

Attitudes of Norwegian Mental Health Service Users Toward Electronic Medical Records Storage and Use

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Objective: Electronic health records (EHRs) are used for both clinical practice and research. Because mental health service users are underrepresented when seeking perspectives on EHR use, the authors examined service users' awareness, attitudes, and opinions about EHR data storage and sharing.

Methods: A mixed-methods, cross-sectional design was used to examine 253 Norwegian mental health service users who were recruited online to complete a quantitative and qualitative (free-text) survey about EHR utilization.

Results: Most participants were aware that EHRs were stored (95%) and shared (58%). Most thought that patients benefited from storing EHRs (84%), trusted authorities about EHR sharing (71%), were willing to share records to help others (75%), felt they benefited from sharing (75%), and thought EHR sharing was ethical for health care and research (71%). Fewer were aware of record sharing for research (36%), and 62% were aware that shared data were anonymized. Of the participants, 69% recognized privacy risks associated with sharing. Lack of transparency and skepticism about anonymization as well as misuse of data were concerns and perceived risks. Overall, mental health service users thought that EHRs should be shared for policy development (81%), education and training (85%), improving care quality (89%), research (91%), and clinical decision support (81%).

Conclusions: Participants were aware of and supported sharing EHRs for research and clinical care. They supported record sharing to help others, were willing to fully participate in clinical care and research and were willing to share information for their own care, science, and the care of others.

Highlights

- Health care authorities use electronic health records (EHRs) for clinical practice and research, including enhancing quality of care, improving access to care, providing more efficient service delivery, and producing better clinical outcomes.
- Mental health service users are underrepresented in providing their perspectives on EHR use, and information about their opinions toward EHR use is limited.
- Knowledge about service users' awareness and attitudes toward EHR use should be a part of clinical practice and research planning.
- This study's findings indicate that mental health service users support EHR use for improving patient care and research.

The foundations for electronic health records (EHRs) were laid in the 1960s and 1970s, becoming part of everyday clinical practice in the 1990s (1). In most high-income countries, it is now almost unthinkable to store paper-based patient health records, which was the norm just one generation ago. However, EHRs have some drawbacks, including maintenance costs, workflow disruptions, time spent adjusting to new systems, and data privacy concerns (2).

Benefits and Concerns Regarding EHR Use

EHR benefits include improved quality of care and improved access to care (3, 4), more efficient service delivery, and better clinical outcomes (5); additional benefits include improved efficiency of disease prevention, follow-up, and coordination between health care professionals (6). EHRs also open new opportunities for examining longitudinal, cost-effective, and sophisticated data from large, diverse populations and for building clinical decision support systems (CDSSs) (7).

As other digital information concerning individuals, clinical "big data" raise concerns about safety and privacy. To address these issues, the European Union introduced data protection rules (i.e., the General Data Protection Regulation) that added structure and protections for how people can access information about them; in addition, these rules place limits on what organizations can do with people's personal data (8). There is no federal data privacy law like the General Data Protection Regulation in the United States. Although big data (including clinical big data) have received considerable attention from various groups of professionals (9), the voices of service users regarding use of such data are not always heard. Involvement of service users must be a part of clinical practice planning and operations; however, it is still experienced by many as tokenistic and policy driven rather than as genuine concern for the individual (10), which is especially important when evaluating research that can ultimately inform practice (11). Knowledge about service users' awareness and attitudes toward the storing and sharing of their health data should be a part of clinical practice and research planning.

EHRs and Service Users' Involvement

Research that elicits service users' opinions and attitudes toward EHRs is only limited. Weitzman et al. (12) found that nearly all studied community members were willing to share health information to support research and public health; however, half of the participants wanted to control this information whereby a user could decide what information can be shared, with whom the information can be shared, and what information should be excluded from sharing. Such EHR control has increased recently with legislation and transparency about how service users' information is utilized (13). Kim et al. (14) reported that most patients were willing to share general health EHRs as well as biospecimens: 77% chose to control and amend information to be shared. For example, patients wanted to choose to share only what they considered relevant for specific research and to be able to make specific choices. In another general health care study, patients favored broad permission, with "yes" or "no" options only (13). Kim et al. (14) argued that an "all or nothing approach" can lead to loss of EHR data that are useful for research. Zurita and Nøhr (15) affirmed

that patients accepted EHRs and new technologies; however, the patients were adamant that portability (being able to move information across services), access for others providing health care (i.e., family physician having access), and protecting privacy were important.

With rapid digitalization of mental health services (especially during the COVID-19 pandemic), substantial amounts of data are collected. Stigma associated with mental health services was one of the reasons why EHR uptake was slower than in general health care and why mental health EHRs were separated from other EHRs (16–18). As reported by Salomon et al. (19), 63% of mental health professionals expressed low willingness to input confidential or sensitive information, and 83% favored limiting the routine access to patient EHRs. Other behavioral health professionals have found that service users did not wish to share records detailing diagnosis (47%) and substance use (48%); however, they were willing to share records of emergency admissions and treatments (57%) as well as historic patient records (52%) because these records were seen as important for ongoing care (20).

Service Users' Voice on EHR Storage and Sharing

Satinsky et al. (21) found that mental health service users showed little prior awareness of health data uses for research but were largely comfortable sharing their health records. Some participants raised issues of transparency, advocating for clear opt-out options and processes, whereas others stressed an interest in being part of reference groups to stay up to date on findings. Likewise, participants of Kim et al.'s (14) study were willing to share family mental health histories (40%), mental health treatment procedures (39%), details of mental health medications (40%), and mental health disease conditions (40%). Shen et al. (22) reported that mental health service users favored sharing health information, even after considering the sensitive nature of the data. However, data exchange was based on trust and being well informed about how their data benefit others' experiences.

Results from O'Brien et al.'s (23) study showed that most service users were more attentive to the benefits of sharing than the risks; there were few discrepancies in the opinions when general health and mental health service users were compared. Service users were most concerned about EHRs being stolen or hacked (83%) and thought that the largest benefits of sharing included helping doctors make better decisions about health (94%) and making therapies available faster (94%). Overall, service users have been positive about sharing mental health EHRs for research and improving services (14, 22, 23). However, persistent concerns include issues relating to privacy and security, hacking of personal information, and anonymity (21–23).

EHRs can be also used to build a CDSS. A CDSS is a computerized tool that uses patient information and related health care data to make recommendations for clinicians on the best possible next step in a patient's care. CDSSs in child and adolescent mental health settings are uncommon and have major shortcomings (24). Therefore, we are building an Individualized Digital DEcision Assist System (IDDEAS), which is a new CDSS based on clinical guidelines as well as decades of anonymized EHR-derived mental health data (25). Because the EHR is central to CDSSs, it is important to understand service users' perceptions about storing and sharing their records. Therefore, in this study, we investigated mental health service users' awareness that health authorities store and share EHR information, attitudes about EHR storage and sharing, and opinions about the purposes of sharing health records.

Methods

Participants

This study was connected with the IDDEAS innovation project and was conducted in Norway. Mental health service users, who were members of ADHD Norway (a service users' organization), were invited to participate.

Ethical Approval

The regional ethical committee concluded that this study was outside its remit and recommended approval from the Norwegian Centre for Research Data; this approval was obtained.

Questionnaire

An original questionnaire included demographic questions and 19 items that focused on storage and sharing of EHRs. Two items focused on awareness that health authorities store and share EHRs. Twelve items, rated on a 5-point Likert scale, focused on mental health service users' attitudes about EHR storage and sharing. Opinions about purposes of sharing health records were assessed by one question with the following answer options: clinical decision support, research, better health care quality, education and teaching, and clinical practice follow-up. Four open-ended questions had free-text answer options to offer concerns about storing and sharing health data. Survey completion took approximately 20 minutes. ADHD Norway, in collaboration with the Vårres service users' organization, assisted in converting the original questionnaire into an Internet-based EasyQuest survey form.

Procedure and Data Collection

Participants were recruited via e-mail distributed by ADHD Norway to all its registered members (N=5,021). The e-mail contained a link to the survey. Data were collected from March to April 2021. No identifiable data were collected. All data were sent to ADHD Norway for safekeeping and encryption. A passcode was used to safely share data with the coauthors.

Analysis and Interpretation

We analyzed quantitative data with SPSS, version 25.0. Independent-sample t tests, chi-square statistics, and Fisher's exact tests were used for univariate comparisons of demographic characteristics and individual items. Some variables were clustered: education (university ≥ 4 years, university < 4 years, and nonuniversity) and employment (employed or unemployed). The survey also generated qualitative data, consisting of mostly brief one-sentence answers but also narratives. "Comments of interest" are presented in the Results section to amplify quantitative observations.

Results

Demographic Characteristics

All registered ADHD Norway members (N=5,021) were invited to participate in the study. ADHD Norway indicated that approximately 30% of these members had outdated e-mail addresses, leaving a target population of approximately 3,500. Of these service users, 253 participated in the study (7% response rate) (Table 1).

Awareness of Health Authorities Storing and Sharing Health Records

Most service users (N=240, 95%) were aware that health authorities store their EHRs. More than a half (N=147, 58%) were aware that the EHRs were shared among health care professionals and for research. No significant differences were found in outcome variables by education, employment, age, and gender.

Participants' Attitudes Toward Data Storage

Most service users (N=210, 83%) approved of health authorities storing EHRs, could see the benefits of EHRs storage for patients (N=213, 84%), and were not worried about EHRs storage (N=162, 64%) (Figure 1). No significant differences were detected when the outcome variables were compared by education, employment, age, and gender.

Participants' Attitudes Toward Data Sharing

Most service users (N=180, 71%) reported that it was ethical to share EHRs for health care and research. The same proportion (N=180, 71%) trusted health authorities with record sharing; even more (N=190, 75%) were willing to share their records to help others with similar diagnoses and

indicated benefits from sharing them (N=190, 75%). Just above one-third of the participants (N=92, 36%) were not aware that records were shared for research. Almost two-thirds of participants (N=156, 62%) were aware of data anonymization and understood the privacy risks associated with sharing (N=175, 69%); more than a half (N=149, 59%) felt no need to limit use of anonymized data.

In addition, service users who were employed reported significantly more trust in health authorities and saw no need to withhold health data from anonymous use compared with those who were unemployed (Likert scores mean±SD=3.89±1.1 vs. 3.48±1.3, $t=2.72$, $df=251$, $p<0.01$, and 3.72±1.3 vs. 3.53±1.4, $t=2.07$, $df=251$, $p<0.05$, respectively). No differences were detected between unemployed and employed when outcome variables were compared by education, age, and gender.

Participants' Opinions About Reasons for Sharing EHRs

Most service users wanted health records to be shared for policy development (N=205, 81%), education and training (N=215, 85%), improving care quality (N=225, 89%), research (N=230, 91%), and clinical decision support (N=205, 81%). When we compared the outcomes by gender, education, employment, and age, we detected no significant differences on any of the outcome variables.

When service users were grouped by their trust in health authorities with respect to EHR storage, it was found that those who had more trust also had more willingness to share their records (N=173 [90%] vs. N=19 [10%], $\chi^2=60.59$, $df=1$, $p<0.001$) and reported greater awareness about sharing records for research (N=113 [61%] vs. N=71 [39%], $\chi^2=16.92$, $df=1$, $p<0.001$).

Comments of Interest

In the qualitative portion of the study, mental health service users were invited to highlight their perceptions of risks and concerns regarding their EHRs by using free-text responses. Examples of these responses have been extracted to serve as comments of interest because they capture common themes that were shared repeatedly among participants. Among these themes, three main areas of concern included lack of transparency, skepticism about anonymization, and data misuse.

With regard to lack of transparency, the following concerns (among others) were raised:

“Historically, there has been little information for service users about what, how, and which health information is recorded, including access. Lack of info [and] access can create uncertainty for some.”

“What is stored, who has access, and how will they use it?”

The security of anonymizing confidential data was flagged as a concern and potential risk, as was skepticism about the anonymization processes, especially for EHRs containing identifiable or traceable information (e.g., DNA or rare diagnoses):

“I have nothing against health authorities sharing my health information, as long as it's anonymized.”

“I do not trust that they are able to anonymize efficiently.”

Having the EHR end up in “the wrong hands” was mentioned, among other concerns, under the topic of data misuse. This topic was also linked to skepticism regarding anonymization. Mental health service users raised concerns about data misuse related to human error, cyberattacks, and incorrect information being used against them (e.g., employment):

“I am not certain what my information will be used for . . . 1. Sensitive information will be used in relation to employment. 2. Misunderstandings arise among health care professionals

due to previous illness[es] that are no longer relevant. 3. Sensitive information (above) [is] used against me in insurance cases or similar legal matters.”

“Mental health can be stigmatized and misunderstood.”

“Old, outdated records are used in current cases, which can have largely negative consequences.”

Discussion

In this study, we investigated mental health service users’ awareness and attitudes about storing and sharing EHRs while also examining perceived risks and benefits associated with the use of health records in health care and research. Most service users were aware of EHRs being stored by health authorities and had positive attitudes toward storing and sharing. Of the service users, 83% approved of EHRs being stored, and 84% saw it as beneficial.

For the qualitative portion of this study, mental health service users were asked to indicate concerns and risks only via free-text responses mainly on the negative aspects of EHRs. The users identified concerns and perceived risks related to privacy (i.e., anonymization, hacking, misuse of data, and transparency), similar to findings from previous studies (3, 4, 26, 27) that identified concerns about potential for breaches in confidentiality (21–23). Managing these concerns has led to multiple levels of control, including obtaining consent and allowing service users to affirm what data are shared (12–14). However, mental health professionals and service users previously still expressed reservations about sharing EHRs because of safeguarding concerns (19, 20). Participants in this study appeared to trust health authorities who store and share their data. Given this trust, sharing sensitive health data appears relatively unproblematic, and our findings support the notion that trust is linked to higher acceptance of sharing (22).

Similar to results of other studies (14, 22, 23), mental health service users in this study agreed to storage of their EHRs and to sharing of these records for the benefit of others. Findings of this study support the results of Kim et al. (14), who showed that most service users deliberately would choose to share data, and of O’Brien et al. (23), who found that the predominant reason for support of sharing data was that such sharing can improve health care. Previous studies in mental health settings have indicated openness to sharing, along with awareness of where data are going and for what purposes (22) and that increasing transparency on what is shared creates more access to valuable data (28). Regulations alone do not reassure service users that data will be protected. Health care professionals can increase trust among service users by better clarity accurate about use of EHR data (29). Trust emerges as a key factor for service users recognizing positive outcomes for patients when mental health records are stored and shared.

Despite their concerns, participants focused on the benefits of sharing health data for service user care, helping others with similar diagnoses, and policy development. In other words, for them, benefits outweighed concerns. This finding supports EHR data use for the development of future systems to improve efficiency and quality of mental health care through technological advancements, including CDSSs (24, 25, 30–32).

The strength of this study was that it elicited opinions of mental health service users, who are often underrepresented in similar research. We note the low survey response rate and the relatively small sample size as limitations. Additional limitations included a skewed gender distribution and high education levels, lack of younger participants, few unemployed participants, and participation by few non-Norwegians. Lack of information on sociodemographic characteristics of the sample population was also a limitation. We also do not know whether this sample is representative of the larger population and whether these results can be generalized to all members or other groups in the

health care community. The survey was anonymous, meaning that we did not have access to information about nonresponders to compare with the data from responders.

To our knowledge, this study is the first in Norway to explore mental health service users' perspectives on EHR use. We found that although mental health service users were aware of risks of EHR data storage, they were agreed to storage and sharing of their anonymized data to help other patients. This study builds a strong case against separating general medical and mental health EHRs. Our findings should encourage investigators, caregivers, and policy makers to collect and store EHR data from patients with mental disorders for use used in research and policy decision making similar to how general medical data are collected and used.

Conclusions

This study is among only a few to explore mental health service users' perspectives on EHR use. Our results suggest that mental health service users are similar to other patients in the general health care system with respect to the use of their clinical data in EHRs. Mental health service users were aware that clinical data are stored and shared. They were appropriately concerned about privacy and anonymization of their data but trusted that authorities can safeguard their health information. In addition, mental health service users supported the idea that research that uses properly controlled data sharing will positively contribute to general health care, health care policy, and health care innovations. Finally, mental health service users were willing to consent to use of their data to help others.

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FIGURE 1. Attitudes toward storage of electronic health record (EHR) data among Norwegian mental health service users who completed a survey about EHR utilization in 2021 (N=253)

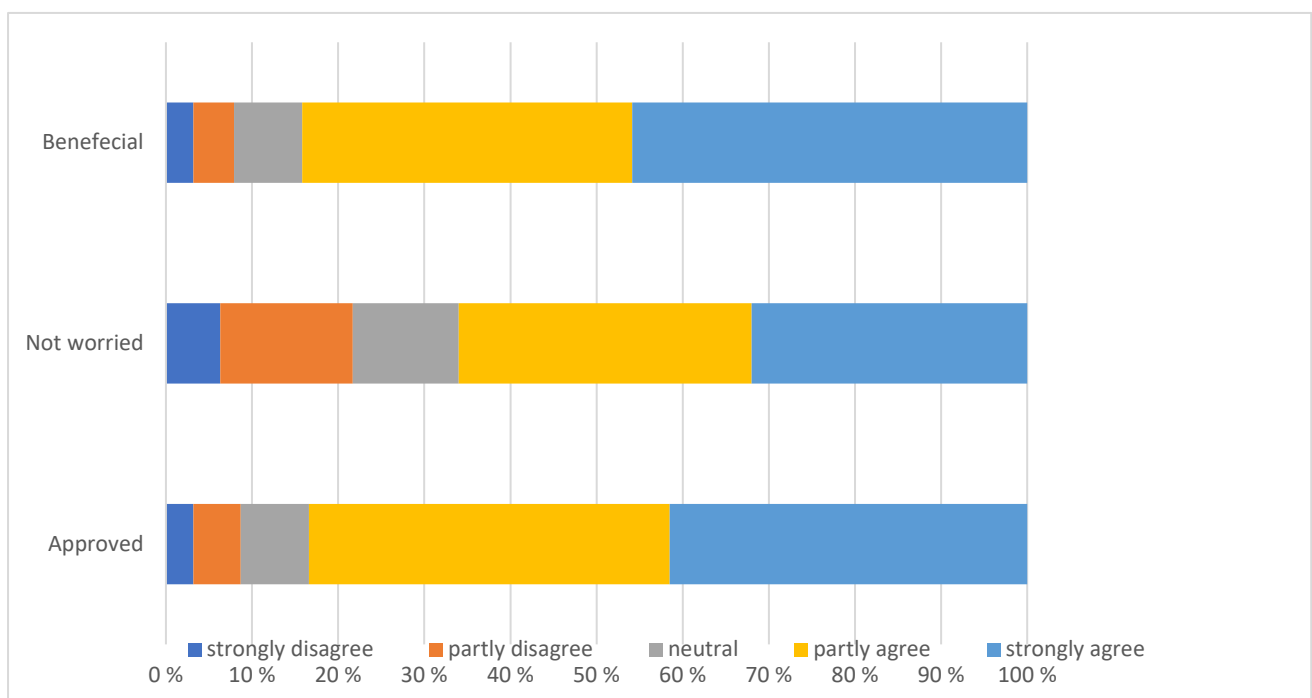


TABLE 1. Baseline characteristics of Norwegian mental health service users who completed a survey about electronic health record utilization in 2021 (N=253)

Characteristic	N	%
Age in years		
0-15	2	1
16-24	4	2
25-34	43	17
35-44	86	34
45-54	83	33
55-64	25	10
65-74	10	4
Gender		
Women	179	71
Men	69	27
Other	5	2
Employment		
Employed	160	63
Unemployed	93	37
Education level		
University, ≥4 years	99	39
University, <4 years	68	27
Nonuniversity	86	34
Ancestry, Norwegian		
Yes	241	95
Other	12	5