

Analysis of Voluntary User Feedback of the Swedish National PAEHR Service

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Abstract

"Journalen" is a patient accessible electronic health record (PAEHR) and the national eHealth service for Sweden's citizens to gain access to their EHR. The Swedish national eHealth organization Inera, responsible for Journalen, created an inbox to receive voluntary user feedback about Journalen in order to improve the service from the user perspective. Based on voluntary user feedback via email. This study explored patients' experiences of using the national eHealth service and identified pros and cons. A mixed method content analysis was performed. In total, 1084 emails from 2016-2017 have been analyzed. 9 categories were identified, the most frequent ones related to questions about why some information was not accessible (due to regional differences), feedback (including only positive or negative comments as well as constructive improvement suggestions), and emails about errors that user found in their record. These data can be successfully used to continuously improve an already implemented eHealth service.

Keywords:

Patient Portals; Health Record, Personal; Consumer Health Informatics; Electronic Health Records; Evaluation

Introduction

eHealth is an increasing part of healthcare worldwide. It involves a service or a tool, which purpose is to improve prevention, contribute to diagnoses and treatment, as well as monitoring and management, and is built up of information and communication technologies (ICT) [1]. An example of an eHealth solution are patient portals, which give patients access to their own health data online and can give the patient access to a patient-accessible electronic health record (PAEHR) [2]. The US initiative OpenNotes is an example of a movement striving to increase and improve patients' access to clinical notes [3], through e.g. patient portals.

Journalen is the national Swedish PAEHR service used by Sweden's citizens to read their health records online. The purpose of Journalen is to contribute to increased quality of care and cost-effectiveness, but primarily to increase patients' empowerment and engagement in their own care [4]. The service aims to give all residents from 16 years access to all information about themselves documented in tax-funded health and dental care [5]. The national eHealth organization Inera AB is responsible for the maintenance and development of the service [6]. To access Journalen, the user must log on to the national patient portal 1177 Vårdguiden through authentication using a nationally approved BankID/eIdentification [7]. Potential users of Journalen are the 10 million Swedish citizens. Currently over

2.6 million citizens use the service, with close to two million logins to the service every month [8]. Sweden has a decentralized healthcare system, i.e. regional responsibility, resulting in that patients have access to different features in the service depending on in which county council or healthcare region they have received care [5].

As Sweden is a world-leading nation in ICT solutions [9-11], it is important also for the healthcare sector that users of different eHealth services find the solutions useful. Since Sweden offers the citizens the right to access their own health documentation online, such a service should also be as easy to use and easily navigated as possible for all kinds of users. In line with the Swedish Vision for eHealth and eHealth Strategy, that all Swedish citizens should have access to all their health information online by 2020 [12, 13], Inera AB created an email inbox in order to get voluntary user feedback about the service to guide their improvement work [5]. From 2015 to spring 2018 users could provide feedback directly to the service provider after logging into Journalen by using the inbox. However, Inera could not provide emails from 2015, as they had only saved emails from 2016.

Despite a lot of interest and debate around the implementation of PAEHR, both in Sweden and internationally, there is still a lack of research and evidence around the benefits and drawbacks of these types of solutions. [14]. In Sweden, the PAEHR Journalen has been studied for various purposes, e.g. to capture patients and healthcare professionals' opinions [15], to analyse the national regulatory framework for citizens access to their health records [16, 17], to describe challenges during the implementation [7, 18] – all relevant to this study. However, there are few studies that focus on how end-users (patients) themselves experience the use of the service. This study will explore patients' experiences of using Journalen as expressed in voluntary feedback to the service provider. Focus is on the problems and benefits, and how Journalen, according to the real users, can be improved by illustrating the problems they have experienced when using the service.

Methods

A mixed method analysis was conducted, including a qualitative content analysis of the emails, and a quantitative analysis of frequency. An inductive approach has been used throughout the research, which followed an iterative process for the categorizations and analysis of the experience's patients/users expressed in the feedback emails. The data consisted of a large amount of emails, all highlighting the views from a user perspective of Journalen. Therefore, the quantitative perspective of

the study was deemed important, as it was of interest to show the number of emails belonging to each category, hence, a mixed method content analysis [19].

In the PAEHR service, the users were invited to share their experiences of the service, and how they used the information in Journalen [5]. The voluntary user feedback was analysed manually, a main-analysis made by the first author and a sub-analysis made by the second and third author. About 1084 emails were examined. The emails were obtained from the national eHealth organization Inera AB. Emails received between the years of 2016-2017 were anonymized and only the content of the emails were analysed further. Each email was read several times, and categorized into a type of email. Nine categories were created during the reading of the emails (Table 1). All emails containing positive and negative feedback, or descriptions of experiences of using the e-service were grouped into a general feedback category that was further divided into sub-categories (Figure 1). No other categories contained sub-categories.

The study was conducted in accordance with the Helsinki Convention and its ethical principles for medical research involving human subjects [20]. The voluntary user feedback contained patient opinions about the eHealth service, and are presented here as anonymous data.

Results

By analysing the emails, commonly used topics have been sorted into categories, which are presented in Table 1. We will here highlight some of the more interesting categories.

Region dependent comments

Each of the 20 regions in Sweden who provide the majority of healthcare, were given their own choice in deciding what information to make accessible to patients and when [16]. This has resulted in major differences in what information can actually be accessed depending on which region you have received care in [7].

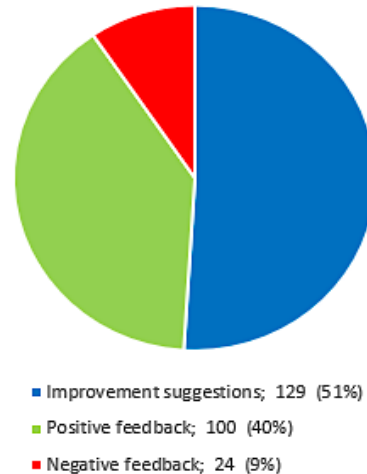


Figure 1. Presents how the feedback category is categorized, and the quantity of the three categories.

40% of the emails analysed in this study were related to users requesting access to information or features that their healthcare provider had decided to not make accessible. The majority of these emails were received during 2016 (308 emails compared to 125 in 2017), which may indicate that the situation was improved over time.

Wrong medical content

A total of 8% (N = 89) of the analysed emails concerned errors that the user had found in their record. We have not made an assessment of the severity of the identified errors, but the emails show that patients may act a quality control for the record content, but also that easier ways of reporting errors to the correct organizations are needed.

Table 1. Identified categories.

Category	Description	2016	2017	Total	
1. Region-dependent comments	The user is missing info or requesting features that do not exist due to decisions of the county council or healthcare region he/she belongs to.	308	125	433	40%
2. Feedback	Improvement suggestions are identified based on a problem the user has with the service, as well as positive and negative feedback comments.	108	145	253	23%
3. Wrong medical content	The user has detected wrong medical content, mostly in the record entries or in the medication list	36	53	89	8%
4. Seeking health care	The user wants to get in touch with his/her medical care provider/healthcare organization	16	25	41	4%
5. Requesting their health record	The user requests his/her health record in paper copies.	18	15	33	3%
6. Block or seal	The user wants to block or seal his/her health record, i.e. the entire service.	7	3	10	1%
7. Access their child	The user cannot see or access his/her child's record.	5	4	9	1%
8. Errors	Emails that are illegible and have appeared in error codes	35	22	57	5%
9. Other	Emails that are difficult to categorize because of its rare occurrence, and cannot be put into an own category	83	76	159	15%
Total		616	468	1084	100

Feedback

This is the category, or topic, that emphasizes users' views about Journalen. The feedback category can in turn be broken down into improvement suggestions, only positive comments

and only negative comments about the service, as presented in Figure 1. The feedback category is region independent unlike the first category in Table 1. Out of all feedback, 129 contains improvement suggestions, 100 only positive comments about the service, and 24 only negative comments. What is meant by 'only' positive and negative comments is when the researchers interpret that the sender has intended to only write something positive or only something negative about the service.

The users who expressed positive feedback (N = 100) (Table 2) believe that the service is a generally good service, which they embrace, and the majority of positive comments simply express that Journalen is a good service in general. About a quarter of the positive comments are praise for specific features, such as being able to access lab results, vaccinations, diagnosis, referrals, and so on. Many users want to share how good the service is, as it serves as a memory support after the appointments. Another recurring positive feedback describes how users appreciate being able to read Journalen in peace and quiet at home since it can be reached online. Journalen is also described as positive when it comes to clarifications, and 10% of the positive feedback emails describes how users check to see if any misunderstandings have occurred after an appointment. Without the e-service, they would never know this, if they would not request paper copies, which itself is a time-consuming process. Some users also expressed how good it is when all information is collected in one place.

Table 2. Categorized positive feedback about the service.

Category	Example of comments	Quantity	
A good service	"I just want to say that the service of reading my online journal is amazingly good and useful"	41	41%
Access to specific info	"It is great and useful to be able to read the lab results"	23	23%
Memory support	"It is good to be able to read the health record, as many details are often forgotten after a doctor's appointment"	12	12%
Peace and quiet	"I find it calm to visit Journalen at home in peace and quiet, which is helpful because of my hearing impairment"	10	10%
Clarifying	"It is good to be able to read my health record online if there were any misunderstandings during the appointment"	10	10%
One place	"It is good that all information is collected in one place and easily accessible. Now I do not have to save and look for paper copies"	4	4%

Emails containing only negative feedback was much rarer (N = 24). The majority of the negative comments concern Journalen as an eHealth service in general, the users express that the service is simply bad and difficult to navigate. Some comment that Journalen is not patient-safe, and that sensitive information should not be available on the internet. A few users believe that

it should be up to each individual to be able to decide on their own medical information and be able to make changes in the information. Since this is not possible it is a bad system according to these users (Table 3).

Table 3. Categorized cons about the service.

Category	Example of comments	Quantity	
A bad service	"I have been logged into it, and it is totally worthless. It is difficult to interpret and understand. It is a big joke!"	17	71%
Not patient-safe	"Such information as someone's medical information should not be available online. It is not patient-safe"	4	16%
Decide about the info	"This is a really bad system. I want to be able to make changes in the content because it is about my identity! I want to be able to decide about the written info about me and how it is formulated"	3	13%

The majority of the feedback category consisted of *improvement suggestions* (N = 129). Most users asked for older health records, and this can be explained by the fact that many regions decided to only give access to notes from the date Journalen was introduced (or shortly before this) which meant that much of what the users expected to see when the logged in was not actually there. This was followed by suggestions on how the interface could be improved to facilitate the navigation, such as making certain buttons more visible. Several users provided improvement suggestions for lab results, such as clarifying information of each lab result. Text reminders for new events in Journalen was also requested, and some wanted to see X-ray/MR results, which are currently not available at all in the service. Improved support for communication with the healthcare providers was also requested, for example having a direct phone number or other contact information visible. There were also some suggestions for clarifications of other specific information in Journalen, such as unclear instructions on how one's health record can be ordered in paper copies. Some of the users had opinions that they needed to see their children's information, and that some sections of Journalen required excessive number of mouse clicks to reach it. Some users considered that Journalen should be individualized and that users themselves should be able to determine what information should be accessible through the service.

A few had opinions about how the search feature in Journalen could be improved, and that only signed and validated information should be displayed to the patient, and that visible unsigned information can be considered a patient risk. Some healthcare providers choose to give immediate access to all notes, whether they are signed or not, whereas others keep unsigned notes hidden from the patient until they have either been signed or two weeks have passed, at which point the note is automatically locked for updates [21]. A few of the users considered that logs should be available to the patients, i.e. who have visited the patient's health record. This feature is currently only activated by a few healthcare providers [22]. Another proposed improvement was to make a glossary of medical terms available in Journalen to all patients.

Discussion

The results presents users voluntarily given feedback about the service with identified pros and cons and experienced issues. There were few complaints and many positive comments. The improvement suggestions pointed to several issues and problems that the user experience, yet overall they mostly expressed positive feelings towards the service and wanted it to continue and be further developed to be even better. This is well in line with a recently published survey study among users of Journalen, in which 96% of the respondents believed that this was a good intervention. [22]. Compared to this figure, the emails analyzed in our study had a much higher expression of negative feedback, however this is likely related to the data source; when asked to voluntarily submit feedback a user who is very negative to an e-service may be more inclined to answer than someone who is positive.

The users' comments about their experienced benefits and problems can also be supported by an earlier interview study which aimed to provide in-depth understanding of cancer patients' attitudes and experiences of online health records [15], and other international studies within this field, for example the OpenNotes initiative in US which focus on patients ability to view clinical notes [3]. The study found that users of PAEHR services uses the service to see that they understood the information they received from the physician correctly. Another study [23] also found that one of the biggest reasons why patients read their health record entries are to be sure that they understood what the care provider said. This is also expressed by some of the users of Journalen in this study who believe that it is very good to be able to read their health records in retrospect to prevent misunderstandings (Table 2).

The study [15] emphasizes that most of the participants find that PAEHR services serve as a memory support, since it is easy to forget information from a physician's appointment. Similarly, several of the users of Journalen who emailed feedback expressed that it was a very good memory support to be able to read on their own what has been said and done during the appointments, as there is often a lot of information provided that is easy to forget about afterwards. Below is a quote from one of the users of Journalen (Table 2):

"It is good to be able to read the health record, as many details are often forgotten after a doctor's appointment"

In a study from the US [24], the purpose was to gain more knowledge about patient experiences where patients/users of a PAEHR service could provide feedback on their visit notes through a specific feedback tool within the service. The conclusion showed that patients can relate to personal, relational and safety benefits. Demand for similar features is also found in the results of this study. Below is a quote from one of the users of Journalen (Table 3):

"I want to be able to make changes in the content because it is about my identity! I want to be able to decide about the written info about me and how it is formulated"

Having other studies [3, 15, 23-24] with similar feedback reinforces the feedback given by the users of Journalen on how a PAEHR service can be improved and made as easy and clear as possible.

Methodological concerns

The data source needs to be considered when discussing the results of this study. We have analysed voluntary feedback that has been sent by the users of Journalen over two years. How

representative this information is of the opinions of all users of Journalen is impossible to say, and therefore the numbers presented in Table 1 cannot be interpreted as valid for all users. As an example, the 8% of emails concerning errors in record does not mean that 8% of all records have errors in them nor that 8% of all users find errors. Yet, that so many individuals have made the effort to send an email about this issue could be considered an important indicator that this is an area to be further explored.

We also consider the fact that this information is voluntarily provided by users without being asked specific questions makes the data source especially interesting. This is feedback given without influence of how questions are formulated, fatigue from filling out a long survey or a willingness to please the researchers asking the questions.

Another limitation that could impact the outcome are the manually counting of the emails. However, the format of the email feedback required an aspect of human interpretation, sometimes the latent content of an email, the tone and sentiment of the message, was crucial for the result of the study. Using an automatic quantification by a software tool would have risked missing some of these subtleties of the material.

Voluntary feedback as formative evaluation

The feedback received through the email inbox have been continuously used by the developers of the e-service to improve it. One example is that since such a high rate of emails concerned missing information, it became clear that the users had trouble understanding *why* parts of their record where not shown. In order to make this more clear to the users, an interactive map of Sweden was implemented in the e-service showing which regions made what information accessible. When choosing a specific part of the record (e.g. diagnosis or lab results), the map will also automatically show which regions make this information available (figure 2). This easily accessible visualization of information access may be the reason for the decline in emails in this category during 2017 compared to 2016.



Figure 2 – map over which healthcare providers show lab results

This may be one way of using rapid, unstructured user feedback as part of formative evaluations to facilitate continuous improvement of an eHealth service.

Future research

The content of the voluntary feedback would be interesting to compare in more detail to results of a recently published survey among all users of Journalen [22]. How does the voluntary feedback correspond to the results obtained when users are asked direct questions about specific features? Repeated surveys should also be performed, as the eHealth service is continuously improved and a steady increase of users can be seen. We need more long-term follow-up of the users experiences, e.g. through re-occurring surveys among the users. As the improvement suggestions are handled in the continued

development of the service, we ought to be able to track and see improvements also in the users feedback. Exploring the usefulness of the voluntary feedback compare to other forms of feedback or evaluations for the developers of Journalen would be of great interest from a methodological perspective.

Conclusions

This research is the first study in Sweden that evaluates and analyses the users' voluntary submitted opinions about Journalen and uses these to emphasize improvement suggestions about the service. These data can be successfully used to continuously improve an already implemented eHealth service. The results shows that having healthcare providers that makes different information accessible through the same eHealth service, will cause confusion and questions from users, but most feedback received was positive, which is in line with other research into patients access to their EHR. The results also shows that the users are channeling their questions to Inera instead of to their healthcare provider, which means other communication paths are needed between patient and healthcare provider.

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References

- European Commission. eHealth [internet]. Retrieved 2018 Mars 14 from: <https://ec.europa.eu/cefdigital/wiki/display/CEFDIGITAL/2017/05/30/eHealth>
- Irizarry T, DeVito Dabbs A, Curran CR. Patient Portals and Patient Engagement: A State of the Science Review. *J Med Internet Res*. 2015; 17(6): e148. doi: 10.2196/jmir.4255
- Payne TH, Beahan S, Fellner J, Martin D, Elmore JG. Health Records All Access Pass. *Journal of AHIMA* 87, no.8 (August 2016): 36-39.
- Inera AB. Journalen [internet]. Retrieved 2018 Mar 13 from: <https://www.inera.se/tjanster/journalen>
- Inera AB. Journalen [internet]. Retrieved 2018 Oct 28 from: <https://www.inera.se/tjanster/journalen/Journalen/#b252ed1d-a977-4dc5-ba63-a0e0ca9a028d>
- Kjellin Lagerqvist N. Inbox for User Feedback as a Method for Evaluating User Experience - A Method Evaluation in Scrum based Software Development [master's thesis]. Uppsala: Uppsala Universitet; 2015.
- Häggglund M, Scandurra I. Patients' Online Access to Electronic Health Records: Current Status and Experiences from the Implementation in Sweden. *Stud Health Technol Inform*. 2017; 245:723-27.
- Inera AB. Statistik Journalen [internet]. Retrieved 2018 Oct 27 from: https://www.inera.se/aktuell/statistik/journalen_statistik/
- Baller S, Dutta S, Lanvin B (eds.). The Global Information Technology Report 2016 – Innovating in the Digital Economy. Geneva: World Economic Forum; 2016.
- Dutta S, Geiger T, Lanvin B (eds.). The Global Information Technology Report 2015 – ICTs for Inclusive Growth. Geneva: World Economic Forum; 2015.
- Bilbao-Osario B, Dutta S, Lanvin B (eds.). The Global Information Technology Report 2014 – Rewards and Risks of Big Data. Geneva: World Economic Forum; 2014.
- Ministry of Health and Social Affairs. Vision for eHealth 2025. Stockholm. Retrieved 2018 Jan 30 from: <http://www.government.se/information-material/2016/08/vision-for-ehealth-2025/>
- Government Offices of Sweden. Nationell IT-strategi för vård och omsorg (Skr 2005/06:139). Stockholm. Retrieved 2018 Jan 30 from: <http://www.regeringen.se/49b69c/contentassets/fe0a1492f548c2ab1451e45b7f6463/nationell-it-strategi-for-var-d-och-omsorg-skr-200506139>
- Conway N, Webster C, Smith B, Wake D. eHealth and the use of individually tailored information: A systematic review. *Health Informatics J*. 2017; 23(3): 218-33.
- Rexhepi H, Åhlfeldt RM, Cajander Å, Huvila I. Cancer patients' attitudes and experiences of online access to their electronic medical records: A qualitative study. *Health Informatics J*. 2018; 24(2):115-124. doi:10.1177/1460458216658778
- Scandurra I, Lyttkens L, Eklund B. Implications of Swedish National Regulatory Framework of the Patient Accessible Electronic Health Record. *Stud Health Technol Inform*. 2016; 228:695-9.
- Scandurra I, Pettersson M, Eklund B, Lyttkens L. Analysis of the Updated Swedish Regulatory Framework of the Patient Accessible Electronic Health Record in Relation to Usage Experience. *Stud Health Technol Inform*. 2017; 245:798-802.
- Häggglund M, Scandurra I. A Socio-Technical Analysis of Patient Accessible Electronic Health Records. *Stud Health Technol Inform*. 2017; 244:3-7.
- Hamad EO, Savundranayagam MY, Holmes JD, Kinsella EA, Johnson AM. Toward a Mixed-Method Research Approach to Content Analysis in The Digital Age: The Combined Content-Analysis Model and its Applications to Health Care Twitter Feeds. *J Med Internet Res*. 2016;18(3): e60. doi: 10.2196/jmir.5391
- World Medical Association. WMA Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects [internet]. Retrieved 2018 May 4 from: <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>
- Häggglund M, Moll J, Åhlfeldt R-M, Scandurra I. Timing It Right – Patients' Online Access to Their Record Notes in Sweden. *Stud Health Technol Inform*. 2018;247:336-340.
- Moll J, Rexhepi H, Cajander Å, Grünloh C, Huvila I, Häggglund M, et al. Patients' Experiences of Accessing Their Electronic Health Records: National Patient Survey in Sweden. *J Med Internet Res*. 2018; 20(11):e278.
- Bell SK, Mejilla R, Anselmo M, Darer JD, Elmore JG, Leveille S et al. When doctors share visit notes with patients: a study of patient and doctor perceptions of documentation errors, safety opportunities and the patient-doctor relationship. *BMJ Quality & Safety*. 2016;26: 257-58. doi: 10.1136/bmjqs-2016-005641
- Gerard M, Fossa A, Folcarelli P, Walker J, Bell SK. What Patients Value About Reading Visit Notes: A Qualitative Inquiry of Patients Experiences With Their Health Information. *J Med Internet Res*. 2017;19(7): e237. doi: 10.2196/jmir.7212

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