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Patients' Access to Their Psychiatric Records - A Comparison of Four Countries

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Abstract. Several Nordic and Baltic countries are forerunners in the digitalization of patient ehealth services and have since long implemented psychiatric records as parts of the ehealth services. There are country-specific differences in what clinical information is offered to patients concerning their online patient accessible psychiatric records. This study explores national differences in Sweden, Norway, Finland, and Estonia in patient access to their psychiatric records. Data was collected through a socio-technical data collection template developed during a workshop series and then analyzed in a cross-country comparison focusing on items related to psychiatry records online. The results show that psychiatric records online are offered to patients in all four countries, and provide the same functionality and similar psychiatry information. Overall, the conclusion is that experiences of various functionalities should be scrutinized to promote transparency of psychiatric records as part of the national eHealth services to increase equality of care and patient empowerment.

Keywords. mental health, psychiatry, psychiatric record, psychiatric notes, patient accessible electronic health record, PAEHR, open notes

1. Introduction

Patients who can access and read their psychiatric record online perceive an increased understanding of their mental health [1,2], a better awareness of potential side effects of, and adherence to, their medications [2], increased feeling of validation [3], and are feeling in control of their care [3]. Several studies have reported these results investigating mental health patients' experiences of reading their mental health notes online, the majority conducted in the USA [4].

Implementation of patient access to Electronic Health Records (EHR) online, also referred to as Patient Accessible Electronic Health Record (PAEHR), is becoming more

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widespread internationally [5]. Via the PAEHR, patients can access and read notes written by clinicians, see lab and test results, diagnoses, and prescribed medications. The new federal law 21st Century Cures Act in the US, mandated all healthcare providers since April 2021 to offer patients access to their clinical information housed in their EHR [6,7]. In Sweden, one of the studied countries here, all citizens were provided access to the PAEHR in 2018, initially implemented in one healthcare region in 2012, and stepwise disseminated to all other 20 regions [7].

Despite positive patient experiences reading the psychiatric record online, access to clinical information from psychiatric care is considered particularly controversial. Studies investigating healthcare professionals' experiences of patients accessing their psychiatric records online report clinicians' concerns of patients becoming confused, anxious, or offended by what they read [2,8–12]. Swedish and US studies report that clinicians in psychiatric care would be pleased if psychiatric records online were discontinued [9,10]. An early Swedish study conducted in 2014, before patients could access their psychiatry records online, reports psychiatry clinicians' fear of increased threats and violence from patients if they would get access to their psychiatric records [13]. In addition, a Norwegian study reports that 29% of clinicians in psychiatric care hide parts of clinical information that should be presented in the PAEHR [14]. Several Nordic and Baltic countries are forerunners in digitalization of patient services and have since long implemented PAEHRs and psychiatric records as parts of the eHealth services. Implementation inevitably entails country-specific and regional differences in what clinical information is offered. The contribution of this paper is to increase the knowledge about differences in how online psychiatric records are implemented. We aim to explore national differences in Sweden, Norway, Finland, and Estonia concerning the functionality, content, and policies of the online psychiatric records. The study is conducted within the international research project NORDeHEALTH [15], which identifies challenges and opportunities in digitalization of health services for patients.

2. Methods

A socio-technical analysis of national patient portals was carried out in Sweden, Estonia, Finland, and Norway. The socio-technical framework proposed by Sittig and Singh [16], especially tailored to health systems, guided the data collection and the analysis. For each of the eight framework dimensions: *Hardware & Software Computing Infrastructure; Clinical Content; Human-Computer Interface; People; Workflow & Communication; Internal Organizational Policies, Procedures & Culture; External Rules, Regulations & Pressures; System Measurement & Monitoring*, as well as the added dimension *Features & Functions,* several questions were developed to cover socio-technical situations regarding development, implementation and use of patient portals. The first version of the data collection instrument was inspired by a recent socio-technical analysis [17], and the original data collection was carried out during four digital workshops with 1-4 topic experts from the above countries between June and November 2021. Between workshops, the topic experts had time to consult and verify the information with representatives from the national providers. A complementary, smaller data collection based on the dimension *Clinical Content* was carried out in December 2021 to elaborate on a subset regarding psychiatry records online. The digital workshop material consisted of a shared google excel sheet prepared with a list of identified questions. The topic experts from each country wrote down their answers in the shared google excel sheet.

The collected data were analyzed by comparing the answers from each country (Table 1). The analysis was based on these questions from the excel sheet:

1. What type of notes that regard psychiatry care does the PAEHR provide?
2. Does the PAEHR provide access to read prescribed psychiatric medications?
3. Does the PAEHR provide psychiatric diagnoses?
4. Are there policies that care professionals can lean on to limit certain patient groups to read their notes (e.g. if considered at suicidal risk)?

3. Results

Results answering questions 1-3 are presented in Table 1, and disclose that all countries offer similar amounts of clinical information from psychiatric outpatient and inpatient care through digital health services. Sweden, Estonia, and Finland offer patients access to their notes from all psychiatric care settings, such as adults, pediatric-adolescents, and forensic settings. All countries offer the similar amounts of information units presented in Table 1.

Table 1. Information units offered to patients in psychiatric care, comparing four national health services online; Journalen (Sweden), Digilugu (Estonia), Omakanta (Finland), and HelseNorge (Norway).

Information units	**Sweden** Journalen	**Estonia** Digilugu	**Finland** Omakanta	**Norway** HelseNorge
Type of notes that regard psychiatry care	Psychiatrists; Other physicians; Psychologists; Nurses; Social workers; Counselors; Referrals; *MDT notes	Discharge summaries; Referrals	Psychiatrists; Other physicians; Psychologists; Nurses; Discharge summaries; Referrals	Psychiatrists; Other physicians; Psychologists; Nurses; Social workers; Discharge summaries; MDT notes
Outpatient psychiatric care	Yes	Yes	Yes	Yes
Inpatient psychiatric care	Yes	Yes	Yes	Yes
Notes are shared in these psychiatric settings:				
Forensic	Yes	Yes	Yes	Yes
Adults	Yes	Yes	Yes	Yes
Pediatric-Adolescents	Yes	Yes	Yes	Yes
Access to read prescribed psychiatric medications	Yes	Yes	Yes	Yes
Psychiatric diagnoses	Yes	Yes	Yes	Yes

*MDT notes are notes written during Multidisciplinary team conferences.

Although all countries in this study give access to both out- and inpatient notes, there are differences regarding the types of notes patients can access.

Results from question 4 show that several safeguards were also used in cases where patients may put themselves or others at risk (e.g. suicidal risks or violence in close relationships). In Sweden, some regions have implemented specific templates for documenting, such as suicide risks, which are not shared with patients [18]. This also applies throughout Finland. Such templates are not used in Norway or Estonia. In both Sweden and Finland, embargo times are implemented in inpatient psychiatric care so that notes are not immediately accessible to patients. This functionality applies in one Norwegian region, while two other regions give immediate access (also in outpatient psychiatric care). In Estonia, patients have immediate access to psychiatric notes but only signed notes. The latter also applies in Norway. In Sweden, patients can read both signed and unsigned psychiatric notes, and as a patient, one can filter which type one want to read. In Finland, patients only can access and read signed notes. Bärkås et al. (2021) explain the meaning of signed notes as a correct and complete note, validated by the clinician responsible for the information in the note. The responsible clinician has not yet confirmed or validated an unsigned note.

4. Discussion and Conclusion

This is the first comparison of PAEHR psychiatric information in Sweden, Estonia, Finland, and Norway. The results show that all four countries offer patients in psychiatric care access to read their psychiatric records online, however, with differences in the amounts of clinical information shared. In Sweden, Finland, and Norway, patients can read their notes from several healthcare professions in psychiatric care. In Estonia, psychiatry notes are limited to discharge summaries and referrals. On the other hand, the lack of delay period and policies limiting the access for any user in Estonia may compensate for how the user experiences the access. Further research is therefore needed to assess real usage by patients, as well as to cover the knowledge gap of patients' and clinicians' current experiences of psychiatric records online in the northern countries and beyond. Future work may also be to compare the implications of immediate or delayed access to clinical information and whether the notes are shared unsigned or signed. The in-depth investigation in [18] could be used as a point of departure.

One unintended consequence of patient access to psychiatric records may be a reduction of stigmatization of people with mental health conditions since psychiatric notes are shared in the same way as somatic notes. In addition, this could reduce psychiatry clinicians' perceived concerns about PAEHRs reported in previous studies [2,8–12] and apprehension of increased violence from patients reading their psychiatric records since no evidence supports the connection of increased violence and PAEHRs [13]. Previous studies almost exclusively report positive patient experiences of accessing psychiatric records [1–4], however, it is conceivable that some patients, for example, persons with borderline personality disorder, posttraumatic stress disorder, patients with eating disorders, or those with suicidal ideation, might become so deeply upset by what they read that access worsens symptoms [19,20]. Further research is needed to understand potential negative experiences of PAEHRs in mental health care [21].

This study concludes that patients receiving psychiatric care in Sweden, Finland, Norway, and Estonia are offered access to their psychiatric records online. Patients receiving psychiatric care in Estonia have access to fewer psychiatric information items in their PAEHR than in other countries, encouraging further studies related to perceived use. There is a call for homogeneity for the various PAEHR systems among the countries [5]. This study shows that these four countries, despite e.g. different systems and implementation models, provide the same functionality and similar psychiatry information to the patients. Our overall conclusion is that experiences of various functionalities should be fully scrutinized to explore the effects of transparency of psychiatric records, as parts of national eHealth services, including investigating the potential to increase care equity and patient empowerment.

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