A Qualitative Study of Swedes’ Opinions about Shared Electronic Health Records

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Abstract

European countries are world-leading in the development and implementation of e-Health. In Sweden, all primary healthcare centres and most hospitals use digital records. Some regions use the same software which allows for clinical information to be shared (regionally shared EHRs), but there is a movement towards making all EHRs inter-operable to allow for a National Patient Summary (NPS). The aim of this study was to explore the opinions of Swedish consumers and health professionals about shared EHRs and the NPS. Semi-structured phone interviews were conducted with consumers and health professionals. The majority of interviewed health professionals were currently using regionally shared EHRs. In their experience, having access to regionally shared EHRs facilitated a holistic patient approach, assisted in patient follow-up, and reduced inappropriate (over)prescribing. Consumers had a poor level of knowledge about shared EHRs and the NPS. Unlike health professionals, consumers perceived a NPS to be of great value. The findings indicate that there was a discrepancy between health professionals and consumers’ knowledge of, and the perceived need for, a NPS.

Keywords:
Electronic health records, qualitative research, Sweden, health personnel, patients, attitudes.

Introduction

Electronic health records (EHR) have the potential to improve the quality of patient care \cite{1, 2}. In Sweden, all primary health care centres and most hospitals use EHRs \cite{3}. Clinical information is entered into EHRs by clinicians and consumers do not have direct access to their EHRs.

There are six different regions in Sweden, some of which use regionally shared EHRs. To allow better access to crucial clinical information for clinicians across regions, a National Patient Summary (NPS) was being implemented \cite{4}. The NPS will contain patient data such as diagnosis, prescribed and dispensed medications, results of investigations and a care plan. Similar project in other countries have had varied success \cite{5, 6}.

The aim of this study was to explore the knowledge, understanding and views held by health professionals and consumers in Sweden regarding shared electronic health records and the future NPS.

Materials and Methods

Participant recruitment

To allow for a rigorous analysis and interpretation of the different views regarding shared EHRs in Sweden a number of health professionals and consumers were contacted via email and informed about the study. They were asked to pass on this information to their colleagues and friends. Using networks and word of mouth to recruit participants is known as snowball sampling \cite{7}. It is a useful method to identify and recruit participants who would otherwise have remained unknown to the researchers. Both health professionals and consumers were recruited in this way. The study was approved by the St Vincent’s Hospital Human Research Ethics Committee.

Data collection and analysis

Two interview guides suitable for the Swedish setting were designed based on the interview guide used by Greenhalgh et al to explore patients’ opinions about the summary care records in England \cite{8}. All interviews were audio-recorded and transcribed verbatim. Transcripts were analysed for emerging themes, without an initial coding scheme, during the data collection period. This technique was used to summarise emerging themes and identify issues that needed further probing. This was done in order to identify new or related themes and to gain more detailed and comprehensive data \cite{9}. Data collection was stopped when no new themes emerged because this was an indication that data saturation had been reached. The properties of the themes that had emerged during the preliminary analysis were re-evaluated and categorised during the thematic analysis that took place once all the data had been collected. Two researchers independently undertook this process with five transcripts to identify as broad a range of themes as possible and to confirm theme saturation. The analytical process was facilitated using QRS NVivo\textsuperscript{\textregistered} Version 8.0.

Results

Demographic characteristics

Seven consumers and 13 health professionals were interviewed once between April and July 2010. Four participants were interviewed in a group interview and the remaining 16 participants were interviewed individually. The interviews lasted between 13 and 36 minutes. The majority of participants (80\%) were female and 41\% of all participants were 40
years or older. All consumers had sought medical attention in the past 12 months but only a minority of consumers (25%) were currently taking prescription medication/s. Health professionals from a range of different work settings in different county councils were interviewed.

Table 1-Summary of identified themes on views of shared EHRs and the future NPS from interviews with consumers and health professionals

<table>
<thead>
<tr>
<th>Themes</th>
<th>Characteristic features</th>
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<tbody>
<tr>
<td>Access to clinical information</td>
<td>• Most health professionals involved in care provision should have access, with the exception of community pharmacists</td>
</tr>
<tr>
<td>Level of access to clinical information</td>
<td>• Tiered levels of access is too cumbersome; all health professionals should have access to all the information but only access to what is relevant to them</td>
</tr>
<tr>
<td>Use of shared EHRs and the future NPS</td>
<td>• Patient consent to access the shared EHRs is not always sought by health professionals. The consent process should be changed.</td>
</tr>
<tr>
<td>Access to own record</td>
<td>• Giving patients’ access to their own records would make the system less secure</td>
</tr>
<tr>
<td>Privacy concerns</td>
<td>• Strict security measures were expected to protect privacy</td>
</tr>
<tr>
<td>Perceived benefits by consumers</td>
<td>• Safer and more efficient care.</td>
</tr>
<tr>
<td>Reported benefits experienced by health professionals</td>
<td>• Legible records. Easy access to relevant information. Chronologically structured information.</td>
</tr>
<tr>
<td>Perceived drawbacks of shared EHRs and the NPS</td>
<td>• No search function available within record. Too much ‘clicking’ to find relevant information. Doctor-shoppers were believed to be less positive about having a shared EHR and a NPS.</td>
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Knowledge about and understanding of shared EHRs

Most consumers were unaware of shared EHRs and the movement towards implementing a NPS.

**Facilitator:** Did you know that, in Sweden, records are being made accessible across healthcare settings, between medical centres and hospitals? **Consumer 3:** No, I didn’t know that but a medical centre is essentially an extension of a hospital, as I see it. It’s a ‘chain of care’. The only difference is that they don’t have any beds, but doctors work there and it’s pretty logical [to share records] and that they haven’t thought about [sharing records] until 2010 is pretty bad.

Health professionals on the other hand were better informed about shared EHRs and the future NPS.

**Facilitator:** What does ‘national patient summary’ imply to you? What does it mean? **Pharmacist 3:** I guess it means that you have the same software in hospitals and medical centres so you can access each other’s notes. **Facilitator:** Nationally? **Pharmacist 3:** Yes, that’s the idea. **Facilitator:** Ok, but that’s not how it’s working currently in [county council]? **Pharmacist 3:** No but I guess we’re on track. There are a few private medical centres which are not connected. The decision has been made to connect everyone but it’s not that easy in reality.

Views on shared EHR and the NPS

Several concepts were linked to eight major themes, summarised in Table 1.

**Access to clinical information**

Swedish consumers appeared oblivious to the fact that health professionals were required by law to obtain verbal consent before accessing clinical information held at a different medical centre or hospital. Most consumers lived in county councils where shared EHRs existed and all consumers had sought medical attention in the previous 12 months. However, only one consumer knew that she had a shared EHR. Consumers had not given much thought to who should have access to their record. Most consumers’ initial reaction was that only doctors should have access to their record. On further discussion, consumers reported that they felt more comfortable sharing their clinical information with most health professionals. However, the majority of consumers and health professionals, including hospital pharmacists, did not think pharmacists working in community pharmacies needed to have access to the shared EHR. Community pharmacists working for newly established pharmacies were especially mistrusted.

**Facilitator:** Should you be able to choose which doctors have the right to access your record? **Consumer 1:** No, I don’t think so. If it [NPS] is to be, then it should be so for everyone but you’d have to sit down and carefully think about all the privacy aspects. **Facilitator:** Do you think that nurses and maybe physiotherapists also should have access to the NPS? **Consumer 1:** Hmm, no. **Consumer 2:** I don’t think so. **Consumer 1:** Maybe there should be some sort of needs assessment? Well, this is what I think, if you make sure that every single person has one [NPS] then it’s up to the individual to choose who should have access [to the NPS]. **Facilitator:** But now you’re contradicting yourself? **Consumer 1:** Then you have to take that responsibility. Yes, I am contradicting myself but then you have to take that responsibility yourself and risk receiving care of a lesser quality by denying [health professionals] access, but on the other hand, how will that be documented in the NPS? I take back everything I’ve said! What was the question again? **Facilitator:** The question was: who should have access to the shared EHR? **Consumer 1:** Everyone!

**Level of access to clinical information**

The level of access each health professional would need was also discussed. There seemed to be general agreement that doctors should have access to all the information. Health professionals other than doctors were not thought to need access to all the information. The task of dividing the record and allowing different health professionals to access different levels of information was perceived as too challenging by some.

**Doctor 1:** I guess all health professionals involved in a patient’s care. It’s difficult, sure you can have levels so that a physiotherapist can access only…, but on the other hand, it’s hard to judge. A medical condition treated at the internal medicine clinic could be relevant for the physiotherapist too. So I think it’s difficult to have different levels of what you can
access. I guess you have to assume that health professionals would only access what’s relevant to them and nothing else.

Use of shared EHRs and the future NPS

Since shared EHRs were implemented, health professionals perceived they were able to access all the relevant information and consequently provide safer and more comprehensive healthcare. However, not all health professionals perceived it necessary to have the NPS but were more content with the regionally shared EHRs. Several health professionals confirmed the assumption by Doctor 1 (quote above) that health professionals only accessed information relevant to them.

Allied health 2: I have never accessed the hospital record. I sometimes access doctors’ notes at the [same] medical centre… I sometimes read the notes from the patient’s last visit so I know what it’s about. But I’ve never actually accessed records from another clinic or hospital or elsewhere.

Controversially, several doctors admitted they had accessed patients’ shared EHRs without first obtaining patient consent. Health professionals knew they were required by law to obtain patient consent each time before accessing the shared EHR. However, they argued that it was impractical to do so. Doctors also perceived that it was in the patient’s best interest for them to access the record to follow-up on test results.

Doctor 3: It’s ridiculous the way it is in Sweden now because you risk being struck off the medical register or getting a warning because you’ve accessed the patient’s shared EHR, even though it was done in the interest of the patient, but without their consent.

Consumers were asked to give their views on this misconduct by health professionals. Consumers reported that if the law states that consumer consent is needed each time before health professional access the shared EHR, then health professionals should get their patients consent. However, consumers also argued that health professionals have a moral responsibility to act in their patients’ best interest. Following up on test results was considered to be in patients’ best interest and obtaining consent before accessing the record seemed impractical. Instead of obtaining consent each time before accessing the shared EHR, consumers suggested several alternatives. These suggestions included giving their GPs a ‘generic consent’ which would allow the GPs to access the shared EHR as they saw fit or that the referring health professional obtained consent to follow up on results at the time of referral.

Access to own record

Consumers interviewed in this study had no interest in accessing their own shared EHR or the future NPS over the internet. Their main reason was that they thought it would make the system less secure. Health professionals did not want consumers to have access to their own records over the internet either but for slightly different reasons. Although both consumers and health professionals reported that they thought consumers should have the right to request a copy of their record, they thought the copy should only be given after thorough consideration and with a health professional present to explain the content and answer any potential questions.

Consumer 4: No I think that would be too cumbersome… I think the main point should be transparency and that you should be entitled to know what has been documented about you but not over the internet. It wouldn’t be safe.

Doctor 2: The shared EHR is an instrument we use in our profession and we must be able to use it to write thoughts and ideas that you don’t always share with patients before the investigation is complete. It could bring on a lot of unnecessary anxiety… It’s our tool first and foremost and we must have the right to use a professional language. If a law is passed that states we have to write so that everyone can understand… then the record would eventually become a hollow and worthless instrument.

Privacy concerns

When asked “what are the main drawbacks with shared EHRs and the future NPS?”, few of the consumers mentioned confidentiality and privacy concerns. When asked directly if they had any privacy concerns, all of the consumers acknowledged privacy breaches as a potential risk. Nevertheless, they expected the system to have strict security measures and that health professionals would adhere to their professional code of conduct and not misuse the information. Also, potential benefits of digitally sharing clinical information were thought to outweigh potential privacy risks.

Consumer 4: Well, I don’t really think there is a privacy concern because you’ve sought medical attention or ended up there in one way or another and you have the medical history you have. Facilitator: So you don’t have any privacy concerns as long as health professionals comply with their professional secrecy? Consumer 4: No I really don’t. I think it’s rather good to try different ways and that patients don’t have anything to lose if they don’t have anything to hide. … I think it’s the patient trying to cheat the system rather than the other way around. I don’t think the other way around is a common phenomenon.

Consumers reported that they had never experienced breaches in privacy. Health professionals did not perceive that accessing a consumer’s shared EHR without explicit consent a breach of privacy if the consumer was a patient of theirs and the intention was to follow-up on a referral or test result. Health professionals, when asked about breaches of privacy, only reported anecdotes they had read about in the press where health professionals had inappropriately accessed records to ‘snoop’. Although not a breach of privacy, most health professionals discussed the appropriateness of some of the information documented about patients.

Allied health 2: You have to be careful with what you write and how you express yourself. I’ve read notes that may be perceived as insulting, some expressions, so I’m very careful about what I write. I write thinking that the patient should be able to read [my notes] and think it is okay.

Perceived benefits by consumers

The majority of consumers were unaware of the existence of shared EHRs and the future NPS but could think of several benefits. Frequently mentioned benefits included safer and more efficient care, no lost records as well as time and cost savings over time.

Reported benefits experienced by health professionals

Most health professionals had worked with paper records and were therefore able to compare paper versus electronic records. Electronic health records in general were perceived as safer in terms of legible writing, provided easier access, and the information was better structured (i.e. no loose notes, everything documented in chronological order). Shared EHRs were perceived to further improve safety and the quality of healthcare because it provided a more complete medical history, no lost referrals or discharge letters, and allowed for a more holistic patient approach.
Pharmacist 2: [shared EHRs] are very beneficial from my point of view. It's much safer [to have shared EHRs] when I'm working on medication reconciliations. I've previously used the EHR kept at the healthcare centre and [the EHR] should have discharge letters from the hospital and things like that scanned but it's sometimes not there. ... I can produce a safer and more complete medication history with a shared EHR between healthcare centres and hospitals because, well it's all there.

Perceived drawbacks of shared EHRs and the NPS

Consumers could identify potential drawbacks for other consumers but not for themselves. Like health professionals, consumers thought that individuals who doctor-shop would be less positive about having a shared EHR and a NPS than patients "who have nothing to hide". Health professionals identified several drawbacks with the shared EHRs. Most of these drawbacks related to the software that is, no search function available within the record and too much clicking made it difficult to extract the information needed. Even though the information was in one continuous list, health professionals could in some software programs indicate that they only wanted to read, for example, physiotherapists or doctors' notes. The lack of this function in other software programs was perceived as a drawback as it made it more difficult to quickly scan the notes in search of relevant information.

Discussion

This qualitative study explored the knowledge, understanding and views of 20 health professionals and consumers in Sweden regarding regionally shared EHRs and the future NPS. Consumers and health professionals from different county councils were interviewed. The results of this study showed that few consumers knew about the shared EHRs and the efforts to implement a NPS before taking part in this study. Interestingly, some health professionals were also unaware of the future NPS, indicating that information describing the NPS has not been well disseminated among health professionals or consumers. Research has shown that consumers and health professionals in other countries, where similar records have been implemented with various degrees of success, also had poor level of knowledge of their respective nationally shared records [8, 10].

Of note, health professionals were aware, but did not always follow, the laws regarding shared EHR. The Patient Data Act (2008:335) states that it is the responsibility and obligation of health professionals to obtain patient consent before accessing clinical information held at other locations through the shared EHR [11]. A recent court case involving a doctor, who seven times accessed a patient’s shared EHR despite no longer being actively involved in the patient’s care and without patient consent, was dismissed. The doctor was consulted in 2009 and he admitted that he later accessed the record several times for professional reasons to find out what had happened to the patient following an unconventional treatment choice [12]. Consumers in this study accepted and expected that health professionals access shared EHRs to follow up on patient outcomes, as long as it is for professional reasons, and did not report any feelings of violation or offence. Consumers reported that they trusted the shared EHR system and that any breaches or misconduct would be dealt with appropriately. Other health professionals were reported after accessing patients’ shared EHR for whom they have never had any care responsibilities [13].

To prevent health professionals from accessing certain information, patients can choose to have their information "blocked". If information is blocked, health professionals accessing the shared EHR can see that additional information exists but has been blocked, and also which health professional blocked the information. It has been reported that annually approximately 500 Swedes choose to block their information [3]. Consumers interviewed in this study were unaware of their rights to block information.

A similar study conducted in Australia regarding health professionals and consumers’ attitudes about the personally controlled electronic health record (PCEHR) found that consumers appeared more concerned about privacy [10]. Although not directly comparable, the shared EHR holds more detailed information than the PCEHR. Many Australian consumers reported that they would not opt-in to have a PCEHR. Also, those who reported that they would opt-in would not allow all health professionals involved in their care to have access to their PCEHR [10]. Since the national roll-out of the PCEHR in Australia in July 2012, 12,500 Australians have signed up for a PCEHR [14]. In Sweden, consumers perceived that it was in their own best interest to have a shared EHR, and a NPS, and that all involved health professionals should be able to access the information in their records. Having strict guidelines and frequent spot-checks to ensure health professionals adhered to those guidelines were perceived as sufficient security measures.

Interestingly, more Australians than Swedes appeared willing to share their information with pharmacists. A possible reason is that pharmacists in Australia are better integrated in healthcare teams and more involved in direct patient care. Consumers in Australia were also better informed about the role of pharmacists and the additional information they are able to provide. In Sweden, approximately 150 pharmacists were employed by county councils and were directly involved in patient care [15]. New pharmacies, owned by chains or individual pharmacists, have entered the Swedish market since the deregulation of the pharmacy monopoly. Consumers in this study thought that privately owned pharmacies only wanted to make money and that it was wrong to profit from sick people. They reported that they trusted pharmacists working at Apoteke AB (Government run pharmacies) more than pharmacists at other pharmacies. This is in line with the results of a recent web survey completed by 150 individuals, representative of the Swedish population, which found that pharmacists working at Apoteke AB pharmacies were perceived as more knowledgeable and trustworthy compared to pharmacists in other pharmacies [16].

Health professionals, as well as consumers, also reported perceived or experienced drawbacks with shared EHRs. Consumers had concerns about getting second opinions and being deemed a ‘difficult’ or a ‘frequent flyer patient’. For health professionals, the reported drawbacks with shared EHRs included the layout of the record and the risk of missing important information due to the large amount of available information. The layout of the shared EHR involved a lot of ‘clicking’, which some health professionals found frustrating. Problems with the layout have also been reported in the literature [17]. It has been argued that the layout was more like a diary written by different health professionals with their own perspectives, and that this obstructs the clinical assessment of patients and therapy evaluation [18].

This study had some limitations. Participants were recruited through networks and word of mouth and it is possible that these participants had a biased view. To minimize recruitment...
bias, participants from multiple different networks were recruited. Nevertheless, the results of this qualitative study are not generalizable to the wider Swedish population, but they could assist in the creation of a survey that could be effective in assessing attitudes of a much larger cohort. Finally, collecting qualitative data in Swedish that would be presented in English had its issues. For the interpretation to be as factual as possible when compared to the raw data, the interpretation was based on the Swedish transcripts. Quotations to highlight the emerging themes and concepts were translated into English. Not all words and expressions in the raw data were easily translated to English. It is possible that the tone and meaning of statements may have changed slightly during translation. To ensure that the translations were as accurate as possible, and not misrepresented, they were checked by an independent Swedish-English bilingual consultant.

**Conclusion**

Most interviewed consumers were uninformed regarding the use of regionally shared EHR and the future NPS. However, they reported that it was in their best interest, as patients, if the treating health professional had access to their complete medical history. Most interviewed health professionals had access to, and used the information in the shared EHRs daily. They perceived that they were able to provide safer and better care when they had access to complete medical records.

Findings from this qualitative study suggested that Swedish consumers and health professionals support the implementation and use of shared EHRs and the NPS. Efforts should be focused in the safe and compliant use of these systems in order to achieve improved processes of care.

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**References**


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