and understanding of the implications of stigmatization and stereotypical threats, possibly making it easier for individuals to identify such issues in their clinical notes [88].

The higher prevalence of errors, omissions, and offenses reported in the mental healthcare sample compared to the non-mental healthcare sample in Study IV, is likely not solely attributed to the younger age and "other" gender identification of the participants, as the difference between groups remained in the stratified subsamples matched for age and gender. However, this remains an interesting aspect to discuss since the younger sample, with more identifying as the gender "other", constitutes one of the big differences between the mental healthcare group and non-mental healthcare group. Nevertheless, the occurrence of these findings needs to be studied further and include more patient characteristics, such as mental health diagnosis, functional limitation, ethnicity, or religion. For instance, in another study using data from the NORDeHEALTH Patient Survey, Norwegian responses were analyzed, including free-text responses from the open-ended questions [79]. The study found more comments on diagnose-related errors among patients in mental healthcare compared to patients in other healthcare settings. Further research is needed to explore diagnosis-specific experiences in mental healthcare. Most importantly, it is crucial to explore the underlying reasons for these disparities, which is particularly relevant since the stratified analysis of Study IV, with equal distribution of gender and age between the mental healthcare group and non-mental healthcare group, did not change the higher rates of errors, omissions, and offenses among the mental healthcare respondents. Including information about specific mental health diagnoses of the respondents could increase the understanding of whether various diagnosis-related aspects contribute to the experiences of errors, omissions, and offenses. For instance, a patient with severe paranoia may approach errors or omissions differently than a patient with other experiences, such as a history of stigma associated with a specific diagnosis, which may make them more susceptible to feeling offended due to past experiences.

Implications for Practice

The included studies in this doctoral thesis have highlighted some challenges with ORA in mental healthcare, which will be further discussed in this section for implications for practice.

Education for HCPs

Some challenges identified in this theses include, among others, patient-experienced errors, omissions, and offenses in the PAEHR, which could lead to serious patient safety risks, such as providing incorrect treatment or medication due to inaccurate medical information in the EHR. These risks could potentially be mitigated by ensuring that HCPs receive education and training on documentation practices, stigmas, and biases in mental healthcare. Findings of Study I emphasize the need for education among HCPs on documenting clinical notes, especially guidance on how to handle challenging and sensitive topics in the notes. Education among HCPs on overcoming biases in documentation could effectively minimize occurrences of negative patient experiences. Additionally, education on documenting clinical notes in mental healthcare is needed, as this may help HCPs modify or eliminate stigmatizing language [88].

Education for Patients

Education is important not only for HCPs but also for patients. A study emphasizes the importance of improving the designs of online health solutions, combined with providing education to patients about ORA, to maximize the usefulness of ORA for patients [95]. The same study underscores how digital literacy among patients is now considered a social determinant of health. Additionally, patient education should include information on how record-keeping is conducted, why certain aspects of record-keeping are important to document even if patients may not perceive them as necessary, and ensuring that educational materials and tools are easily accessible for patients in the PAEHR to enhance their understanding of the content in their health records.

Challenges and Proposed Solutions in Swedish Psychiatric Care

Psychiatric care in Sweden has been suffering from long waiting times for several years, with reports indicating patients in a northern city waiting up to three years for neuropsychiatric assessments [96]. A project initiated by the Swedish Regions and Municipalities and the Government in 2022 highlights a rapid increase in the need for psychiatric care attributed to factors such as the aftermath of the COVID-19 pandemic, the Ukrainian war, and climate-

related threats [97]. Consequently, Swedish psychiatry is suffering from understaffed, stressed, and overworked HCPs, as acknowledged by the Swedish Government [98]. This situation raises questions about whether HCPs in Swedish psychiatric care are more prone to documentation errors or omissions due to their challenging work environment, hence the findings of Study IV. In response, the Swedish Government has proposed an anti-stigma program aimed at reducing biases and stigmatization of mental illness in society by enhancing public knowledge about mental illness and stigmas. They have also proposed various national strategies aimed at strengthening Swedish psychiatric care to, among others, provide a better working situation for the HCPs [98]. Whether these strategies are enough to minimize patients' negative experiences of PAEHR in mental healthcare needs to be followed up and studied further.

Enhancing Patient Care and Policy Implications

Addressing these challenges could help improve social and economic impacts in society in terms of better health and well-being among some individuals with mental health conditions, as ORA in mental healthcare also, in many ways, benefits patients, such as enhanced understanding of their mental health [58,69], diagnosis [56], medication symptoms [58,59,68,69], and better remembering booked appointments [70] (Study I). Providing patients with ORA to their clinical information enables them to be included and participate in their care. Policymakers can draw insights from these results and utilize this thesis as guidance for implementing necessary actions, such as education and guidance on dealing with sensitive and challenging patient information in the notes, with decisions ideally made at a national level to ensure consistent quality and equal care (in terms of shared clinical information with patients). Currently aspects of ORA in mental healthcare depends on which region the patient has received care in, as the Swedish healthcare system is decentralized (Study II). By implementing the suggested actions (such as strengthening the understaffed psychiatric care in Sweden, implementing education in documentation for HCPs, providing guidance on how to document sensitive patient information, education about ORA for patients, and actions minimizing biases and stigma of mental health conditions among HCPs and society), patients' negative experiences maybe can be reduced as the quality of the notes amends, and potential biases among HCPs would hopefully diminish.

Methodological Considerations and Limitations

This doctoral thesis has explored patients' experiences of ORA in mental healthcare, placing a strong emphasis on empirical data to establish a foundational basis for future theoretical research. Notably, the thesis includes two

studies conducted through patient surveys, further demonstrating the empirical approach taken in this research.

The Literature Review

Study I was conducted as a scoping review to identify existing international evidence regarding patients' experiences of ORA in mental healthcare. This review was the first to explore this topic at the time of its conduct. The choice of a scoping review method was made due to the relatively unexplored nature of this research topic, which allowed for exploring a broad and poorly defined research area encompassing various study designs [36]. While a systematic review typically focuses on well-defined research topics with a narrow range of quality-assessed studies, a scoping review was deemed the most suitable method for this study [36].

Among the included studies, potential response bias may have influenced the findings of survey-based studies, thereby affecting the overall results of the review. The majority of the included studies were based on surveys. In some cases, participants were pre-selected, such as American veterans or individuals selected by treating clinicians for specific studies, who were then granted access to their EHRs as part of their participation. Therefore, the generalizability of the review findings should be interpreted with caution, as they are limited to a lesser extent to the broader population of individuals in mental healthcare.

The Document Analysis and Key Stakeholder Email Interviews

Study II employed a qualitative approach to comprehensively map the implementation of PAEHR in mental healthcare across Swedish regions and some private care providers. The study entailed thoroughly examining and analyzing the web pages of these regions and private care providers to gain insights into how PAEHR in mental healthcare was shared with patients. Additionally, the study explored policies and regulatory documents concerning PAEHR in mental healthcare. Key stakeholder interviews were conducted via email to validate and supplement the findings obtained from the web-based analysis. However, it is important to note that while the results were accurate at the time of the study, they should be considered in that context. When conducting a document analysis in combination with other qualitative methods, such as email interviews as in this Study II, a "confluence of evidence breeds credibility" [42]. To combine document analysis with other qualitative methods is common [42].

To mitigate the risk of receiving an "I do not know" response during physical interviews, the questions were transmitted via email, allowing for review by colleagues and the freedom to attach relevant documents. However, despite encouraging participants to redirect questions they needed clarification on to

the appropriate individual, ensuring this was consistently executed was not feasible. The key stakeholder email interviews were crucial for ensuring the credibility of the data [99], as the information on web pages may not have been consistently updated with current and accurate information. Furthermore, the study was limited to the regional level, omitting an examination of potential variations in patients' access to PAEHR at local levels, such as within specific hospitals or departments.

The NORDeHEALTH Patient Survey

Study III and Study IV were online patient survey studies with data from the same "NORDeHEALTH 2022 Patient Survey" [3]. The survey was distributed in each of the four participating countries; Sweden, Norway, Finland, and Estonia. In Study III, the survey data set from each country was analyzed to gain an overview of patients' experiences of PAEHR in mental healthcare. However, some study limitations could have affected the results. The survey was initially designed in English and then translated into each country's national language (Swedish, Finnish, Norwegian, Estonian, and Russian). The various translations could have provided some language differences in the distributed questions, which were mandatory to answer in Sweden and Norway but optional in Estonia and Finland. Moreover, in Sweden, Finland, and Norway, the survey was placed so that only logged-in users to the PAEHR could respond. In Estonia, however, the survey was placed externally from the PAEHR, making it possible for participants to respond that never logged into their PAEHR. Due to the technical differences in survey distribution between the countries, the results should be considered carefully. Analyzing data from four countries presents a challenge due to variations in the implementation of each country's PAEHR systems, despite sharing similar content of the clinical mental healthcare information with patients [77]. For example, Norway does not offer ORA access to primary care records [33], and Estonia provides summaries rather than detailed clinical notes [33,77]. This necessitates adaptation and flexibility in the analysis process to accommodate the diverse structures across national systems. Study IV only focused on the Swedish data set, where a comparison of respondents with self-reported mental healthcare experience and respondents with self-reported care from other healthcare settings was utilized.

Study III and IV approached the data set in different ways. Study III provided an overview of patients' experiences of PAEHR in mental healthcare. In contrast, Study IV provided a deeper analysis of the research topic by comparing two self-reported patient groups. However, both Study III and Study IV focused on patients with mental healthcare experience, based on the survey item "Have you been in contact with a HCP in the last two years for any of the following?" There was no possibility to verify if those who responded "yes, mental healthcare" (i.e. the mental healthcare group) had been in contact with

a HCP in mental healthcare since the survey was not connected to the health record, meaning the researchers were not able to access any health information via the health record. Moreover, due to the participants' self-reported survey responses, response biases could have affected the accuracy of the findings.

Study III and IV have focused on patient-reported errors. Since these errors are self-reported by patients, it is uncertain whether they truly represent errors, as they are subject to the patients' interpretation. This ambiguity also applies to omissions. Patient-reported errors and omissions can also be of minor clinical consequence, but still appear important to the patient. Despite not being clinically relevant, such errors and omissions could potentially have a negative impact on the patient's trust in the HCP and their therapeutic alliance.

Quantitative Measurements of Patients' Experiences

In this thesis, patients' experiences have been explored using quantitative methods, similar to other studies that have explored experiences using quantitative approaches [8,59]. This thesis describes patient experiences as "user experiences" since the patients are users of a technical solution (PAEHR). The definition of user experiences is: "Users' perceptions and responses include the users' emotions, beliefs, preferences, perceptions, comfort, behaviors, and accomplishments that occur before, during and after use. These experiences are influenced by the user's internal and physical state resulting from prior experiences, attitudes, skills, abilities and personality; from the context of use" (ISO 9241 210:2019) [4].

Patients' emotions, beliefs, preferences, comfort, and other aspects have not been analyzed qualitatively in this thesis, such as through analysis of free-text answers. Instead, quantitative measurements have been employed to assess the rates and occurrences of errors, omissions, and offenses, among other variables. These measurements are based on patients' experiences, which, in the user experience field, could be explained as user satisfaction ("satisfaction: the degree to which the user was happy with his or her experience while performing a task") [100]. In the realm of user experience, the way of measuring or evaluating a phenomenon is called "metrics", which aims to "reveal something about the interaction between the user and the technical solution" [100]. A metric can be, for example, user satisfaction, errors, or task success and must be quantifiable with numbers. User experience metrics are crucial for optimizing the efficiency of complex technical solutions and can help better understand usage behavior and other patterns [100]. Therefore, it has been essential to quantify the rates and occurrences of patients' (users') experiences, including negative and positive experiences (satisfaction), with the PAEHR (technical solution) in mental healthcare. This approach facilitates a comprehensive overview of the issue of patient experiences with the PAEHR. Future qualitative studies are needed to gain a deeper understanding of why patients

have positive and/or negative experiences with the content of their clinical information PAEHR.

Future Directions

We know patients in mental healthcare are experiencing errors, omissions, and feeling offended by the content of their health records; however, this thesis has not explored any reasons for these findings. Study IV in this thesis indicates that patients in mental healthcare are experiencing errors, omissions, and offenses at a higher rate than patients in other healthcare settings. Further studies are needed to explore why patients in mental healthcare are experiencing errors, omissions, and offenses, but also to further explore the differences between the patient groups. To include mental health diagnoses in future studies could be important to understand if some diagnoses are more vulnerable to errors, omissions, and the feeling of offense when reading the clinical information. This thesis has focused on patients' experiences. However, future studies should study HCP's experiences with ORA in mental healthcare due to the limited research in Sweden on HCP's experiences.

Conclusion

When patients were asked about their experiences with reading their health records, most reported positive rather than negative experiences. Common patient-reported benefits of ORA in mental healthcare were feeling in control of their care, increased trust in their clinician, improved understanding of their mental health diagnosis, potential side effects from medications, better remembering to take their medications, and better recall of their scheduled appointments. Despite these predominant positive experiences, only 17 of 21 regions in Sweden offered ORA in mental healthcare.

Moreover, it is important to understand the negative experiences as they represent major concerns. Common negative experiences reported by patients were, among others, feeling judged and labeled by the content of the notes, confused and blindsided when discovering diagnoses that were never discussed, and worried that inaccuracies in the notes could affect their treatment. Some patients also experienced errors and omissions and felt offended by the content of their clinical information. However, patients in mental healthcare experienced errors, omissions, and offenses at a higher rate than patients in other healthcare settings.

Educational standards on documentation in mental healthcare and guidance on handling sensitive patient information in the EHR should be provided to HCPs. These standards would ideally be established at a national level to ensure consistent quality and equal care in terms of shared clinical information with patients. Additionally, educational materials about ORA should be made available to patients. Given the controversial nature of ORA in mental healthcare, the findings of this thesis could help alleviate concerns among HCPs. Denying mental healthcare patients access to ORA due to concerns about potential harm could instead perpetuate biases and stigma within this patient group.

Main Findings:

- Mental healthcare patients' experiences of Online Record Access (ORA) are predominantly positive, such as feeling in control of their care, increased understanding of their diagnosis, and enhanced trust in their clinician.

- Patients with mental healthcare experiences of ORA in Sweden, Estonia, Finland, and Norway are mainly similar between the countries, with minor differences. Increased trust and improved communication are more shared experiences in Finland and identified errors, and omissions are more common in Sweden, Finland, and Norway.

- Patients with mental healthcare experience in Sweden find errors and omissions in their health records and feel offended by the clinical content at a higher rate than other patients.

- Despite the ambition of the Swedish National Regulatory Framework (NRF) to provide all patients access to all their health information, only 17 out of 21 regions in Sweden offered ORA in mental healthcare in 2021.

Sammanfattning på svenska

I Sverige fick patienter i Region Uppsala för första gången tillgång till sin journal via nätet redan 2012, en innovation som sedan spritt sig till hela landet. I januari 2024 loggade 1 650 927 personer in och läste sin journal, och totalt fanns 6 595 669 inloggningar i 1177 Journalen registrerade. Att ge patienter tillgång till sin journal online blir också allt mer vanligt förekommande internationellt, och forskning visar på många positiva effekter. [skriv något kort om vad de positiva effekterna är]. När patienter ges tillgång till sin journal via nätet, så har journaler från psykiatrin ofta uteslutits, baserat på oro från vårdpersonal.

Det övergripande syftet med denna avhandling är därför att utforska hur patienter med psykisk ohälsa upplever att läsa sin journal via nätet. Fyra studier har utforskat detta: 1) en litteraturöversikt som syftade till att utforska den aktuella litteraturen om effekterna av delad journal inom psykiatrin bland patienter, familj, vänner, och vårdpersonal, 2) en policyanalys kombinerad med intervjuer av nyckelpersoner via e-post, vilken syftade till att utforska i vilken utsträckning patienter har fått tillgång till sina journaler från psykiatrin i Sverige, 3) en enkätstudie online vilken syftade till att förstå patienter med psykisk ohälsas upplevelser av att kunna läsa sina journaler i Sverige, Estland, Finland och Norge, och 4) en enkätstudie online vilken syftade till att förstå om och hur patienter med psykisk ohälsas upplevelser av att läsa sina journaler via nätet skiljer sig från andra patienters upplevelser.

Enkätstudierna visade att patienter med psykisk ohälsa hade mer positiva än negativa upplevelser av att läsa sina journaler, likaså litteraturöversikten. Bland annat upplevde många patienter att journaltillgång bidrog till en ökad känsla av kontroll över sin vård, förbättrad förståelse av sin diagnos, samt att det ökade chansen att komma ihåg sina bokade vårdmöten. Bland de som hade negativa upplevelser så var det en del patienter som kände sig upprörda eller dömda av journalens innehåll. Dessutom identifierade vissa av patienterna fel och information som saknas i journalen, och kunde känna sig kränkta av innehållet. Enkätstudien visade att patienter som fått vård för psykisk ohälsa hade dessa upplevelser i större grad än andra patienter. Litteraturöversikten visade att de flesta studier om effekterna av delad journal inom psykiatrin var genomförda i USA, och ett fåtal från Sverige och övriga Nordiska länder. Vid policyanalysen av i vilken utsträckning delad journal inom psykiatrin fanns i Sverige år 2021, så uppgav 17 av 21 regioner att de delade journal med patienter

inom vuxenpsykiatrin, 15 regioner från barn- och ungdomspsykiatrin, och sju regioner från rättspsykiatrin.

Sammanfattningsvis så har patienter som fått vård för psykisk ohälsa negativa upplevelser av att läsa sin journal via nätet i högre grad än andra patienter. Dock är patienternas upplevelser övervägande positiva i båda patientgrupperna. Trots detta så delade enbart 17 av 21 regioner psykiatrijournal med patienterna år 2021. Att neka patienter tillgång till journaler från psykiatrin på grund av till exempel oro kan snarare ge motsatt effekt och istället öka stigma för patienter inom psykiatrin. Denna avhandling kan fungera som vägledning till olika beslutsfattare om lika vård för alla i form av delad journal från psykiatrin.

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