

## Health Professionals' Experience with Patients Accessing Their Electronic Health Records: Results from an Online Survey

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### Abstract

*The aim of this study was to investigate hospital professionals' experience and attitude with patients accessing their own electronic health records. The study was conducted one year after service establishment. Data was collected through an online survey. In total, 457 replies were received. The results revealed a quarter of the administrative staff received feedback from patients or relatives regarding mistakes or missing information in their EHR. In addition, 67.5% of health professionals expected more patients to have basic knowledge of their health status in the future, and 21.4% found patients already gained better knowledge about diagnosis, treatment, or follow-up. The results also revealed some challenges with the service, especially for health professionals working in psychiatry, with some scepticism on whether the service is suitable for the sickest and most vulnerable patients.*

### Keywords:

Electronic Health Records, Patient Access to Records, Telemedicine

### Introduction

Patient-accessible electronic health records (PAEHR) are developing in many countries, including Norway [1]. In Norway, the Electronic Health Record (EHR) has been fully established for many years now, and the patient is both the object and the owner of the health record. Patients have, since 2001, had the right by law to access their health record [2] and, in 2013, a White Paper stated patients should have digital access [3]. In accordance with the Norwegian Patient Right Act § 5.1 [2], health professionals can deny patients' access to either the full record or to specific documents in the journal if it is "necessary to avoid endangering the patient's life or serious damage to the patient's health", or if access to the information is inadvisable for persons close to the patients.

Currently, two of four health regions in Norway offer patients ages 16 or older, and parents of children under the age of 12, digital access to their hospital's EHR via the national health portal Helsenorge.no. Northern Norway was the first health region that offered all patients in the region digital access to their own EHR. In general, all documents available in digital format, including psychiatry reports, are made available for the patient as soon as they are approved/signed by health professionals, unless health professionals decide to deny access. In addition, a log list, showing those who accessed the record was made available to the patient at the time of this survey.

Before PAEHR was established, the University Hospital North Norway (UNN) sent their patients epicrisis by post after each consultation or hospitalisation. The other hospitals only sent it to the patient by request. In general, access to full or specific parts of the health record was given upon request where print or CD was sent via ordinary mail.

Patients reported to be generally satisfied with the PAEHR, recommended it to others, and generally understood the content [4]. At the same time, as the patients received this new service, a variety of tasks previously performed by secretaries or other support staff were transferred to the doctors [5]. Media claimed the time Norwegian doctors could use to direct patient care declined from about 60% in 2004 to less than 43% in 2012 [6]. It is not known whether PAEHR will increase the health professionals' workload and impact their work practice [7], create a different impact between health professionals (e.g. doctors and nurses) [8], and differ between somatic care and psychiatry, as others have been reluctant to provide open access to psychiatric records, considering it too sensitive [8].

The primary aim of this study was to investigate hospital health professionals' experiences and attitudes with patients accessing their own EHRs. The secondary aim was to explore whether there were differences in experiences and attitudes based on the implemented practices between hospitals, between doctors and nurses, and between psychiatry and somatic care.

The study was carried out in collaboration with the Northern Norway Regional Health Authority and the Norwegian Directorate of eHealth.

### Methods

Data collection was performed through an online survey by sending a link via e-mail. The survey was distributed to all employees through a common e-mail list for the four hospitals in Northern Norway. The study was conducted in December 2016, after one year of experience with the service.

The respondents received different questions based on their professional background. The questionnaire to the health professionals and the administrative staff consisted of 25 and 14 items, respectively, including background variables such as job position, employment fraction, hospital, main working field (somatic/psychiatry/both), duration of practice, gender, and age. The questionnaire comprised of a combination of multiple choice questions, follow-up questions depending on the choices, and free text fields. Questions and quotes have been translated from Norwegian to English.

The questionnaire was anonymous. A questionnaire used in a pilot study was used as a template for the survey development. The questionnaire was pilot-tested by four researchers several times until no suggestion for modification came up.

No questionnaires were excluded from the analysis due to incomplete answers. The research objectives were investigated by descriptive statistical analyses using the statistical program R, version 3.4.2. For calculating the mean, the questions "Not applicable" and "I do not know" were omitted, and the response options were assumed to be at the interval level. A two-sample Student's t-test was used to test whether the differences in attitudes between health professionals from somatic care and psychiatry were statistically significant.

When presenting frequencies in the Results section, the "Totally agree" and "Quite agree" categories were merged into "Agree", and the "Yes, sometimes" and "Yes, quite often" categories were merged to "Yes". When comparing experiences and attitudes between doctors and nurses, both psychiatrists, psychologists, and physicians were included under the term doctor.

The free text responses were subjected to a content analysis aimed at identifying dominant themes related to the specific questions. Responses from health professionals within psychiatry and somatic fields were analyzed separately.

Some overall results from this study have been previously reported in Norwegian via oral presentations or the web.

## Results

### Demographics

In total, 457 replies were received. The responses were divided among the four hospitals as follows: 212 from UNN, 194 from Nordland Hospital (NH), 39 from Finnmark Hospital, and 12 responses from Helgeland Hospital.

As many as 77.7% of the respondents were female, and 80.7% of the respondents had a full-time position. The age distribution was quite uniform: 29.3% between 50 and 59 years old, 24.3% between 40 and 49, 24.1% between 30 and 39, 10.7% younger than 30, and 11.6% older than 59.

Most of the respondents worked in the somatic field (65.2%), while 27.4 worked in the psychiatry field, 3.5% in both fields, and 3.9% in other fields. Among respondents there were nurses (29.5%), doctors or psychiatrists (17.9%), other clinical positions (13.6%), psychologists (5.5%), social workers (2.2%), physiotherapists (1.8%), ergotherapists (1.3%), and radiographers (0.9%) in addition to administrative positions (27.4 %).

### General Experiences Among Health Professionals and Administrative Staff

There were 332 responses from health professionals, and 125 responses from administrative staff members.

The main finding was that more than a quarter of the administrative staff received feedback from patients and/or their relatives regarding mistakes or missing information in their EHR (25.6%).

More than one third of both clinical (36.4%) and administrative (36.8%) staff received questions from the patients and/or their relatives related to use of the PAEHR. The same number of administrative staff forwarded requests from patients and/or their relatives to responsible health personnel (36.8%). Among

health professionals, 15.4% received feedback from patients and/or their relatives regarding mistakes or missing information in their EHR. 72.8% of clinicians and 54.3% of administrative staff knew where to find information about the service.

### Health Professionals' Experiences

The main finding was that 67.5% of the health professionals expected more patients to have a basic knowledge of their health status in the future, and 21.4% found patients were better informed about diagnosis, treatment, or follow-up than before (Table 1).

In addition, 28.3% experienced that the patients or their relatives referred to information from their EHR, and 19.6% of the health professionals planned to use the PAEHR in future follow-ups, for example, by adding more information in the EHR. 26.5% of the health professionals reported they had changed their way of writing in the EHR, while 71.4% meant that they should, in principle, complete the EHR documentation earlier, regardless of the patient's access. More results are presented in Table 1 below.

Table 1 - Health Professionals' Experience with PAEHR  
N=332

Do you agree with the following statements?	Yes <sup>a</sup>	No <sup>a</sup>
I expect that more patients will have basic knowledge of their health status in the future.	67.5	17.2
I find that patients are better informed about diagnosis, treatment, or follow-up than before.	21.4	36.8
I experience that patients/relatives refer to information they have found in their EHR.	28.3	69.6
I receive requests where I think: "Patients could easily find this information in their EHR, if they access it through the service".	26.8	69.9
I would use the patient's access in the follow-up, for example by adding more information to the patient in the EHR.	19.6	38.3
I changed my way of writing in the EHR.	26.5	61.8
In principle, I mean that we should write the EHR documentation earlier, regardless of the patient's access.	71.4	17.7
I inform patients that they can read their own EHR and check their referrals through the service.	50.8	38.3
I am worried that I need to spend a lot of time explaining journal content.	17.5	56.9
I am worried that I need to spend a lot of time reassuring patients because they have read their EHR.	26.5	46.4
During the past year, I discussed with colleagues whether there is a basis for denying a patient access to their EHR.	26.2	64.5

<sup>a</sup> "Yes" and "No" is presented in %. The "I do not know" category is not included in the table.

### Differences in Practices Among Hospitals

The quantitative results showed no significant difference in attitude and experience between UNN (the only hospital that for several years sent epicrisis to the patients by mail after a consultation) and the other hospitals. However, by limiting the results to the psychiatry field, only, for the two hospitals with the most responses, 47.4% of the respondents from NH claimed they changed their way of writing in the EHR, while the corresponding figure for UNN was 30.8% (less than 40 clinicians responded at both institutions,  $p=0.139$ ).

### Differences in Experiences and Attitude Between Health Professionals in Psychiatry and Somatic Care

The results showed statistically significant differences in experiences and attitude between health professionals in psychiatry and somatic care regarding the use of PAEHR (Table 2).

The main finding was that as many as 43.9% of the health professionals in psychiatry reported they changed the way they wrote in the EHR after the service was established, compared to 23.6% from the somatic field. On the other hand, 77.4% of health professionals from psychiatry and 83.0% from somatic care expressed they should, in principle, write the EHR documentation earlier, regardless of whether the patient has online access or not.

In general, 27.2% of health professionals had discussed with a colleague whether to deny a patient access to information in their EHR or not. The problem was much more relevant in psychiatry, where as many as 60%, compared to 15.2% in somatic care, discussed this issue.

There was also a small difference between psychiatry and somatic care with regard to how often patients refer to information they find in their journal (18.4% vs. 25.4%).

Table 2 - Differences in Experiences Between Psychiatry and Somatic Care, 95% KI,  $p < 0.05$

Related to Use of the PAEHR-Service:	Somatic Care	Psychiatry	p
I experience that patients/relatives refer to information they have found in their EHR <sup>a</sup>	1.25 (1.20 - 1.31)	1.43 (1.28 - 1.48)	0.013
I changed my way of writing in the EHR <sup>b</sup>	3.24 (3.11 - 3.36)	2.70 (2.49 - 2.90)	<0.000
In principle, I mean that we should write the EHR documentation earlier, regardless of patient's access <sup>b</sup>	1.82 (1.70 - 1.94)	2.06 (1.88 - 2.24)	0.028
I discussed with colleagues whether there is a basis for denying a patient access to their EHR <sup>a</sup>	1.17 (1.12-1.23)	1.72 (1.58 - 1.86)	<0.000

<sup>a</sup> 1-no, 2-yes, sometimes, 3-yes-often

<sup>b</sup> 1-totally agree, 2-quite agree, 3-quite disagree, 4-totally disagree

### Differences in Experiences and Attitude Between Doctors and Nurses

While 37.8% of the doctors were worried they would have to spend a lot of time reassuring patients or their relatives after reading their EHR, only 15.1% of the nurses expressed the same concerns ( $p < 0.000$ ).

While 37.8% of the doctors claimed they changed the way they wrote in the EHR, only 24.8% of the nurses changed their practice ( $p = 0.045$ ).

### Qualitative Feedback on the Service

A total of 99 respondents provided additional comments in the open text field. There were 58 comments from health

professionals from somatic care and 38 comments from health professionals in psychiatry, while three were categorised as both/other. From the somatic field, 39 comments came from UNN, 14 from NH, and five from the other hospitals. Of the 38 comments from psychiatry, 17 came from UNN, 15 from NH, and six from the other hospitals. Some comments included both support and criticism of the service, while others raised several concerns. Comments that did not contribute any specific experience with the service were categorized as neutral (Table 3).

Table 3 - Comments from the Respondent

Comments	Psychiatry			Somatic		
	UNN	NH	F	UNN	NH	F
Number of comments	17	15	6	39	14	5
Neutral	3			17	8	1
Positive	5 <sup>a</sup>		2	6 <sup>a</sup>	1	4
Critical	11	15	4	20	5	
Content of critical <sup>b</sup> comments regarding the PAEHR service						
Not suitable for any mentally ill patients	2	1	1			
Not suitable for all patient groups	8	5	1	1		
Patients should only be able to access parts of the EHR		2				2
Patients might misunderstand		1		7		2
Need to deny access	3	2	1			
Omit information	1	4		1		
Write a hidden journal	1	2				
Suggest delaying the information		2	1	1		
Complicates their work	2	4	3	8		2
Worry for their own security		1		1		
Skeptical of the new logging functionality	1	2		1		1
Other comments	1			7		

<sup>a</sup> Two of these also include critical comments, <sup>b</sup> Some critical comments raised several concerns

The positive comments from both fields mainly support the establishment of the PAEHR as a service.

The frequency of comments from psychiatry (38/125=0.304) was higher than that from the somatic field (58/298=0.195). In addition, 79% (30/38) of the comments from psychiatry were critical, compared to only 43% (25/58) from somatic care. Looking at the content of the critical comments, we also found more concerns were raised from psychiatry, compared to the somatic field (52 vs. 34).

The respondents' main concern was that PAEHR was not considered suitable for mentally ill patients (4), while 14 respondents considered it unsuitable for all patient groups in psychiatry. Examples of unsuitable patient groups were the sickest patients with psychosis, delusions, unrest, and utterance, where reading the EHR could worsen the situation. In addition, concern was raised towards vulnerable children with parents accessing the EHR on their behalf. Parents in a conflict situation, or if the child is a victim of abuse, could cause further

problems to the child. Vulnerable adult patients could also be threatened to show their EPR to others.

Some respondents commented patients should not be able to read the whole EHR, but maybe only the epicrisis. They worried patients with severe illness might misunderstand information, especially in the middle of a therapy period. Respondents referred to experiences where patients refused to speak with health professionals based on what they had read in the journal.

Some health professionals denied access to information they worried might harm the patient or their relationship with the patient. However, some pointed out that the functionality for denying access to information was complicated to use and little known. Other respondents reported they omitted some information from the EHR, and a few others reported they wrote a "hidden" journal containing the information they did not want the patient to read. Other suggested to delay displaying the journal documents, for example, until after the therapy period in psychiatry was completed. A number of respondents, from both fields, commented that PAEHR complicated their work, caused more work, and worsened the treatment. They felt they had to spend more time to evaluate what they should write or not. They had to write in a manner that the patient would not find offensive, and had to consider who they wrote to, a young person, old person, or a very sick person. If they decided to deny access to information, this could harm the patient-therapist relationship, as the patient might become suspicious and mistrustful. The service could also make it complicated to reflect on patients' symptoms through documenting "suspected" illness. Other comments focused on the difficulty to use the service for elderly patients, who might not receive any information from the hospital unless the epicrisis is sent by ordinary post as before.

Some of the respondents worried about the new functionality which provides patients with a log list of those who access their EHR. The respondents worried the service could complicate their work and patients could question their motives since they often accessed other journals to look for similar symptoms, used them as a template, or used them for teaching purposes.

A doctor working in psychiatry stated the PAEHR "*<...>complicates my work and worsens the treatment and alliance I will build with the patients*". Another said: "*I think it is not right that patients in psychiatry should have access to their journal. In fear of writing something "offensive" I think many therapists unfortunately have to do double-journal entries. Which again is vulnerable to getting lost. I deny the access when I know it's information that can be a trigger for the patient, but frankly, within psychiatry, there's a lot to be offended by, especially if you're mentally ill, and it could be impossible to predict what someone sometimes can take offence at*".

## Discussion

The results of this online survey demonstrates several positive effects of the PAEHR. The fact that administrative staff received feedback from patients or relatives regarding mistakes or missing information in their EHR might improve the quality and correctness of the journal content and hence ensure patient safety and quality of the health service. This is very important for the patient in order to receive a correct diagnosis and a correct treatment. Two of three health professionals expected patients to gain more knowledge of their health status in the future, and more than one fifth found patients were already better informed about diagnosis, treatment, or follow-up than

before. Despite some questions may be interpreted to cover more than the PAEHR, we believe the results of this survey demonstrate the potential clinical relevance of this service.

More than one fourth of the health professionals reported they changed their way of documenting in the EHR, as reported in other studies [8], while more than two thirds reported that, in principle, they should write the EHR documentation earlier. Future studies might explore potential changes over time, for instance, if more health professionals will alter their way of documenting due to the patients' access.

The results showed no significant difference in attitude and experience between UNN, the only hospital that for several years had sent the patients epicrisis by post after the consultation, and the other hospitals. However, looking at the psychiatry field, health professionals from NH claimed to have changed their way of writing to a greater extent than the health professionals from UNN. The results were not statistically significant, but supported by the comments from the two hospitals. There were more positive and neutral comments, and less critical comments from UNN compared to NH, where all the comments were critical (Table 3). These comments might support that UNN's earlier practice of sending out the epicrisis making the transition to the PAEHR service easier for their employees working in the psychiatry field.

The results revealed some challenges with using or adapting to the service, especially for health professionals working in psychiatry. Almost twice as many respondents from psychiatry than from somatic care reported they have changed the way they write in the journal, and nearly four times as many health professionals from psychiatry compared to somatic care have discussed with their colleagues whether to deny patients access or not. When comparing the frequency and content of the text comments, the PAEHR might have put an additional burden on some health professionals, especially those dealing with psychiatric patients. Many respondents questioned if the service was actually suitable for the sickest and most vulnerable patients. The health professionals could deny patients' access, but some respondents commented they did not have a strong enough reason to hide information, while others found the functionality to hide the information not user-friendly. Health professionals could benefit from information on, and continuous training on, how and when to deny patients' access to journal records.

Health professionals in the somatic field received more questions from the patients regarding information in the EHR than health professionals in the psychiatry field (25.4% vs. 18.4%). There is therefore little reason to believe that higher levels of patient demand was the reason why health professionals within psychiatry seemed to raise more concerns towards the PAEHR.

More doctors than nurses claimed they changed their way of reporting, and twice as many doctors than nurses worried that they will have to spend more time reassuring patients, or their relatives, after they read their journal. This finding has probably more to do with the fact that the doctors who diagnose the patient, and have extensive knowledge, also have the overall responsibility for the patient, thus implying a stronger relationship. This might lead to a more negative attitude to the PAEHR as they feel a greater threat to their autonomy [9,10].

Norway and Sweden have comparable healthcare systems, and comparable PAEHR solutions in the way that patients have access to mainly all the information in the EHR system. Patients reported they are satisfied with the service [4,11], and the service fills important needs for them [11]. In Sweden, criticism has been raised from the clinical professions, and mainly from

physicians [8,9,12,13]. Physicians are mainly negative toward patients reading their health record online, while nurses are mostly positive, and nurses with some experience from patients using this service are more positive than nurses with no experience [9]. Physicians who used the PAEHR for themselves, as a patient, had a more positive attitude compared to physicians without such an experience [9]. Physicians were concerned patients could misunderstand the information in the EHR, something that would affect their work process and workload in a negative way [9,10]. A systematic review of studies from primary care indicated patients increased convenience and satisfaction, while health professionals were concerned about impact on workload and that the information would cause worry for the patient [7]. No changes in health outcomes were reported, but medical errors were detected, which may improve patient safety, and uptake of prevented care improved [7]. Several studies reported concern over increased workload, while only some demonstrated an actual increase in workload, and then in e-mail or online messaging, with face-to-face contact staying the same or falling [7]. In another study including 105 General Practitioners (GPs) and 13,564 patients, the GPs expected to increase their workload, while no significant increase in workload was showed after one year of experience. At the same time, patients reported an increased sense of control, better understanding of their medical issues, and they felt better prepared for future visits, in addition to improved adherence to medications [14].

Today, the PAEHR is well integrated in the two health care regions, and we believe that the positive benefits will compensate for the possible additional workload for health professionals. However, the issues raised by the health professionals from psychiatry should be followed up.

There are some limitations with this study which should be acknowledged. The online survey was sent to all employees through a third party (the IT-support organisation), using a common e-mail list, regardless if they had journal access or not. As a consequence, it was impossible to calculate an accurate response rate. However, the response rate was relatively low. We acknowledge that this type of recruitment for research easily leads to responses from people with strong opinions, very positive or very negative, more often than those who have not made an opinion. It is therefore important to be aware that the data material may be subject to this bias in the interpretation of the results.

More knowledge on how the service will influence both patients and health professionals in the future is necessary through further studies.

## Conclusions

Health professionals' experiences and attitude with patients accessing their own EHRs was investigated through an online survey. The results revealed several positive findings, including patients identifying mistakes in the EHR and being better informed about diagnosis, treatment, or follow-up than before. The results indicate minor differences in experiences and attitudes based on the different practices existing at the different hospitals, and between doctors and nurses. On the other hand, major differences in experience and attitude were found between psychiatric and somatic care.

Health professionals working in psychiatry questioned if the service was suitable for the sickest and most vulnerable patients. Some adaptations, instructions, or training might be necessary to make the service more suitable for the psychiatry field.

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## References

- [1] A. Essén, I. Scandurra, R. Gerrits, G. Humphrey, M.A. Johnsen, P. Kiergegaard, et al., Patient access to electronic health records: Differences across ten countries, *Health Policy and Technology* 7 (2018) 44-56.
- [2] HOD, The Norwegian Patient Right Act (LOV-1999-07-02-63), (2001). [https://lovdata.no/dokument/NL/lov/1990-07-02-63#KAPITTEL\\_6](https://lovdata.no/dokument/NL/lov/1990-07-02-63#KAPITTEL_6).
- [3] Stoltenberg-government-II, Meld. St. 9 (2012-2013) Æn innbygger – én journal: Digitale tjenester i helseog omsorgssektoren, (2012). Only in Norwegian. [One Inhabitant- One Journal]. [www.regjeringen.no/no/dokumenter/meld-st-9-20122003/id708609/](http://www.regjeringen.no/no/dokumenter/meld-st-9-20122003/id708609/).
- [4] T. Sørensen and M.A. Johansen, Developing and implementing patients' full-scale electronic access to their health record, *Stud Health Technol Inform* 228 (2016) 85-89.
- [5] I.H. Amundsen, Vi har I det stille overtatt sekretærbjobben, in, VG, (2013). <http://www.vg.no/nyheter/innenriks/artikkel.php?artid=10119286> (accessed November 23, 2018).
- [6] I.H. Amundsen, Sykehuslegene fanget I papirmølla, in, VG, (2013). <http://www.vg.no/nyheter/innenriks/artikkel.php?artid=10119284> (accessed November 23, 2013).
- [7] S. de Lusignan, F. Mold, A. Sheikh, A. Majeed, J.C. Wyatt, T. Quinn, et al., Patients' online access to their electronic health records nad linked online services: A systematic interpretative review, *BMJ Open* 4 (2014), e006021.
- [8] L. Petersson and G. Erlingsdottir, Open notes in swedish psychiatric care (part 2): Survey among psychiatric care professionals, *JMIR Ment Health* 5 (2018) e10521.
- [9] T. Alander and I. Scandurra, Experiences of healthcare professionals to the introduction in Sweden of a public eHealth service: Patients' online access to their electronic health records, *Stud Health Technol Inform* 216 (2015) 153-157.
- [10] C. Grunloh, A. Cajander, and G. Myreteg, "The record is our work tool!" – Physicians' framing of a patient portal in Sweden, *J Med Internet Res* 18 (2016) e167.
- [11] J. Moll, H. Rexhepi, A. Cajander, C. Grunloh, I. Huvila, M. Hagglund, et al., Patients' experiences of accessing their electronic health records: National patient survey in Sweden, *J Med Internet Res* 20 (2018) e278.
- [12] M. Hagglund and I. Scandurra, Patients' online access to electronic health records: Current status and experiences from the implementation in Sweden, *Stud Health Technol Inform* 245 (2017) 723-727.
- [13] L. Petersson and G. Erlingsdottir, Open notes in Swedish psychiatric care (part 1): Survey among psychiatric care professionals, *JMIR Ment Health* 5 (2018) e11.
- [14] T. Delbanco, J. Walker, S.K. Bell, et al., Inviting patients to read their doctors' notes: A quasi-experimental study and a look ahead, *Ann Intern Med* 157 (2012) 461-470.

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