

# Patients' Experiences of Unwanted Access to Their Online Health Records

Annika BÄRKÅS<sup>a,1</sup>, Anna KHARKO<sup>a</sup>, Rose-Mharie ÅHLFELDT<sup>b</sup> and Maria HÄGGLUND<sup>a</sup>

<sup>a</sup>Department of Women's and Children's Health, Uppsala University, Sweden

<sup>b</sup>School of Informatics, University of Skövde, Sweden

ORCID ID: Annika Bärkås <https://orcid.org/0000-0002-1209-7714>

Anna Kharko <https://orcid.org/0000-0003-0908-6173>

Rose-Mharie Åhlfeldt <https://orcid.org/0000-0002-8607-948X>

Maria Häggglund <https://orcid.org/0000-0002-6839-3651>

**Abstract.** Patient-Accessible Electronic Health Records (PAEHR) are particularly disputed in mental healthcare. We aim to explore if there is any association between patients having a mental health condition and someone unwanted seeing their PAEHR. A chi-square test showed a statistically significant association between group belonging and experiences of someone unwanted seeing their PAEHR.

**Keywords.** mental health, patient-accessible electronic health record (PAEHR)

## 1. Introduction

Patient-Accessible Electronic Health Records (PAEHRs) are secure web-based portals that are becoming more widespread but continue facing resistance in mental healthcare. Healthcare professionals (HCP) are concerned that mental health patients may be harmed by the content of their PAEHRs, while patients, in contrast, report benefits from reading their psychiatric records. Mental health is often considered particularly sensitive and stigmatized, and patients are often considered vulnerable and unable to manage their own care [1]. Patients with mental health conditions may therefore be more concerned about confidentiality and privacy issues related to their PAEHRs. This study aims to explore if there is an association between patients with mental health conditions and the experiences of someone unwanted seeing their PAEHR.

## 2. Methods

This 46-item survey was designed within the research project NORDeHEALTH (NordForsk Project #100477). The survey was distributed through the Swedish PAEHR platform 1177 for three weeks in January 2022. The survey responses were anonymous. This paper focuses on two participant groups; the Mental Health Group (MHG), which

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<sup>1</sup> Corresponding Author: Annika Bärkås, Dag Hammarskjölds väg 14b, 1 floor, 751 85 Uppsala, Sweden.  
E-mail: [annika.barkas@kbh.uu.se](mailto:annika.barkas@kbh.uu.se)

includes respondents self-reporting experiences with mental healthcare, and the General Group, in which participants reported any other healthcare. Data analysis was performed in Jasp (v0.16.2) and included descriptive statistics and a chi-square test.

### 3. Results

The total number of respondents included in this analysis was 12,334. A chi-square test showed a statistically significant association between group belonging and the experiences of someone seeing their PAEHR without consent ( $\chi^2(2, N=12334) = 234.57, p < .001$ ). In both groups, the majority responded that they have not experienced someone unwanted seeing their PAEHR; however, the proportion of those who had experienced this was larger in the MHG (see Table 1).

**Table 1.** Responses to the item "Have you experienced that someone has seen your health record that you did not want to share?"

Survey Item	MHG (n=3131)	General Group (n=9203)	P value
<b>Has anyone seen your PAEHR?</b>			< .001
Yes	256 (8.18%)	245 (2.66%)	
No	1894 (60.49%)	6539 (71.05%)	
Don't know/don't remember	981 (31.33%)	2419 (26.28%)	

### 4. Discussion

Respondents in both groups stated they had experienced someone seeing their PAEHR against their wish; however, the proportion was higher in the MHG. One could hypothesize that this is either due to more sensitive content in the MHG's records (hence less comfortable sharing), or that this group is viewed as more vulnerable and unable to care for themselves so others are more likely to try to access their records without their consent. Previous research indicates that the Swedish population trusts the healthcare system's ability to protect their information in the PAEHRs [2]; further research is needed to explain why patients in mental healthcare experienced more unwanted access to their health records.

### References

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