

# Pilot Testing and Evaluation of Participatory Patient Record in Psychiatric Care

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## Abstract

The PEPPPSY (Pilot Testing and Evaluation of Participatory Patient Record in Psychiatric Care) project is a new initiative from the Digital Health group of the Centre for Health Services Research in Brandenburg. PEPPPSY stands for “Pilot Testing and Evaluation of a Participatory Patient Record in Psychiatric Care”. The project is based on the United States-based initiative, OpenNotes[1], an international movement promoting and studying transparent communication in healthcare. The project is created with open communication in mind, as it aims towards giving patients insight into their treatments by accessing their psychiatric records. This will hopefully increase trust, engagement, and understanding of both themselves and the therapeutic process.

## Keywords

Health Informatics System, User Centred Design, PAEHR, mental health, patient portals, user involvement

## 1 INTRODUCTION

A Patient Accessible Electronic Health Record (PAEHR), which includes visit notes, laboratory results and diagnoses, is not common practice in Germany. Patients can claim their records by law, but it is a bureaucratic process, making it rare for the patients to do so[2]. Of the patients surveyed, only about 41% of the patients have claimed this right, and of all cases UPD1 handles, about 44% are cases of record-accession conflicts[2]. For psychiatric patients, there are even stronger boundaries, such as needing the permission of a clinician.

Studies indicate that patients may not remember even half of the information relayed to them by their healthcare provider[3][4]. Providing clients with real-time access to their health records will minimize the loss of important information and allow post-appointment reviews. By reading through their notes, patients can identify mistakes and ensure that their patient records are accurate[1]. Giving patients access to their therapist's notes creates mutual trust, which in turn leaves the patient feeling more in control of their health[2].

OpenNotes, and the sharing of patient records, is about transparent communication in general. What makes PEPPPSY unique is that PEPPPSY is centred around providing psychiatric care patients access to their notes made by their health care providers.

The 18th Scandinavian Conference on Health informatics, Tromsø, Norway, August 22-24, 2022. Organized by UiT The Arctic University of Norway. Conference Proceedings published by Linköping University Electronic Press at <https://doi.org/10.3384/ecp187>. © The Author(s). This work is licensed under the Creative Commons Attribution-NonCommercial 4.0 International License. To view a copy of this license, visit <http://creativecommons.org/licenses/by-nc/4.0/>

The Digital Health group at MHB implemented the first pilot of PEPPPSY[5]. The pilot is a web application that functions as a digital one-way message platform. It makes all notes made by health professionals available to the patient that the note is about. The further development of the PEPPPSY project was performed by a group of students at the Norwegian University of Science and Technology as part of their bachelor program.

## 2 METHODS

The PEPPPSY pilot[5] started in June of 2021, and is an ongoing research project that follows an explorative and qualitative approach. The research group based in Germany conducted data analysis and evaluated the pilot in practice. Nine health professionals and 14 service users participated in the study and evaluated the prototype. The study is conducted at a rural German mental health day clinic. The bachelor group based in Norway implemented changes based on the feedback gained from the study and further developed the application over a 5-month period.

The application is developed with Next.js, a hybrid static, and server rendering node framework. It also uses React, for rendering the page, and Webpack, for minifying the code. The user authentication is handled by Next-Auth, a plug-in for Next.js, and Everify for two-factor authentication. The web application has a three-tiered

client-server architecture. The separation of presentation, logic, and data storage makes it easier to develop those three independently of each other. Furthermore, modularization increases maintainability as it results in smaller fine-grained components. Using a RESTful API helps separate the presentation of, and the logic surrounding retrieval/storage of data. The resource sent to the client is conceptually different from the internal representation in the database. This allows the data storage and consumption to be developed independently, as long as the interface stays consistent. We followed an agile development process to iteratively including findings from the ongoing pilot phase in practice, and to evaluate newly introduced features.

### 3 RESULTS

The resulting prototype currently being used is organized based on the three main user types: Health Professionals, Patients and Administrators. For data privacy and GDPR concerns it was important to restrict users to only data they had permissions to access.

The administrator users can create, edit and delete patients and therapists as well as clinics. To maintain confidentiality, the administrators are restricted from accessing the patients' notes or any information about an individual patient. Patient users can only access information about their own notes created by health professionals, and all Health professionals in a clinic can view information and notes pertaining to patients in their own clinic. The health professionals can create and edit patients in their own clinic, as well as create and edit notes on a patient in their own clinic. The health professionals can comment on notes made by themselves or another health professional.

The key feature of the existing solution was the patients' ability to read notes that therapists had published on them. The patients could see when a note was published as well as which occupational group the author of the note belonged to. Along with the ability to publish notes on their patients, the therapists could create patient users. The administrator did not have the ability to read patients' notes, and the admin could not access any information about patients or clinics, nor any information about therapists after they had been created. Even though the project centres around providing the patients a certain amount of information concerning their care, it should not substitute the actual institution which provides said care. The patients cannot use the service provided by PEPPSY as a 24/7 on-call therapist, and the service is only available during opening hours of the clinic.

In the feedback from the current prototype being tested in Germany, a need for more two-way communication was discovered, therefore comments on notes were implemented into the solution. The user can edit and delete comments on their notes, for the purpose of creating a better communication flow between health professionals and patients. When receiving a new note or comment, the users

get a notification. Another important feature added is that administrator may also download a .CSV file that details statistics of every clinic to help with further research. This CSV file only contains clinic level information and does not include individual patients.

### 4 DISCUSSION AND CONCLUSION

Our implementation addressed needs and challenges uncovered during the pilot phase of the initial system. Patients requested a way to interact with their notes and to create comments. Comments on notes can facilitate discussion of subsequent therapy sessions and provide an asynchronous communication channel for both patients and therapists. Yet, the role of these comments for the therapy process needs to be clearly defined. The wish to interact with notes are in line with previous research [4].

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