

Design of a Patient-Accessible Electronic Health Record System in Mental Health

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Abstract. Patient accessible Electronic Health Records (PAEHRs) are increasingly implemented internationally. However, studies carried out in the mental health care setting report several practical and ethical challenges when introducing PAEHRs. In this paper we aim to explore the requirements of a PAEHR system in mental health. As part of a participatory design process, we collected qualitative data from service users and staff in a rural mental health day clinic setting, which can be summarized in the following themes: I) Function and way of the documentation; II) Impact on Treatment; III) Concerns about PAEHRs; IV) time of access to PAEHRs; V) Different views on what to share; VI) Access, Data Privacy and Special Features. Our study uncovered the complexity and special requirements and barriers to the design of PAEHR in mental health. While we are in an early stage of our study, we will continue this iterative process and adapt the PAEHR system to the specific needs of the users and domains.

Keywords. OpenNotes, Participation, Mental Health, Psychiatry, Pilot, Co-Design.

1. Introduction

Over the last years, patient access to their electronic patient records has proceeded in many countries and various healthcare domains [1]. Previous research hints at the positive effects of sharing notes with people affected by mental health conditions, yet more research is needed. Specifically, there is little known about how the service users wish to use their notes [2]. Hence, the aim of this study is to explore the requirements on a PAEHR in mental health, which supports both access and interaction with the notes.

2. Method

The study started in June 2021 and is an ongoing research project that follows an explorative and qualitative approach. Data were analyzed inductively and categories emerged from open coding [3]. In this paper, we present preliminary findings. Four focus

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group sessions [4] were conducted to co-design the pilot, which subsequently was evaluated in practice. We implemented the feedback between the sessions and discussed the pilot. Nine health professionals (HP) and 14 service users (SU; persons who use mental health services, i.e., patients) participated in these sessions. The study took place in a rural German mental health day clinic.

3. Findings

Both groups (HP and SU) expect that shared documentation will have different effects on the language used in documentation. While HP are concerned that shared documentation can influence their use of language, SU wish respectful but honest documentation. One critical point relates to apparent transparency, i.e., less honest documentation or an incentive to duplicate documentation.

Both HP and SU believe that shared documentation can influence how therapy is carried out. SU report that this can lead to a more trusting relationship between HP and them. On the other side, HP are concerned that this can result in less open conversations. HP and SU both agreed that, besides the possibility of getting more involved in therapeutic processes, there is also a risk for the SU of feeling overwhelmed or overloaded caused by data transparency. Furthermore, HP assumed a lack of comprehensibility of medical and psychological terminology for SU and were therefore concerned about an increased workload. However, both groups also see shared documentation as an opportunity for increased transparency throughout the therapy, which can also uncover discrepancies or mistakes. Finally, they both would welcome a system that allows active participation by the SU, e.g., comments and changes by SU.

4. Discussion and Conclusion

Our findings align with the body of literature on this topic [1]. The findings indicate that before implementing a PAEHR, general reservations and preferences about shared documentation need to be identified and considered. Previous research showed that some concerns would weaken once the users experience PAEHR. At the same time, our findings show the need for a flexible system that fits both the SU's and HP's needs.

The study uncovered requirements and barriers for the design of PAEHR in mental health care. While we are in an early stage of our study, we are impressed by the diversity and high quality of comments and discussions the focus groups provided. Further findings will be published in an upcoming article, and we will iteratively adapt the pilot to the specific needs of the users and domains.

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