



'I do not share it with others. No, it's for me, it's my care': On sharing of patient accessible electronic health records

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Abstract

This study explores patients' perspectives on sharing their personal health data, which is traditionally shared through discussions with peers and relatives. However, other possibilities for sharing have emerged through the introduction of online services such as Patient Accessible Electronic Health Records (PAEHR). In this article, we investigate strategies that patients adopt in sharing their PAEHR. Data were collected through a survey with 2587 patients and through 15 semi-structured interviews with cancer

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patients. Results show that surprisingly few patients share their information, and that older patients and patients with lower educational levels share more frequently. A large majority of patients trust the security of the system when sharing despite the high sensitivity of health information. Finally, we discuss the design implications addressing identified problems when sharing PAEHR, as well as security and privacy issues connected to sharing.

Keywords

e-health, electronic health records, health care, security and privacy, sharing

Introduction

Healthcare trends portray the future as increasingly digital and personalized. E-services are often put forward as instrumental to more patient-centred and transparent care processes.¹ In parallel to this, efforts have been made to make healthcare information more understandable and usable for patients. However, little research has focused on patients sharing their healthcare information.

A premise for storing healthcare information digitally in patient portals is keeping it secure. However, not all users are willing to actively safeguard their records^{2,3} assuming patient portals are secure a priori. The situation is also complicated by the fact that health information is shared outside of the portals both offline and digitally.⁴ When information is shared *in person*, patients have a higher degree of control, as they can choose when and what to share, comment, and provide additional context. However, offline sharing does not allow either remote access to the records by others as is made possible in Patient Accessible Electronic Health Records (PAEHR).⁵

When sharing *digitally*, information can usually be consulted at any time or location. Sharing the entire health record is also common in e-health systems, including *historical* information or certain types of records patients may not be comfortable with giving access to.^{6,7} Hence, it is important to understand the benefits and drawbacks related to different modes of sharing to help the development of current and future e-Health systems more responsive to patients' needs.

This study aims to explore the patients' perspective on what technical, ethical, security, and privacy challenges need to be considered when designing systems for sharing medical information. Applying a mixed-methods approach based on a national survey (N=2587) and an interview study (N=15) to elaborate on the quantitative data, the study aims to answer the following research questions (RQs):

- *RQ1*. What values, considerations, and conditions motivate patients to share or not to share medical records?
- *RQ2*. What are the critical issues constraining the sharing of medical information in person and digitally?

Based on the results, we discuss the different modes of sharing and provide design and policy recommendations. The empirical focus of this study is on the Swedish national PAEHR *Journalen*. *Journalen* was first introduced in the Uppsala region in 2012⁸ and from late 2017, patients from all Swedish regions have been able to access the system.

Background

Patient portals are e-Health systems that provide access to personal health records and communication with health service providers.⁹ Crotty et al.⁶ also describe them as a 'hub for families' implemented through 'proxy access' that let patients share their health information, and account for

changing ‘dimensions of information sharing (what information, to whom, when, how much, and under what circumstances)’.

Shared e-access to PAEHR has both positive and negative implications: not only an enhanced partnership between formal and informal caregivers of patients, better inclusion of the latter into the care process,¹⁰ but also value tensions¹¹ and privacy and security issues.⁹

Still, the benefits of being able to share PAEHR have conclusively been shown in a large number of studies. Yamasaki and Hovick¹² investigated the impact of sharing of family health history that prevents ‘health-related secrecy of prior generations’, which is detrimental for the wellbeing and health of family members. Huvila et al.¹³ present a study on patients reading their medical records and identify that ‘individuals caring for close relatives have the greatest interest in medical records’, confirming the importance of information sharing in informal caregiving and collaborative partnership with professionals.¹⁴ Hence, accessing a relative’s PAEHR can be a form of care, however, not always legitimate due to the lack of defined access roles for care partners.

A much-debated question, which has grown in importance in light of recent changes in European and global legislation in 2018, is whether there should be a possibility to share the access to PAEHR or access someone’s records. Specifically, the sharing of medical records is impacted by the adoption of the General Data Protection Regulation (GDPR) (EU) 2016/679 (A regulation in EU law on data protection and privacy for all individuals within the European Union that was enforced on 25 May 2018), raising concerns with stakeholders and patient groups.¹⁵ However, at times, legal regulations about personal health records and their availability can be very difficult to interpret. For example, a decision by the Supreme Administrative Court (June 2018) in Sweden prohibits the function where patients can share their information with others, finding it to be in conflict with the Patient Data Act (A part of Swedish Data Protection Act (2018:218) and Swedish Data Protection Regulation (2018:219) that entered into force on 25 May 2018), which refers to allowing only patients themselves direct access to their medical records – not someone else.

Patient information is stored and communicated within global networks, distributed databases, and even in the cloud. This implies an increased risk of lost control over its dissemination,¹⁶ which does not always match the views of patients and might still be perceived as safe.¹⁷ Vodicka et al.¹⁸ investigated patients’ access to their medical information, showing that even if there are privacy concerns, they do not negate patients’ willingness to have and access their information online. Increased circulation of patient information also means increased security risks that underline the importance of security controls to minimize them.^{19,20}

In Sweden, patients can access their medical records (e.g. test results, referrals, diagnosis, and medical notes) online through Journalen. Until the summer of 2018, patients could share their health records in Journalen with any person in Sweden by adding the social security number of the person to share with, and choose what parts of the medical records they would like to share. The possibility to share was later removed due to GDPR, but as the data collection presented below was carried out while the sharing function was still in use, the data are particularly valuable today for elucidating the attitudes and practices relating to the use, usefulness, and perceived risks relating to that particular function.

Methods

A mixed-methods approach combining a survey and interviews (to elaborate survey results) was used in this study. Both studies were approved by the Regional Ethical Review Board in Uppsala, Sweden (EPN 2017/045).

Table 1. Demographic characteristics of interview participants.

Attribute	Range	Sample size
Gender	Female	12 (80%)
	Male	3 (20%)
Age (years) ^a	<44	3 (21.4%)
	45–54	1 (7.1%)
	55–64	5 (35.7%)
	>65	7 (50%)
Illness duration (years)	<1	4 (26.7%)
	1–2	5 (33.3%)
	>2	6 (40%)

^aOne participant did not provide her age clearly.

National patient survey

An invitation to participate in an online survey was shown during 5 months in 2016 for all patients logging in a national PAEHR system on the system login page. A total of 2587 patients (out of the 423,141 who logged in during that period) initiated the survey. All but two respondents coming from the parts of the country, where the system was not yet in use, were included in the analysis. The study was anonymous and the questionnaire contained 24 questions on a five-point Likert-type scale covering attitudes towards, experiences with, and use of Journalen in addition to demographics and respondent background. In this article, the questions relating to demographics, sharing behaviour, and system security (five questions in total) were analysed. An overview of the results of the survey has been published by Moll et al.²¹

Apart from descriptive statistics, the Friedman tests were used for detecting contrasts between different modes of sharing (using the share function, discussing with relatives, and discussing with care staff) for age, education, and disease groups. The Wilcoxon signed-rank tests, with the Bonferroni corrections applied, were used for group-wise comparisons in cases where the Friedman tests showed significant results. The Jonckheere–Terpstra test has been used to find age- and education-related trends in the data. Significance levels were set to 95 per cent in all tests. The data used in the statistical tests of group-wise differences and trends are based on a numerical conversion from the Likert-type scale alternatives (1 (strongly disagree) and 5 (strongly agree)).

Semi-structured interviews

Fifteen participants were recruited in the summer and autumn of 2013 using an information leaflet at an Uppsala University Hospital. Eligible participants had cancer in different stages and were users of Journalen. Table 1 depicts the participants' information.

Three researchers including the second and the fourth authors with extensive experience in qualitative data collection conducted 45–60-min-long semi-structured interviews in person in the patients' homes and at the hospital, which were then transcribed and categorized focusing on the questions related to sharing health information. Predefined categories based on the interview template were used in the data analysis. Data were first analysed by the fourth author and thereafter discussed and further analysed by a team of several researchers. The interview study has resulted in another publication.¹⁷

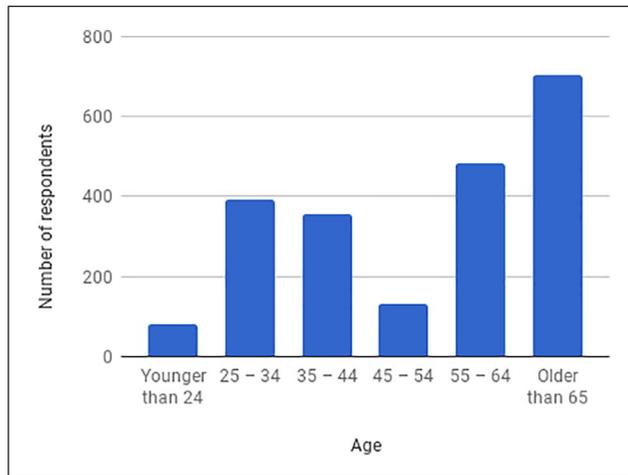


Figure 1. The age distribution of respondents to the survey.

Results

Among the respondents of the survey ($n=2587$ (in the following, we report on statistics of the actual number of patients who responded to each question)), 63 per cent identified as female (1629 out of 2587) and 30.9 per cent as male (798 out of 2437). As for education, 38.5 per cent of all the respondents (945 out of 2455) reached post-secondary education of 3 years or more and 19 per cent of all the respondents (467 out of 2455) reached post-secondary education of <3 years. Moreover, 39.8 per cent (1030 out of 2441) of all respondents stated that they were working or had worked in the healthcare sector. One-third of the survey respondents (702 out of 2148) were older than 65 years, while the least represented age groups were 45–54 years old and younger than 24 years (see Figure 1).

Users of online sharing in PAEHR

In the survey, patients were asked about the strategies in sharing their health records: discussing with relatives, with staff, or using the ‘Share’ function. In total, 626 respondents out of 2587 (24.2%) indicated that they have used the PAEHR ‘Share’ function: 13.6 per cent (353 out of 2587) of them to share PAEHR in parts and 10.5 per cent (273 out of 2587) to share everything.

The age distribution of those who used the ‘Share’ function is presented in Figure 2. In total, 33.8 per cent (204 out of 626) of these users were older than 65 years (32.7% in the overall survey population). Younger adults (<24 years) was the least covered age group in the survey as a whole, only 3.7 per cent (22 out of 626) of the respondents from that age group stated that they use the ‘Share’ function. The Jonckheere–Terpstra test did not show any age-related trends regarding the usage of the ‘Share’ function ($JT=1,117,800.5$, $p=0.647$).

Respondents who share online associate themselves with the following disease groups: 24.6 per cent (165 out of 670) with *high blood pressure*, 21.2 per cent (142 out of 670) with *psychiatric diseases*, and 13.6 per cent (85 out of 626) with *cancer*, which also corresponds to the overall survey statistics (23.7%, 19.5%, and 13.4%, respectively). In total, 38.3 per cent (240 out of 626) of those who use the ‘Share’ function stated that they worked in healthcare, which is similar to the overall number of the respondents (39.6%). The most common education level was a high school with 3 years or more,

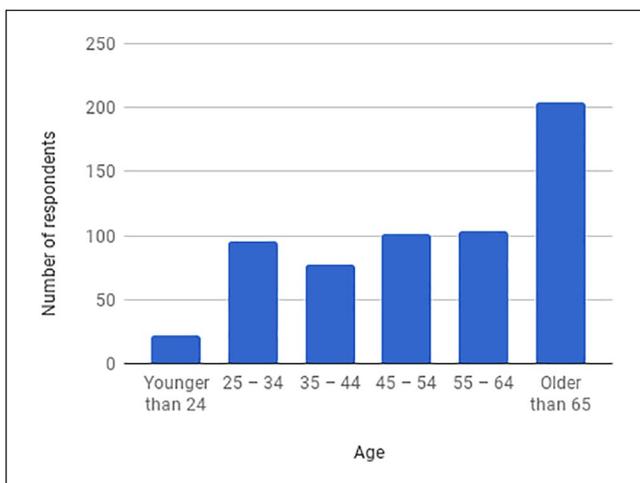


Figure 2. The age distribution of users who use the 'Share' function.

which summed up to 28.6 per cent (173 out of 604 of answered) of all online sharers. The Jonckheere-Terpstra test showed a significant trend related to the level of education ($JT=938,513.0$, $p<0.001$), which shows that the use of the online share function decreases as the education level increases.

Survey free-text field questions were used by only 86 respondents where many of them (20 out of 86) highlighted that they do not share their records with others. Another common response (14 out of 86 respondents) was that there was 'no information to share'. Some commented that they have never used the share function or did not know that it exists (7 out of 86).

The relatively low rate of respondents sharing online was also supported by cancer patients who expressed a variety of perspectives in regard to sharing in the interviews:

- *Others would not check if they share.* They believe that there is no point in sharing since family members would not read their health-related information: 'No. I do not know why would they go there and check out' (female, 33 years old).
- *No need to share online with those with whom they live together.* Cancer patients expressed their preference towards sharing in person with their family members at home: 'I talk to those [I] live with and tell, but I do not share online journal' (female, 51 years old).
- *Feeling protective of their data.* Some patients would disclose and discuss medical information offline upon request but not otherwise, not proactively: 'No, I do not share it with others. No. It's for me. It's my care. ././ I have not shared (using) the service' (female, 43 years old).

Offline sharing through discussing

A common view expressed in both the interviews and the survey was that PAEHR is discussed in person with relatives, but not shared online. One interviewee explained this in the following way: 'I discuss what's correct with my partner. I also discuss what is meant by medical terms. I did not know that you could share the journal with others, and I do not want to do it' (female, 35 years old). In total, 60.3 per cent (1568 out of 2587) of the survey respondents agreed that they share their health-related information with relatives and/or medical staff, and this is about 2.5 times higher than the number of respondents sharing through the online share function in Journalen (24.1% or 626 out of 2587). The opinion that sharing should be done in person was a recurrent theme in the

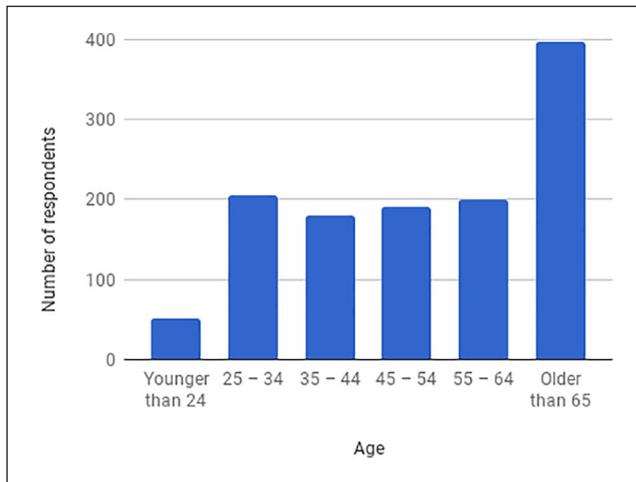


Figure 3. Age distribution among those who share by discussing with relatives.

interviews: ‘If there is anything that I want (to share)? Hm. I would like it to be that we sit down and looked at it, me and the oldest son. / . . . / That we sit together watching the same screen’ (female, 70 years old). In total, 48.7 per cent (1265 out of 2587) of all survey respondents stated that they share their health information by discussing with relatives, and 32.5 per cent of those (398 out of 1225) were older than 65 years (Figure 3).

The Jonckheere–Terpstra test did not show any age-related trends regarding sharing by discussing with relatives ($JT=1,179,011.0$, $p=0.141$). It did, however, show that this mode of sharing is used less with increasing level of education ($JT=977,556.5$, $p<0.04$). Figure 4 shows common diseases of patients that shared PAEHRs by discussing with relatives, and high blood pressure is the most common one (22.2% or 300 out of 1351) as in the overall survey.

Sharing by discussing with medical staff. A total of 41 per cent of all the survey respondents (1066 out of 2587) share health information by discussing them with medical staff. In total, 29.2 per cent of those (302 out of 1033) are older than 65 years (see Figure 5).

The Jonckheere–Terpstra test showed a significant trend regarding age ($JT=1,179,639.5$, $p<0.001$) – respondents discussed their health record with healthcare staff more with increasing age. The test did not, however, show any significant trend related to the level of education ($JT=944,426.0$, $p=0.066$). The main type of diseases of those who share by discussing with staff members is depicted in Figure 6.

Sharing when you have cancer or psychiatric disease. The disease groups ‘Cancer’ and ‘Psychiatry’ were analysed individually since they have been specifically highlighted in research on PAEHR in both Sweden and abroad.^{17,22} The Friedman test showed significant effects on modes of sharing for both cancer ($\chi^2=296.4$, $p<0.001$) and psychiatry patients ($\chi^2=332.2$, $p<0.001$) (Table 2). The post-hoc analysis with the Wilcoxon signed-rank test with a Bonferroni correction applied gave a significance level set at $p<0.017$.

Sharing by discussing with relatives. Cancer patients used the online sharing function significantly less than offline sharing by discussing with a relative ($Z=-12.794$, $p<0.001$) and with staff ($Z=-12.769$, $p<0.001$), respectively. No significant differences were found between the two

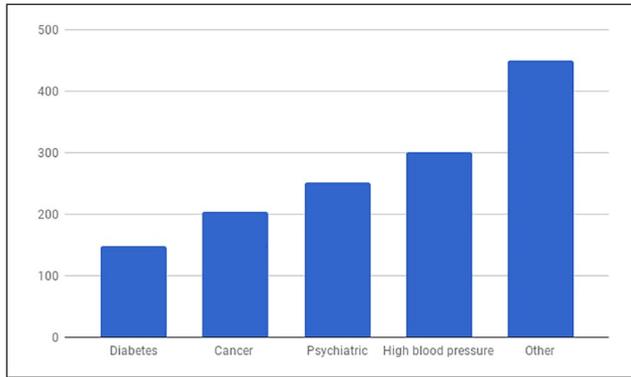


Figure 4. Diseases of those who share by discussing with relatives.

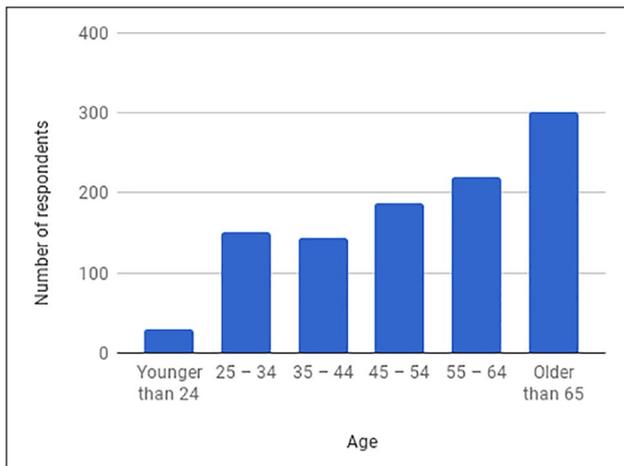


Figure 5. Age distribution of the patients sharing by discussing with staff.

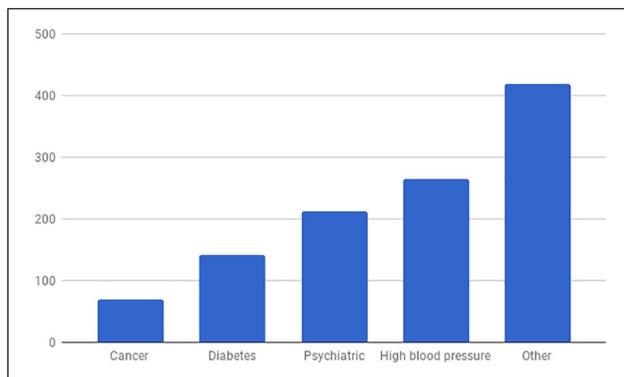


Figure 6. Diseases of those who share by discussing with staff.

Table 2. Descriptive statistics for the different modes of sharing for cancer and psychiatry patients, respectively.

Modes of sharing	N	Mean	SD
Cancer patients			
Online sharing function	330	1.53	1.08
Discussing with relatives	338	3.39	1.52
Discussing with staff	330	3.33	1.35
Psychiatry patients			
Online sharing function	498	1.58	1.09
Discussing with relative	502	3.02	1.57
Discussing with staff	497	2.93	1.48

SD: standard deviation.

5-Point Likert-type scale questions (1 (strongly disagree) and 5 (strongly agree)).

Table 3. Descriptive statistics for the different modes of sharing for the different age groups and education levels.

Modes of sharing	Using share function			Discuss with relative			Discuss with staff		
	N	Mean	SD	N	Mean	SD	N	Mean	SD
Age groups (years)									
<24	81	1.37	0.81	81	3.35	2.60	81	2.85	1.43
25–34	388	1.59	1.11	390	3.14	1.52	388	2.78	1.45
35–44	352	1.48	0.99	355	3.00	1.56	352	2.90	1.38
45–54	427	1.57	1.05	430	2.88	1.56	424	3.03	1.43
55–64	461	1.47	1.06	467	2.82	1.59	460	3.13	1.40
>65	659	1.52	1.03	675	3.31	1.50	642	3.12	1.36
Education levels									
No formal education	64	1.98	1.35	66	3.38	1.55	63	3.37	1.45
Elementary school	148	1.76	1.27	155	3.43	1.39	145	3.15	1.33
High school, <3 years	240	1.56	1.09	240	2.94	1.46	238	3.00	1.38
High school, ≥3 years	394	1.61	1.10	397	3.14	1.56	394	2.99	1.39
University, <3 years	454	1.46	0.99	459	3.05	1.59	451	3.05	1.38
University, ≥3 years	920	1.44	0.96	929	3.00	1.58	910	2.92	1.43
Doctorate	73	1.47	1.00	74	2.95	1.54	74	3.09	1.48

SD: standard deviation.

offline sharing modes ($Z=-0.329$, $p=0.742$). Psychiatry patients used the online sharing function significantly less than offline sharing modes sharing by discussing with a relative ($Z=-14.181$, $p<0.001$) and with staff ($Z=-13.724$, $p<0.001$). No significant differences were found between the two offline sharing modes ($Z=-1.286$, $p=0.198$).

Sharing and caring. More than half (62.3% or 376 out of 604) of patients who share online agreed that sharing is essential to be able to actively participate in decisions about their or their relatives' health. Also, 60 per cent (324 out of 540) of those who access Journalen for an overview of their relatives' records reported that they do it to provide their relatives with better care.

Moreover, over one-third of those who share online (201 out of 597) acknowledged that access to Journalen leads them to take better care of their relatives' health, while for the overall population

Table 4. The Friedman test effect of sharing modes for all age groups and education levels.

Age groups (years)	χ^2	p	Education levels	χ^2	p
<24	75.35	<0.001	No formal education	43.05	<0.001
25–34	273.4	<0.001	Elementary school	120.8	<0.001
35–44	266.9	<0.001	High school, <3 years	169.8	<0.001
45–54	300.0	<0.001	High school, \geq 3 years	284.3	<0.001
55–64	344.9	<0.001	University, <3 years	370.6	<0.001
>65	596.2	<0.001	University, \geq 3 years	709.9	<0.001
			Doctorate	57.5	<0.001

this number was 19.8 per cent (160 out of 809) and for those who share by discussing with family or staff it was 26.2 per cent (311 out of 1185) and 23.6 per cent (238 out of 1010), respectively.

One of the ways of caring was expressed in the interview with cancer patients:

(I would share) if I felt that I did not understand much and wanted someone (to help), so I think that my grandmother would share it with me to help her but (for me) I do not know anyone who would be helpful and support (me) with my journal in any way. But it may be good for someone. (female, 33 years old).

Comparing modes of sharing

Table 3 shows the descriptive statistics for the different modes of sharing for the age and education categories used earlier in this section. The Friedman test showed a significant effect of sharing modes for all age groups and educational levels as can be seen in Table 4.

The post hoc analysis with the Wilcoxon signed-rank test with a Bonferroni correction applied gave a significance level set at $p < 0.017$. All pair-wise comparisons between the online and the two offline sharing modes gave significant results ($p < 0.001$). When it comes to the two offline sharing modes, no significant differences were found for any of the education levels. However, significant differences between offline sharing modes were found for age groups of the following: <24 years ($Z = -3.054$, $p < 0.01$), 25–34 years ($Z = -4.512$, $p < 0.001$), 55–64 years ($Z = -4.367$, $p < 0.001$) and ≥ 65 years ($Z = -3.075$, $p < 0.01$).

Security factors of survey data

Survey data analysis consistently shows that there is a high level of trust in security through all types of sharing: online and offline, and it is slightly higher in sharing with staff. In total, 88.2 per cent (2170 out of 2460) of overall respondents think there is a high level of security, while for those who share by discussing with staff it is 91.4 per cent (947 out of 1036).

Only 7.1 per cent (174 out of 2444) of respondents did not agree that only authorized medical staff is accessing their medical records in Journalen and even less (3.7%) do not feel very safe and secure when they perform actions in it (3.7% or 91 out of 2482). In those two groups of respondents, 39.7% (69 out of 174) and 47.3% (43 out of 91) agreed that they still share their PAEHR with relatives.

Discussion and conclusion

Our aim was to understand patients' perspectives and views on sharing medical information online and in person when a possibility of sharing PAEHR through a patient portal exists. By discussing

and analysing the characteristics of the population who share or do not share (RQ1) and the main barriers and difficulties in sharing (RQ2) including those related to PAEHR systems, we provide design and policy recommendations to support the development of e-health systems and services.

Patients' characteristics and sharing

Older and less educated patients share more. The results show an association between sharing and education level of the respondents (Table 4). The lower the patient's education level is, the more they share online and discuss with relatives. This may be related to a willingness to share to find support or explanations,²³ which was also mentioned in the interviews.

The older the patients are, the more they share, in particular, through discussions with medical staff. As chronic long-term illnesses and multiple diseases are more common at higher ages,²⁴ older patients might simply have more to share. Besides, they preferred offline sharing, which reflects their general preference towards face-to-face communication.

As a whole, less educated and older patients form a vulnerable population group. While they could benefit from digital health services by receiving support through sharing their health information, they also might have a 'lower baseline sense of control' over their data flows²⁵ (p. 10) and become more exposed to security and privacy risks. Patient portals should ensure privacy and security by design, for instance, by implementing recognizable sharing features and communicating related risks. Considering the complexity of current PAEHR systems,²⁶ sharing PAEHR through them should also be adapted to a diversity of knowledge and abilities of the users, such as ageing-related declines and lack of information and communication technology (ICT) skills.

Health conditions and illnesses affect sharing. The health of patients affects their willingness to share PAEHR and expectations from those they would share with. The interviews showed that cancer patients were hesitant to share online, which is also true for psychiatry patients from the survey responses. Our data analysis did not identify that chronic disease patients share more than overall participants online; however, they share slightly more offline: with family and medical staff.

As different conditions might cause a range of feelings in patients regarding sharing their health information, such as the fear of stigma²⁷ or making other family members worried,¹² opportunities of digital sharing should provide a sense of control and dynamic sharing options, taking into account the patients' situation and allowing to provide comments and context.

Views on the types of information to share vary. Another common reason for not sharing PAEHR was 'no information to share' or no worthy information to share. While some respondents possibly did not yet have notes or diagnoses to share, thereby rendering the sharing action useless, it is still a recognized phenomenon in current research.²⁸

However, a more pertinent issue might be that the opinions of patients and care providers on the importance of particular types of health information might differ and not align.³ In this respect, PAEHR sharing platforms could facilitate transparency to reach a common understanding of the relevance of certain information for sharing.

Sharing is connected to its usefulness. Interviews show that cancer patients do not share if they do not see the use of it, a finding, which is consistent with the literature. Older patients who report on sharing their PAEHR with relatives value the helpfulness of the sharing for them.⁶

While being involved in the care of one's relatives was a common reason for accessing Journalen, those taken care of might still want to keep control over the information their caregivers are accessing, and their rights and opinions should be emphasized. When representing

patients and making decisions on their behalf, caregivers must account for the values and preferences of those whom they represent. Moreover, defining the roles for family caregivers to access PAEHR while respecting patients' privacy could support their joint efforts with professionals and ensure the continuity of care.²⁹

Security related to sharing

Participants trust the system and treatment of their medical information in it; they feel safe using Journalen. While this behaviour concurs with the findings of Rexhepi et al.¹⁷ and Vodicka et al.,¹⁸ patients also might not be aware of online sharing risks or have related misconceptions.³⁰ One can also note that patients who do not trust the system still share their health records by discussing with relatives offline.

Implications for policy and practice

From our study, it is clear that a key policy priority should be to plan for more transparent implications of the sharing and delegating one's health-related information. More attention should be directed towards ensuring that patients are fully informed about current information sharing practices and security issues relating to storing medical records online and sharing their medical records with relatives.

Another priority is personalization/customization of services that is also widely confirmed in related literature.^{6,31} The design and development of future systems similar to Journalen should incorporate dynamic and flexible access control policies that can be adapted to meet patient preferences.

We note that offline sharing of personal information with trusted ones cannot be replaced. Offline communication is richer compared to the superficiality of sharing online. Nevertheless, transparent and safe ICT tools can support sharing and caring for each other but their effect could be enhanced by recognizing the importance of patient participation and involvement as end-users.

Limitations

One limitation of the study is that the interviews were conducted in 2013 1 year after the launch of PAEHR. Respondents' relatively short experience of using PAEHR needs to be taken into account when interpreting the results. When comparing their perceptions with the views of the respondents of the survey, which was conducted in 2016, it is, however, clear that the views were highly similar between the two groups.

Another limitation is the samples in the two studies are different (cancer patients vs all patients). Even if the interview results are only used to elaborate on the findings of the survey study, it is possible that the full spectrum or relative significance of the factors affecting the views expressed in the survey is not fully represented in the qualitative data. Furthermore, as in all studies focusing on sensitive personal information, there is always a possibility that respondents are inclined to leave out information that would be of high relevance to the study. The possible effects, in this case, are naturally hard to evaluate.

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Declaration of conflicting interests

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