# Electronic Health Records - Non-Swedish Speaking Refugee's Perspective

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Electronic health record (EHR) is a ubiquitous e-health tool that includes both Electronic Medical Record (EMR) and personal health record (PHR). EHR is aimed to be a versatile digital tool that can benefit both caregivers and patients through Quick and easy access to medical information at any time from hospitals or primary care units. However, the fact that the bulk of core records, including self-service data for patients, is only available in Swedish may limit the scope, availability and feasibility of self service through EHRs access for refugee patients who are non-Swedish speakers. Research results suggest that the EHRs should be meaningful, modified, and improved based on patient's needs, by actively involving patients in their healthcare. The issues diagnosed in this research work such as EHR an information sharing communication System, lack of Information about using EHR, language barrier a hinderance in using EHRs, EHRs as medical recommendation system, better instructions about EHRs, presenting medical information in diagnosis part in EHRs in other languages and presenting medical information in diagnosis part in EHRs by sound are very important to address non-Swedish speaking refugee patients' needs to use and benefit from EHRs.

### **Keywords**

electronic health records, refugees, immigrants, information system

#### 1. Introduction

E-health refers to the type of healthcare that uses internet and other information and communication technologies (ICT) for sharing medical information [1, 2]. Healthcare professionals utilize ICT in different ways such as, to access the patient's information, monitor public health, handle administrative work, and uncover opportunities for observations and research on public health [3]. Electronic health record (EHR) is a prevalent e-health tool that includes both Electronic Medical Record (EMR) and personal health record (PHR). EMRs maintain the database that gathers the administrative and clinical information in digital form during the patient's care, and the records can be accessed and shared between health professionals and patients. PHRs contain electronic information that patients get from healthcare professionals [4, 5, 6]. In many countries, including Sweden, EHRs have largely replaced the traditional paper-based records [7, 8].

Electronic health record is aimed to be a versatile digital tool that can benefit both caregivers and patients. EHRs can maintain larger amount of information than paper-based records and make it readily and simultaneously available for multiple care providers [7, 9]. Quick and easy access to medical information at any time from hospitals or primary care may enhance the safety and efficiency in healthcare, and reduce the administrative burden on doctors, nurses and other medical support staff [10, 11, 12]. Moreover, EHRs can support and improve the decision making process of health care professionals, and also help to develop research in this area [13]. From the patient's point of view, EHR enables the access to patient's medical records and empowers citizens to take responsibility and control of their own health and to actively manage their prescribed medicines. At a practical level, EHRs can help to save the time that would otherwise be used for face to face contact, appointments, making calls or sending enquiries for information to health care facilities [14, 15].

Electronic health records have potential to improve the quality of healthcare in Sweden. However, the fact that the bulk of core records, including self-service data for patients, is only available in Swedish may limit the scope, availability and feasibility of self service through EHRs access for patients who are non-Swedish speakers. According to patient data law in Sweden, information in the EHRs must be in Swedish, but the government in Sweden can decide that the language of the EHRs could be another language [15]. The Swedish National Board of Health makes some provisions for workers who

are foreign language speakers with accredited diplomas, enabling the use of English, Danish or Norwegian by healthcare sector workers [16].

An important part of the Swedish society are the refugees that Sweden have accepted during the years 1970-2019. Many of the recent refugees came from Syria, and Sweden has also taken in refugees from Somalia, Afghanistan and Eritrea [17]. What is more, many refugees may need immediate medical care when they arrive in Sweden. If the patient cannot use EHRs to get the necessary information due to a language barrier, illiteracy or lack of computer skills, he/she needs to call the healthcare personnel to arrange a time to meet the doctor or another healthcare professional. During the visit, the care professional needs an interpreter to discuss the patient's conditions. In addition, the patient will also need interpreter's help in order to translate the information that is recorded in the EHR. This procedure will be more costly and time-consuming, and the patient will not be motivated to use the electronic system as long as they don't possess the necessary skills [18, 19].

This paper is based on the primary author's Master's thesis, which investigated how the EHRs could be improved to motivate non-Swedish speaking refugees in Sweden to use their EHRs. The study was conducted at a hospital in the region Västra Götaland. The rest of the article has been arranged as follows. We describe the related research in section 2. Section 3 highlights the methods adopted for this research work. Section 4 provides a summary of the results. We discuss the results in section 5 and end the section with further research suggestions.

### 2. Related Research

As was claimed in the introduction, e-health solutions and tools can be used in many different ways. Generally, e-health is expected to contribute to improving healthcare quality with lower costs, via easily accessible communication systems between the health care professionals and patients, and through empowering patients to be more involved [1]. People who use e-health solutions feel better when they know about their health status and are involved in making decisions and the medical health information can be shared widely, faster and cheaper between patients [20]. E-health has properties such as efficiency, enhancing quality, evidence based, empowerment of patients, encouragement of a relationship between the patient and healthcare professionals and decision sharing between them, education of physicians and patients by online sources and enabling communication and information exchange between health professionals and patients [2].

EHR is one of the digital infrastructures that can help the hospitals to deliver safe, efficient care and support public health [21]. According to Nøhr [22] and Häyrinen et al., [23] documentation, booking service, communication system, diseases and test results are some of vital components in EHRs: Documentation: The texts and notes which are documented by a nurse, a patient or a doctor. Booking service: This service allows the patients and healthcare professionals to book appointments when needed. Communication system: This system facilitates the communication between healthcare professionals e.g. pharmacies, doctors or nurses, and patients. Diseases: This part shows patient's diseases. Test results: This part shows test results such as blood tests. In addition, one of the EHR's successes occurs when patients can use it to access information and become involved in their medication and treatment, having greater responsibility for their health and allowing them to discuss the doctor's diagnosis [14].

EHRs provide opportunities to enhance patient care, embed performance measures in clinical practice, and facilitate clinical research [24]. The structure of EHRs show that socially aligning and structuring content and appropriate information storage is important since the social circumstances of patients play an integral role in decisions regarding healthcare [23]. A better understanding of social circumstances with a view to improving inclusivity could help promote uptake and service delivery to patients [23]. Ennis et al [19] identified relevant population, difficulties including access to ICT and the relation between empowerment and EHRs. This elaborates on the fundamental role that social circumstances play in the development of better-quality healthcare, with reduced cost and time spent managing health records as a result. They assert, based on their study that EHRs design should be a fit to the patients expected to use and benefit from it. In a study by Rao and Edlavitch [25], they present software tailored to the needs of cancer patients enabling specialised and socially aligned access to EHRs. They outline the Collaborative Data Network (CDN) to share EHRs with cancer patients. Tuikka et al [18] discussed the empowerment of patients in EHRs which shows that identification of needs should engage patients. They further identified that implementation of patientled requirements in EHRs should include patients who are beneficiaries of the work. In a separate study, Bantom et al [26] explored the accessibility of personal healthcare records for patients, identifiying the need for patients who lack formal education to access and understand their health

records, and considered the possible limitations and cautions that should exist for EHRs to be useful for the care receivers. There are several applications which concern public health for example, ehealth, m-health and smart health systems. The patients can make their own decisions about their health, and this improves both the social and economic aspects of healthcare in society [27]. By using the method known as m-health, the diagnostics and treatments can be accessed. M-health means using mobiles to improve health systems. The smart health systems refer to use ICT to get higher quality data and large-scale sharing between, patients, doctors, nurses and other staff if needed.

The transition from paper-based records to EHR may be both expensive and complex. Financial costs for installing the EHR system can include implementation costs, loss of revenue and purchasing of hardware and software [7]. The medical information in EHRs doesn't stay in one organization but is shared, and therefore any information or medical history stored therein might be disclosed to other parties which can lead to a privacy problem. The healthcare personnel need time to learn the new work structure with EHRs. They might also need education to learn how to properly record data in the EHRs. It can cost the healthcare system both time and money. The transition to EHRs has increased clinician stress due to poor design of EHR products, which are sometimes not designed with sufficient understanding of patient and healthcare personnel needs [7]. EHRs should be meaningful, modified, and improved based on patient needs. That can happen when the patients are active members in their healthcare. There are several opportunities to improve EHRs in a way that improves care quality [28, 29].

According to the Office of the National Coordinator, meaningful use of EHRs, as well as the access to EHRs and E-health services can be increased. The meaningful use of EHRs has been developed in many steps according to requirements. The first stage requires healthcare professionals to give the patients paper or electronic access to their health information and information about their healthcare visits. The second stage requires healthcare professionals to use e-mail with the patients and share their health information with a third party. In the third stage, the Office of the National Coordinator explores the ways to share the medical information with patients and enable patients to access the EHRs [20]. The use of EHRs eliminates the errors in patient's medical information that improves work and cash flow. The errors can be eliminated by changing from handwritten paper-based record to Electronic Health Records [9, 30]. With the use of EHRs, the access to computerized records is made easier and faster [30]. According to Menachemi and Collum [30], by having patient information stored electronically, the cost associated with storing paper files and administration charts is reduced, as is the staff's time spent on managing patients. The EHRs also reduce the mail copies of test results because the results will be found in the EHRs.

Designing and developing appropriate EHRs is not an easy task. There are many end users of the EHRs, for example, physician, nurses, services and patients, and each user has his/her own needs and goals. There are eight rights required for delivering a safe EHR for all users: *Right software*, *Right content*, *Right user interface*, *Right personnel*, *Right communication*, *Right organization characteristics*, *Right rules*, *Right monitoring* [7, 31].

### 3. Methodology

This research work draws on the interpretive paradigm as the objective is to understand how EHRs might be improved to motivate non-Swedish speaking refugee patients. The research work is based on a qualitative case study as research strategy. Case study helps to understand a phenomenon in real life contexts [32, 33]. The data was collected by interviews and observations. The participants whose human perspectives were collected in this study are immigrants who are refugees in Sweden and healthcare personnel who care for such patients and use EHRs.

The sample in this research was three of the healthcare professionals at a hospital and five patients who couldn't speak Swedish (Table 1).

SR. No	Persons interviewed	Duration
001	3 health care professionals	45-60 min each interview
002	5 refugee patients	45-60 min each interview
003	n/a	Discussion and observation with Staff Nurse who attended phone calls with refugee patients. Total duration: 3 hours

Table 1 Interviewed persons

The study was conducted at hospital in region Västra Götland. Approval from the Head was obtained to conduct this study. An appointment with a doctor at the hospital in order to be informed about the study was booked. Interviews were then scheduled with three care professionals. The researcher selected the patients for interview. The primary researcher contacted everybody and asked them if they wanted to participate in the study. They were informed about the problem area and the purpose of the study. Of those patients, who wanted to participate, five patients were selected. We decided together a time for an interview, which were conducted at a place of their choice. Interviews with care professionals were conducted face to face and depending on their availability. Face to face meetings were held at the hospital. The questions to care professionals were in Swedish. Each meeting focused on refugee patients and Electronic Health Records. Information about participants such as name, nationality, disease, country, role, or age was not mentioned in this study according to ethics for the research.

The data in this research was collected by semi-structured interviews to get direct answers for the questions and help researchers to know the patient's and healthcare personnel's thoughts. That is, to investigate how the EHRs can be improved to motivate the patients to use the EHRs. The researcher contacted the patients by telephone to inform them about the study, asked if the patient wanted to participate in the research study, and inform him/her about ethics. If the patient wanted to participate, a time and place were decided according to the availability of the participants. The interviews were conducted in Arabic with patients who could speak Arabic, which is primary researcher's mother tongue. But the interviews with healthcare professionals were conducted in Swedish. All answers were written during the interview on the paper. The data was first translated to English language for the purpose of analysis.

During Observation part, the researcher needed to be at the place to see what happens when a patient contacts the health care to get the information which was stored in EHRs but, he/she could not speak Swedish. This method was chosen because it was useful to understand the behavior and problems of the patients and healthcare personnel. According to Bricki and Green [34]: "Observational data is also very useful in overcoming discrepancies between what people say and what they actually do and might help you uncover behaviour of which the participants themselves may not be aware." Observation was conducted at the hospital. During this time, the nurses took the telephone calls from patients and it took about three hours. The researcher was sitting and listened to nurses who answered the patients. This observation might help researcher to see what healthcare personnel do and how they help the patients through the telephone and what happened when they need the information stored in their EHRs. Data analysis starts when the data is gathered [35]. Analysis starts with words, and therefore, it is very important to write everything during data collection. The goal of analyzing the words is to make them available for thematic analysis in qualitative research [35]. According to Lichtman [35], the researcher needs to put the gathered data in a separate file using a word format because it is easy to add colour, brackets, etc. There will be several files depending on the amount of data. Litchman's model "The three Cs: Coding, Categorizing and Concepts" was followed: the data was initially coded (codes can be words or phrases). The coded data was re-read to reduce or rename them. An initial list of categories was developed from the codes. Further careful analysis and re-reading of the categories helped to modify the initial categories accordingly. This revisiting in an iterative manner helped to develop themes from the categories. Overall, the data collected by interviews and observations, was analysed using thematic analysis. Through a detailed and careful examination, the gathered data produced themes from interviews and observations. The themes were identified and analysed to get the answers for research question.

## 4. Empirical Findings

The research work attempted to explore how the EHRs can be improved to motivate non-Swedish speaking patients to use EHRs with a specific focus on refugees. Through thematic analysis based on Lichtman's [35] recommendations, the following themes were identified:

- 1. EHR an information sharing communication System
- 2. Lack of Information about using EHR
- 3. Language barrier a hinderance in using EHRs
- 4. EHRs as medical recommendation system
- 5. Better instructions about EHRs
- 6. Presenting medical information in diagnosis part in EHRs in other languages
- 7. Presenting medical information in diagnosis part in EHRs by sound

These themes helped the researchers to map the problems related to the use of EHRs by refugee patients specifically related to the diagnosis part in EHRs.

#### 4.1 Overview of Empirical Findings

The results of the analysis are summarized here in the table below. Table-2 represents the themes and their findings. We discuss these results in discussion section.

**Table 2 Summary of findings** 

Themes	Findings
EHR an information sharing communication System.	<ul> <li>Patients can read about their medicine, disease and health information.</li> <li>Healthcare personnel use EHRs to get patient's medical information or to inform patients and other healthcare personnel.</li> </ul>
Lack of Information about using EHR.	<ul> <li>Healthcare personnel could not actively inform patients about EHRs.</li> <li>There is no information in other languages about EHRs in vårdguide 1177.</li> <li>Patients heard about EHRs from their friends.</li> </ul>
Language barrier a hinderance in using EHRs.	<ul> <li>Non-Swedish speaking refugees feel left out of the EHRs system due to language barrier.</li> <li>There is no use to inform patients about EHRs when it is still in Swedish.</li> <li>Patients can't read the EHRs because it is in Swedish only.</li> </ul>
EHRs as medical recommendation system.	<ul> <li>Patients are not referred to check their EHRs when they need their medical information.</li> <li>Healthcare professionals don't inform the patients that they can read their EHRs at the last visit.</li> <li>Patients get confuse when they are not referred to read their information upon contact with the healthcare personnel and have questions which are already answered in EHRs.</li> </ul>
Better instructions about EHRs	<ul> <li>In most cases refugee patients don't know how to use EHRs.</li> <li>Patients have no idea about the information available in their EHRs.</li> <li>There are no instructions in other languages about EHRs on vårdguide 1177.</li> <li>Patients often don't get important instructions about using EHRs from healthcare professionals</li> </ul>
Presenting medical information in diagnosis part in EHRs in other languages	<ul> <li>Medical information about the patient's last visit with doctor can be typed with patient's native language and scanned in his/her EHRs.</li> <li>There is a need to have translate function in EHRs to translate the information stored in EHRs to other languages.</li> </ul>
Presenting medical information in diagnosis part in EHRs by sound	Patient's last visit to the doctor can be recorded at the time the interpreter interprets and this version could be added in EHRs.

### 5. Discussion

The aim of this case study was to investigate how EHRs might be improved to motivate computer literate non-Swedish speaking refugees to use EHRs. The first perspective that we can discuss is about the issue of how refugees and other healthcare professionals perceive the use of EHRs? The resulting themes such as "EHR an information sharing communication System" mentioned in section 4 suggests that both healthcare personnel and refugee patients perceive EHRs as a communication and information sharing system. The patients can use EHRs to gain knowledge about their prescribed medicine or diagnosis. Healthcare personnel use it to maintain patient's data, inform patients about their medical details and communicate the same information with other healthcare personnel. Overall,

healthcare personnel use EHRs for communication, management, visit procedures, planning, laboratory test, referrals and support.

The theme "Lack of Information about using EHR" revealed that some of the refugee patients did not receive complete information about EHRs from the healthcare personnel but they got acquainted with EHRs through some local Swedish speaking friends who have been using it for some time. This situation shows that if the patients can get some training and awareness from the very beginning directly from the medical staff such as healthcare personnel, they can make use of EHRs properly. This can further lead to reduced visiting times for refugee patients who are trying to call and book appointments with the healthcare personnel just to inquire about their medical information. It is also in accordance with the patient's requirements that the patients must be informed about new technologies to use it [36]. The theme "Language barrier a hinderance in using EHR" depicts that the Patient's also refer to the Swedish language as the only language used while writing EHRs data about them. This situation shows that EHRs can be useful for refugee patients only if they get information in a language which they can easily understand. The theme "EHRs as medical recommendation system" suggests that the patients should be referred to read their EHRs at home after their last visit with the doctor. This can lead to reduction in the confusion and the patients will feel empowered and motivated to learn more about the usage of EHRs. Although most of them will still need help from some Swedish speaking relative or friend to translate and discuss the information. Translating the most important part of the information for refugee patients and send it to them could also be helpful in this scenario.

Overall, the EHRs can be enhanced to improve the service quality for patients and in accordance with that providing "better instructions about EHRs" usage can also improve the situation for non-Swedish speaking refugees. These instructions could be the gateway to complete training and awareness program which could be managed by healthcare personnel to facilitate refugee patient's use of EHRs. Another important area that was highlighted by refugee patients was described in the last two themes "Presenting medical information in diagnosis part in EHRs in other languages" and "Presenting medical information in diagnosis part in EHRs by sound". These two themes attempt to answer the question that how can computer literate non-Swedish speaking refugees be motivated and enabled to utilize the diagnosis section of EHRs? The empirical findings showed that the patients with computer skills were active and conducted search on Vårdguide [37] to get some instructions in their native languages about it. However, Vårdguide [37] have limited translated material on the website. The instructions for EHRs users and the data in EHRs is only available in Swedish not in other languages. According to themes and findings there should be some functionality of translation available in EHRs so that the refugee patients can also make use of it. It is also vital that the patient's diagnosis part is available in other languages so they can understand their own medical records. Another important view that came forward from last two themes presented above was that refugees are accompanied by translators while they discuss with doctors about their medical situation such as surgery or other procedures. This information can be recorded in the refugee's native language (while translator is helping) and provided as part of the information available in EHRs. Some refugee patients stressed that at least the information from the last visit to the doctor could be both typed in and recorded in their native language while the interpreter interprets at the meeting between healthcare personnel and the patient. The recorded sound can be saved in patient's EHRs.

These themes attempt to describe the non-Swedish speaking refugee patients' needs to use EHRs. The study also confirms that empowering the patients in using EHRs is vital and the EHRs can be implemented according to patient's needs to involve them in their healthcare actively. This research work is limited to patients who are non-Swedish speaking refugees with computer skills and cannot use EHRs. However, this research didn't explore the patients who are illiterate or cannot use EHRs due to this or other similar reasons. Further research work shall be focused on exploring and presenting the holistic perspective of EHRs usage by a broader audience including illiterate people.

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