

# Linneuniversitetet

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**Master Thesis in Informatics** 

# Improving Electronic Health Records for Non-Swedish Speaking Refugees

A Qualitative Case Study



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### **Abstract**

Information and communication technology is used in healthcare in Sweden to improve health quality. Electronic Health Records are one of the technologies in healthcare which can increase a patient's involvement in his/her healthcare and decision-making related to it. The patient can discuss the treatments, analyses and medical information stored in Electronic Health Records. The aim in this study is to investigate how the Electronics Health Records can be improved to motivate refugees in Sweden who cannot speak Swedish. This research is a qualitative interpretive case study. The methods used in this study are observation and interviews. Thematic analysis was used for data analysis. The findings show that refugees don't receive information or instructions about how to use electronic health records properly. The language is the biggest hurdle to use electronic health records for refugee patients without knowing Swedish language. The findings further show that the electronic health records can be improved by adding sound or translated medical information in the diagnosis part of the electronic health record. This research might contribute to the healthcare process of any country in the world which has refugees and they use electronic health records.

### Keywords

Electronic Health Records, EHRs, 1177, Immigrants, Information's System, Information and Communication Technology, qualitative research, observations, case study, Interviews.

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| ICT                         | Information and Communication Technology |
| IT                          | Information Technology                   |
| EHRs                        | Electronic Health Records                |
| E-Health                    | Electronic Health                        |
| E-services                  | Electronic services                      |
| US                          | United States of America                 |
| EMR                         | Electronic Medical Records               |
| PHR                         | Personal Health Records                  |
| IS                          | Information system                       |
| CDN                         | Collaborative Data Network               |
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### 1. Introduction

This chapter presents the background of Electronic Health Records, research purpose and research questions. It concludes with topic justification, scope and limitations of this study and the organisation of the thesis.

### 1.1 Background

Information and communication technology (ICT) has played an important role in various sectors, such as education, business and healthcare. In the area of healthcare, it has contributed to many improvements. Using ICT, patients can get information about their health and become involved in their broad treatment range. This way, they take greater responsibility for their health. Patients are able to discuss the doctor's diagnosis since they have access to information technology (IT) and online resources (Grando et al, 2015) for doing so.

IT in healthcare also provides health professionals access to patient information, the ability to more easily monitor public health, a reduction in administrative work, and more opportunities for observations and research on public health(Montevoy, 2011).

The medical information about patients was traditionally stored in paper based records, but those have since been changed to Electronic Health Records (EHRs) (Wang, Yu and Hailey, 2015). The EHRs is one of the ITs in the health sector. By allowing the patients' access to their EHRs, they promote a high health quality in those patients. Moreover, the use of EHRs systems has revolutionised the way technology is harnessed. It has contributed to increasing service, enhancing the facilitation and efficacy of patient care and reducing the administrative burden on doctors, nurses and medical support staff (Vaughn & Breeden 2016). The EHR is a digital document with medical information about patients, which can be accessed by patients and healthcare personnel. All healthcare professionals have access to the medical records, which facilitates patient identification by the information stored in EHRs after every healthcare contact. According to Bonney (2012), the EHR is information about patient health stored in the database, to be available to medical staff for treatment and information exchange. It is easier and faster to access the medical information stored in the EHRs than the paper based records when the medical information is saved electronically (Fernández-Alemán et al, 2013).

EHRs can be used to help develop research and provide information for the patient (Riksdagen, 2017).

Direct accesses to health records empower citizens, since it gives them responsibility and control of the care they receive. Reading EHRs reduces the amount of face to face contact and time spent on appointments, making calls or sending enquiries for information to health care facilities. The access to EHRs can help patients to actively manage their prescribed medicines, since their prescriptions are written in EHRs.

The EHRs improved the quality of healthcare in Sweden when it was used in many hospitals. The medical information could be accessed at any time it was needed, even if it was needed in different hospitals or primary care (Lehnbom, 2013; Li, 2015).

So if the patient changes his/her region, s/he can still access the information. Likewise, healthcare personnel can access the information whenever and wherever they want.

Sweden is a peaceful country. It accepted several refugees during the years 1970-2016. Since the war in Syria began, Sweden received many foreign refugees. In addition to

Syrian refugees, Sweden has taken in refugees from Somalia, Afghanistan and Eritrea (Migrationsinfo, 2016). Immigrants can be students who are coming to Sweden to study, workers who get jobs in Sweden, and refugees. A person who has received a permanent residence by the Swedish Migration Board due to his/her need for protection according to the Geneva Convention or the human rights is called a refugee. The immigration has increased in Sweden since the 1970s and that has been a big reason for the increase in population in Sweden during the last years (Razavi et al, 2011). Healthcare in Sweden has a long waiting list because of a shortage in healthcare personnel and increase of number of patients. According to patient data law in Sweden, information in the EHRs must be in Swedish, and it must be written with simple and understandable words. This is done in order for the patients to understand the contents of the EHRs. The government in Sweden can decide that the language of the EHRs could be another language than Swedish (Riksdagen, 2017). 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 (Vårdhandboken, 2015). However, the bulk of core records, including self-service data for patients, are still only in Swedish even when the patients primarily speak another language than Swedish. This, in principle, can limit the scope, availability and feasibility of self service through EHRs access for patients who are non-Swedish speakers.

There are many refugees who need immediate medical care when they came to Sweden. When a patient accesses healthcare services, their data is held in the EHRs. The nurse will write the information about the patient in his/her EHRs e.g. why the patient has called the healthcare centre and which health problem s/he has(Vårdhandboken, 2015). The information will be available for patients to read whenever they want.

The current Swedish EHRs are delivered using ICT tools on modern IT platforms, enabling access to medical notes, prescriptions, referral data, vaccine records and test results (Vårdguiden, 2017). Some of this information is readily available to patients via self-service. After all treatments, the doctor will meet the patient to inform him/her about the treatments, medicines, diseases etc, and that will become the last visit. This information, including the patient's discussion with the doctor, will then be published in the patient's EHR in the diagnosis section. The patient can access the information in his/her EHR anytime (Grando et al, 2015) and therefore, after this visit, the patient does not need to arrange a time to meet a physician to get the latest information.

But if the patient cannot use EHRs to get the information s/he needs due to a language barrier, s/he needs to call the healthcare personnel to arrange a time to meet the doctor or another healthcare professional. The care professional needs an interpreter to discuss the patient's conditions. If a normal interview takes half an hour, it will take a longer time for non-Swedish speaker. Since the healthcare professional hires the interpreter to communicate with patients at the meeting, it will cost more money and take more time for both the healthcare system and the patient. It is very difficult to arrange a time at a hospital due the large numbers of patients who need healthcare. In addition, the patient will not actually get new information at this visit, but s/he will get the information which has already been written in his/her EHR after the last visit.

If the healthcare prints the information to send it to the patient, the information will be in Swedish and the patient still cannot read it. If the healthcare uses an interpreter to translate the information, write it and send it to the patient, s/he might be able to read it, but the procedure will still cost the healthcare system money. Furthermore, it will not motivate the patient to use EHRs since they still cannot understand the language.

In this study, the researcher investigated how the EHRs could be improved to stimulate the non-Swedish speakers in Sweden to use their EHRs. At this time, there are many refugees who need to use their EHRs, a shortage of healthcare personnel and high healthcare costs. There are many problems which make the patients unable to use their EHRs (Tuikka et al, 2015; Ennis et al, 2011), such as the language, illiteracy, lack of computer skills, lack of information

about ICT or EHRs, and so on.

This study was conducted at a hospital in the region Västra Götaland. It investigated how EHRs might be improved so that they could be used by refugee patients without Swedish language skills, but who might have computer skills and literacy in another language. The researcher highlighted refugees in this study because most of them spoke the researcher's native language, which could facilitate the interview processes. Another reason for motivation was that the researcher has experienced this problem when she came to Sweden as a refugee. It is difficult to be involved in health care when somebody cannot speak Swedish and how s/he is feeling when s/he cannot read the EHRs to get the information after the visit to doctor. Furthermore, Sweden accepted many refugees from other countries like Syria, Iraq, Somalia, Eriteria..etc (Migrationsinfo, 2016). For those reasons the researcher highlighted just the refugees in this study. If the number of meetings between these patients and healthcare personnel can be reduced the workload on the personnel could similarly be reduced.

### 1.2 Related Studies

The social circumstances of patients play an integral role in decisions regarding healthcare and should be pivotal to the development of EHRs systems. A better understanding of social circumstances with a view to improving inclusivity could help promote uptake and service delivery to patients (Häyrinen et al, 2008). In a study of EHRs to find out how EHRs are defined, the structure in EHRs, who access the EHR, and which components in EHRs are used, Häyrinen et al (2008) determined that socially aligning and structuring content and information storage appropriately is important. They highlight that EHRs can be more functional to patients needs by doing studies about EHR's component and requirements.

Ennis et al (2011) identified relevant population, difficulties including access to ICT and the relation between empowerment and electronic patient health records. It 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 (2010), 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. The CDN was developed for large-scale sharing of EHRs. The study was based on cancer patients because the cancer was the second biggest reason for deaths in the US (Roa and Edlavitch, 2010), and it highlighted the challenges that are coming with large-scale sharing of EHRs.

When designing healthcare record systems, engaging end users is also important. Tuikka et al (2015) conducted a study which focused on EHRs and patient involvement. In their research, they discussed the empowerment of patients in EHRs. Their study showed that identification of needs/needs should engage patients.

They further identified that implementation of patient-led requirements in EHRs should include patients who are beneficiaries of the work. In a separate study, Bantom et al (2016) explores the accessibility of personal healthcare records for patients. They

identified the need for patients who lack formal education to access and understand their health records, and considered the possible limitations and caveats that should exist for electronic health records to be useful for the care receivers. These studies indicatively support the exploration of direct patient needs and understanding of the limitations that exist. However, they do not highlight the language as one of the causes for difficulties in accessing EHRs.

### 1.3 Purpose Statement and Research Questions

The purpose is to study how Electronic Health Records might be improved to stimulate the refugee patients with non-Swedish language in Sweden to use their EHRs. The answer to this question may be helpful to the medical staff by reducing the number of patients who have questions after the doctor's visit since the answers are found in EHRs, and help patients unable to speak Swedish to be involved in their care like other patients in Sweden. The healthcare services would become more equal for all patients despite differences in culture and languages. In this study, the following research questions will be answered by refugees and healthcare professionals as users in first and second question and as providers in third question.

#### **Research Questions:**

- 1. How do refugees and healthcare professionals as users perceive the use of EHRs?
- 2. How can computer literate non-Swedish speaking refugees be motivated and enabled to take increased access to the diagnosis section of EHRs, according to healthcare professionals and refugees?
- 3. How can patient medical information be organised in the diagnosis part of EHRs to enable access and understanding of records for patients, according to healthcare professionals and refugees as providers?

Answering these research questions could contribute to making EHRs more useable and available for patients and motivate the patients to use them before they contact the healthcare system. It might reduce time and costs for both patients and healthcare professionals at healthcare visits. The time which might be reduced is the time that is needed to meet the patients when they need to arrange more time at healthcare. The costs, which might be reduced, are the costs for the interpreters and the costs for healthcare visit. This might help the healthcare professionals by reducing the number of patients who need answers after the doctor's visit and help patients who are unable to speak Swedish to be involved in their care.

### 1.4 Topic Justification

As mentioned before, there are many refugees in Sweden who cannot speak Swedish. Therefore, it is a problem that at this time, the EHRs is only available to patients in Swedish. This can cause many patients to contact the health care personnel to arrange a time to get the information which can be found in EHRs, causing the health care personnel to become overloaded.

There are many refugees who are literate, have computer skills, and are willing to use their EHRs, but cannot do so due to their lacking Swedish.

It can take a long time for patients to learn the Swedish language in order to read their EHRs, especially if they have health problems and need to contact the healthcare system continually during their early time in Sweden.

The reason for this study is the large number of refugees (Migrationsinfo, 2016) without Swedish language and the small number of healthcare professionals currently in Sweden (Olsson, 2016). After the last meeting between a doctor and a patient, all the information about the patient visit will be documented in the diagnosis part of an EHRs in Swedish (Riksdagen, 2017; vårdhandbok, 2015). The use of EHRs improves the quality of patient health (Lehnbom, 2013; Li, 2015) when the patients can access their health information and be involved in their health care (Grando at el, 2015; Stimson and Botruff, 2017; Hydari et al, 2015).

The patients can read this information at any time. But if the patient cannot read Swedish, it can be difficult to understand the data stored in the EHR. The patient needs to arrange an appointment at the healthcare centre to get the information S/he needs by using an interpreter. Usually, the healthcare system contacts an interpretation company to reserve an interpreter. The interpreter can mediate in the meeting between the patient and healthcare personnel, either at the hospital or through the telephone. That can cost both time and money for healthcare professionals because the costs for interpreters should be paid by the healthcare system.

The patient can get help from relatives or friends who can speak Swedish. But a lot of the patients do not want to share their own health problems with others because they arenot confident in their friends' and relatives' language knowledge or they believe that healthcare information is their own private matter.

This study will hopefully contribute to enhancing the diagnosis sectionin EHRs for non-Swedish speakers. The study is mainly focused on the diagnosis part of EHRs because the health information that the patients are asking about is stored in diagnosis part. Healthcare professionals write about patient's health problems and diagnose of the medical problem in this section (vårdguiden, 2017). The patients as it mentioned before contacts the healthcare to ask about their health information. All information related to patient's health is stored in diagnosis part. Another reason that only the diagnosis part might be improved in this study is the time constraints of the study.

### 1.5 Scope and Limitation

The scope of this study was limited to explore patients who had computer skills, were literate and couldn't use EHRs due to a lack of knowledge of the Swedish language. This study was further limited to explore just the information after the last visit in the diagnosis part of EHRs.

The research settings were based on one of the hospitals in the regionVästra Götaland in western Sweden. More information about the hospital will not be discussed according to ethics for this study. The researcher chose three of the healthcare professionals at the hospital and then five patients who could speak at most a few words of Swedish were chosen. The age of the patients was between 25-65 years in this study. The researcher excluded the patients who couldn't speak the researcher's native language, English or Swedish. That was because it could be difficult to communicate or translate other languages due to the short time for this research.

This study focused on just the medical information from the last visit in the diagnosis section of the EHRs. The researcher excluded the other notes in this section, as well as the other sections in the EHRs, due to the limited time for this study and the importance of information in diagnosis part. The researcher translated all the collected data to English, which was the language of this master thesis.

In order not to go outside of the research questions, the aim is to study how EHRs might be improved to inform the refugee patients. The human aspects in this study were limited to refugees in Sweden and healthcare professionals who give care to patients and use EHRs.

### 1.6 Thesis Organization

This thesis consists of six chapters. Every chapter has many sections. In the first chapter the researcher presents an introduction about this study, the purpose of the research and the questions would be answered to achieve the purpose. Finally, the scope and limitation of the study is explained.

In the second chapter the researcher discusses the relevant literature to this study and the terms which are relevant for my research, e.g. E-health, ICT, EHRs and their benefits and disadvantages, and the eight rights which should be in a good EHR.

In chapter three, the researcher develops the methodology, methods, data analysis and ethics for my study.

In chapter four, the researcher presents the empirical findings which were formulated after data collection and data analysis.

In chapter five, the findings as a result were discussed, and in chapter six, the researcher writes about conclusions, contribution and suggestions for future research.

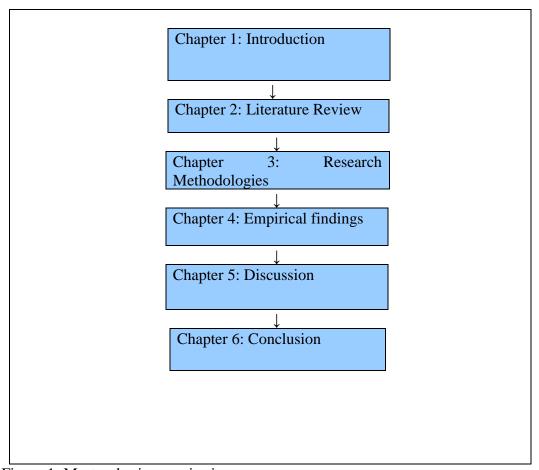


Figure 1: Master thesis organisation.

### 2. Literature Review

This chapter introduces a literature review of ICT and health, E-health, EHRs, benefits and disadvantages of EHRs and the eight rights to safe EHRs. This literature gives the important points for this study.

### 2.1 Information and Communication Technology

The term ICT refers to telephone and computer networks and systems. ICT can be seen as a synonym for IT but ICT also has integrated communication (Chan and Holosko, 2015).

The ICT has an important role in many different places in our lives. The ICT is designed to help people in their daily life. They use the internet to get information they need in their daily life, to get the latest news, and to communicate with their friends and relatives (Nieminen, 2016; Sims et al, 2016; Koivusilta, 2005). Beyond that, ICT can also be used in a variety of professional fields, such as education, work life, healthcare and for the development of economics (Nieminen, 2016).

The firms can enhance their global supply chain by using the ICT. For example Agilent, an electronics company, implemented an IT system to communicate with other Enterprise Resource Planning (ERP). ICT are also used in the pharmacy. By using the communication links between the pharmacy, the pharmaceutical manufacturer and the regulatory body, the pharmacist can document about the drug and can know if the drugs are counterfeit if so, the regulatory body must recall the product sender (Tang and Zimmerman, 2013).

### 2.2 ICT and health

ICT are electronic tools which facilitate communication and information in society. ICT have been adapted and improved to fit the needs in society (Chetley et al, 2006) as it gives the informational and communicational electronic means to get better quality in healthcare. Mobiles, computer programs and the Internet are good examples of ICT which can be used in healthcare. ICT has contributed to improving the quality of medical programs in order to improve healthcare, as well as helping people to get better living conditions by making them aware about their health (Chetley et al, 2006; Wu and Raghupathi, 2012).

The applications which concern public health can, for example, be e-health, m-health and smart health systems, explained below. The patients can make their own decisions about their health, and this improves both the social and economic aspects of healthcare in society (Chetley et al, 2006). These improvements in the health care sector cannot be reached if the patients cannot access the ICT.

At the same time, the delivery of healthcare by ICT needs high costs. The global health policy must focus on making ICT a delivery method of public healthcare with lower costs (Wu and Raghupathi, 2012) that many countries can get benefits from ICT at the time the ICT helps health workers to make better treatments, patients can get safe care, and people can be informed about their health. The costs for delivering of healthcare by ICT could be for software, systems, updates, services. Furthermore, ICT can inform the government about health needs, and the development in healthcare can be more effective and efficient if ICT are used in the health sector. ICT can help people to access

the information to get better health and be involved in their treatments. (Chetley et al, 2006).

There are many systems and applications that are created to improve health for people. By using the method known as m-health, the diagnostics and treatments can be accessed. M-health means using mobiles to improve health systems. Some social companies have used ICT to help people by delivering water and food during crisis times to get better conditions (Crean, 2010).

According to Wu and Raghupathi (2012), ICT can be used to help healthcare professionals to prepare the analyses, diagnostics and treatments for diseases. By sharing diagnostics, information and drugs through ICT, information about diseases could be spread. An example of ICT at work is the EMR for HIV/Aids patients in Kenya, and the web-based communications systems to share material and child death in Peru (Wu and Raghupathi, 2012). ICT are also used to share information about drugs and as communication systems e.g through Global Media the information about prevention of acquired immunodeficiency syndrome (AIDS) was spread.

The smart health systems refer to use ICT to get higher quality data and bigger sharing between, patients, doctors, nurses and other staff if needed.

There are many factors that affect the improvements in healthcare by ICT. The accessibility is one of the important factors, as is the state-level economy in the country. A country with a strong economy and a high standard of living will get more improvements from ICT in healthcare than countries with a weak economy (Wu and Rahupathi, 2012).

### 2.3 E-Health

E-health is a new type of healthcare which uses internet and other technologies for sharing medical information, referring to healthcare and business and health services (Wicks et al, 2014; Eysenbach, 2001). E-health can contribute to increasing healthcare quality with lower costs, firstly though bettered communication systems between the health care professionals and patients, and secondly through empowering patients to be more involved in their healthcare (Wicks et al, 2014).

The patients can get contact with other patients with the same diseases and conditions all over the world, and they can learn from each other, discuss treatments, tests and so on. In addition, healthcare professionals are not the only ones who spread the medical information to patients (Wicks et al, 2014).

In addition, the E-health tools increase patient access to EHRs, patient e-mail, PHRs, health apps. People who use e-health solutions feel better when they know about their health and are involved in making decision and the medical health can be shared widely, faster and cheaper between patients (Ricciardi et al, 2013).

According to Eysenbach (2001), E-health has the following properties:

*Efficiency*: E-health reduces costs by promoting communication between healthcare professionals and patients to increase involvement in their health care.

**Enhancing quality:** The E-health improves the quality of healthcare by involving patients in their care.

*Evidence based:* E-health should be evidence-based. That means E-health's effectiveness and efficiency must be scientifically evaluated.

**Empowerment** of patients by making the knowledge bases of medicine and personal electronic records accessible to patients.

**Encouragement** of a relationship between the patient and health professionals and decision sharing between them.

**Education** of physicians and patients by online sources.

*Enabling* communication and information exchange between health professionals and patients.

### 2.4 Electronic Health Records (EHRs)

An Electronic Medical Records (EMRs) contains the administrative and clinical information which has been gathered during the patient's care and have been between health professionals and patients (Ambinder, 2005). The personal health records, PHRs contains electronic information which patients get from health professionals.

EHRs include both EMRs and PHRs. EHRs are one of the E-health technologies used to share medical information, get feedback, and share treatments and goals. Patients can use the EHRs to manage their health (Wicks et al, 2014). According to Ambinder (2005), the EHRs should be accessed by healthcare professionals and the patients should be able to enter the healthcare setting and consult with the healthcare personnel who have full access to EHRs. Medical information about patients will be saved electronically and this way, the EHRs will reduce paperwork and medical errors(Ambinder, 2005).

EHRs has replaced the traditional paper based records and that has opened the door for a digital future, leading to better healthcare quality and safety (Ratwani, 2017).

EHRs can be used by patients, healthcare personnel, hospitals, clinics, laboratories and pharmacies. They use EHRs for communication, management, visit procedures, laboratory test, referrals and support (Ambinder, 2005; Campanella et al,2015)in order to reduce costs and improve the quality of healthcare. One of the EHR's successes occurs when patients can use it to provide their information and become involved in their broad treatment range, having greater responsibility for their health and allowing them to discuss the doctor's diagnosis (Grando et al, 2015).

EHR is one of the digital infrastructures which can help the hospitals to deliver safe, efficient care and support public health (Sheikh et al, 2014). Using EHRs reduces the cost for patient's visits and paper documentation, and it gives quick access to medical information. It is difficult to access the information when needed in emergency if it is stored in paper based records.

The EHRs should have the power to have a large amount of patients' medical information for long time. It should give the patients the rights to share and manage their information. According to Nøhr (2006) and Häyrinen et al (2008) these are some of 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 result like blood tests and so on.

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 (Stimson and Botruff, 2017; Hydari et al, 2015).

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 make patients able to access the EHRs (Ricciardi et al, 2013).

### 2.4.1The benefits of EHRs use

The use of EHRs eliminates the errors in patient's medical information that improve work and cash flow. The errors can be eliminated by changing from handwritten paper-based record to Electronic Health Records (Menachemi and Collum, 2011; Ser et al, 2014). With the use of EHRs, the access to computerized records is made easier and faster (Menachemi and Collum, 2011).

According to Menachemi and Collum(2011), 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.

Having patient data in EHRs makes the data more available. That leads to more opportunities for analyses and research when it is needed (Ratwani, 2017). This research can lead to better EHRs, improved healthcare quality etc.

The transition to EHRs has realized the safety and efficiency in healthcare. The medical information can be readily accessible by multiple care providers at the same time. The EHRs support the decision making based on patient's history and conditions stored in EHRs (Ratwani, 2017). Healthcare professionals can record larger amount of information in EHRs than in paper-based records (Ser et al, 2014) due to it taking more time to type the medical information by hand than write it electronically.

### 2.4.2The disadvantages of EHRs use

Despite of benefits with EHRs use there are some disadvantages. These can be financial costs, security, privacy or changes in workflow (Menachemi and Collum, 2011).

Financial costs can be implementation costs, loss of revenue, costs for installing the EHRs system, and purchasing of hardware and software. The transition to EHRS has been both expensive and complex (Ratwani, 2017). 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 needs time to learn the new work structure with EHRs. They might need education to learn how to properly record data in the EHRs. That 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 (Ratwani, 2017).

Another problem with EHRs use is errors. For example, wrong patient selection. When a patient can be selected and orders to do lab, tests or make other actions that the patient never needs these actions. That can cause wrong care to patients. The information can

be missed or can be not completed when healthcare personnel use the EHRs as a communication system (Ratwani, 2017).

### 2.4.3 The eight rights for safe EHRs use

Designing and developing EHRs is not a small or easy task. There are many users of the EHRs,e.g physician, nurses, services and patients, and each user has his/her own needs and goals. It is difficult to design the EHRs based on each individual user (Ratwani, 2017) but according to Sittig (2009), there are eight rights required for delivering a safe EHR for all users:

- 1. *Right software*: If the software or hardware slows the system down, it will affect the patient safety negatively. EHRs must be supported by proper hardware and software. For example, cloud computing can be used to hinge the internet speed and access.
- 2. .Right content: The content must be evidence-based, structured, and complete.
- 3. **Right user interface**: The interface will be right when it presents a patient's information to allow care professionals to get information about problems, give response and document them.
- 4. *Right personnel*: Knowledgeable personnel are necessary for safe use of EHRs, for example developers and implantation staff.
- 5. *Right communication*: Risk for error is grounded on wrong information transfer. Careful analysis can lead to better identification for EHR use.
- 6. *Right organization characteristics*: Culture of innovation and improvement are factors in organization for safe EHRs use. The organization must report the errors or reasons for errors actively, even local errors.
- 7. *Right rules*: By good regulation, safe use of EHRs can be achieved. Regulations and policies must mention the safety of health information exchange in organizations.
- 8. *Right monitoring*: Many errors related to EHRs systems are the result of the implementation process. The organization must evaluate the use and benefits of EHRs after implementation (Sittig, 2009).

### 2.5 Summarization of Literature Review

All the previous studies have given important insight into the use of ICT in health sector and the EHRs are one of E-health example on ICT in health. The literature review presented above is closely related to this study. The aspects presented in the study concentrated to investigate how the EHRs might be improved to stimulate the refugees' patients with lacking in Swedish.

This chapter started with definition of Information and communication Technology and its role in society in general. The researcher explained then ICT's role in healthcare when ICT is used to get better health quality by applications and programs. As an example an introduction for EHRs the researcher explained E-health and its role to make patients involved in their healthcare. EHRs with their advantages and disadvantages were explained in detail as this study focused on EHRs. Finally, the researcher explained the eight rights that were required to get safe EHRs.

Afterwards, with the help of the knowledge gained from the Literature Review chapter, the researcher analyzed the data which is collected from the interviews and observation.

The outcomes and conclusion were motivated to the points that stated in the Literature Review chapter and previous studies in this research.

### 3. Research Methodology

This chapter presents the methodological tradition, methodological approach, and research strategy. Moreover, it presents the case description and research setting, data collection methods, and data analysis. This chapter concludes with a discussion on reliability and validity, and the ethical considerations.

### 3.1 Methodological Tradition

The epistemology in qualitative research can be interpretive, positivist or critical (Myers, 1997).

"Positivists generally assume that reality is objectively given and can be described by measurable properties which are independent of the observer (researcher) and his or her instruments." (Myers, 1997,p.1).

"Interpretive researchers start out with the assumption that access to reality (given or socially constructed) is only through social constructions such as language, consciousness and shared meanings. The philosophical base of interpretive research is hermeneutics and phenomenology. Interpretive studies generally attempt to understand phenomena through the meanings that people assign to them and interpretive methods of research in IS are aimed at producing an understanding of the context of the information system, and the process whereby the information system influences and is influenced by the context" (Myers, 1997, p.1).

"Critical researchers assume that social reality is historically constituted and that it is produced and reproduced by people. Although people can consciously act to change their social and economic circumstances, critical researchers recognize that their ability to do so is constrained by various forms of social, cultural and political domination. The main task of critical research is seen as being one of social critique, whereby the restrictive and alienating conditions of the status quo are brought to light. Critical research focuses on the oppositions, conflicts and contradictions in contemporary society, and seeks to be emancipatory i.e. it should help to eliminate the causes of alienation and domination." (Myers,1997, p.1).

This research draws on the interpretive paradigm as the objective is to understand how EHRs might be improved to stimulate refugee patients with lacking in Swedish language. It is interpretive because it focuses on people and their understanding of IS (Myers, 1997). I am going to understand the phenomena through the meanings that people assign to them. So through the interpretive paradigm I tried to understand the meaning of the answers that the participants I interviewed gave to me by using thematic analyzing. Their thoughts and experience interpreted so that I had more knowledge to investigate how the EHRs might be improved.

### 3.2 Methodological Approach

### 3.2.1 Qualitative research

Qualitative researches understand phenomena in the real world. The researcher does not attempt to understand the phenomenon for the sake his/her own personal interest, but instead, the researcher understands the phenomena of the real world and studies them as and because they appear there (Golafshani, 2003; Myers, 1997; Merriam and Tisdell, 2015). The participants can give their voices when the study is based on qualitative research(Pathak et al, 2013) and the result in qualitative research does not contain numbers and is not statistical, but it does contain words (Ingham-Broomfield, 2015).

The qualitative research approach is to study social and cultural phenomena in people's life (Myers, 1997) and it is used in studies which have questions (How, Why or What). (Biricki and Green, 2007) and this research method is most usable to understanding a phenomenon by getting the answers from participants in their social life (Stoop and Berg ,2003). This study is a qualitative study, because the researcher was going to understand the phenomenon (Golafshani, 2003; Myers, 1997; Merriam and Tisdell, 2015) which was EHRs and that was based on the answers from the participants, who were interviewed, and observation method. This research is qualitative because the result will be presented by words (Ingham-Broomfield, 2015).

This study was based on patients and EHRs. The purpose of that was to investigate how EHRs might be improved for patients in Sweden without Swedish language by understanding the patient's perception of EHRs and how the patient data can be stored in EHRs to increase the accessibility to EHRs. That might lead to more use of EHRs and offloads healthcare personnel, since at the time Sweden receives many refugees and they need immediate healthcare.

# 3.3 Research strategy 3.3.1 Case study

The researcher selects a qualitative case study as research strategy. Case study understands phenomena (the case) in real life contexts (Golafshani, 2003; Myers, 1997). The case could be a person, an application or a group, etc (Merriam and Tisdell, 2015). The researcher explores a case by using data collecting methods e. g interview, observations (Golafshani, 2003; Myers, 1997). A case study is useful when the researcher should answer the "How" and "What" questions, when the researcher wants to explore a phenomenon or when the researcher has little knowledge around the case (Golafshani, 2003). The case study is based on the theoretical and individual cases which are targeted in this research.

In this study the case study is most suitable, because the data was collected by interviews and observations, was investigated a phenomenon and the researcher answered how, why and what questions. The case study needs a sample. As the aim is to study how EHRs might be improved to inform the refugee patients, the participants whose human perspectives were collected in this study are immigrants who are refugees in Sweden and healthcare professionals who care for such patients and use EHRs.

The sample in this research was three of the healthcare professionals at a hospital. The researcher chose five patients who couldn't speak Swedish. They could speak a few Swedish words. The age of the patients were between 25-65 years in this study, in order

to investigate how the EHRs could be improved and stimulate the patients to use despite of age.

### 3.4 Case description and empirical setting

The study is conducted at hospital in region Västra Götaland. Agreement from the head was obtained. 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. She 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. Then they had to choose if they wanted to participate or not. Of those patients, who wanted to participate, I chose five patients who did not use EHRs due only to lacking Swedish. We decided together a time for an interview, which were conducted at a place they chose. 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. If necessary, additional meetings would be conducted via telephone or mail. 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.

# 3.5 Data collection methods 3.5.1 Interviews

Interviews in qualitative research are a way for the researcher to obtain information from the participant, and that can help the researcher to know their thoughts (Sparkes, 2014, Myers, 1997). There are different types of interviews in qualitative research, namely semi-structured and unstructured interviews, as well as focus groups (Sparkes, 2014).

- -Semi-structured interviews: The interviewer poses direct questions to the participants and uses open-ended questions to give participants more flexibility when they answer the questions. The researcher prepares questions to ask the participants. (Sparkes, 2014). The semi-structured interview is mostly used in qualitative research. The researchers get answers directly to their questions from the participants.
- Unstructured interviews: The researcher has indirect questions to the participants. The researcher starts with a topic that is followed by a question. Open-ended questions are used here, too. It is more difficult to analyze data from an unstructured interview. The researcher will find answers to his/her questions from the participants' explanations and discussion. Unstructured interviews require more time than the semi-structured interview (Sparkes, 2014).

The data in this research were collected by semi-structured interviews to get direct answers for the questions and help me to know the patient's and healthcare personnel's thoughts. That is, to investigate how the EHRs can be improved to stimulate the patients to use the EHRs. The researcher contacted the patient 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 with healthcare professionals conducted at the 18th of August 2017 at the hospital, however the interviews with patients were conducted at between the 20th and the 25th of August 2017 at their respective homes or the hospital. The interviews

were conducted in Arabic with patients who could speak Arabic, which is researcher's mother tongue. But the interviews with healthcare professionals were conducted in Swedish. I used open-ended question to give more flexibility for participants to get their thoughts and feelings and they were free to answer (Foddy, 1993).I told all participants that if needed, a telephone interview could be conducted. However, all interviews were conducted face to face. Then I told the healthcare professionals that if more questions came up after the interview, the researcher would contact them by phone or E-mail. Each interview took about 45-60 minutes. All answers were written during the interview on the paper. The analysis was translated to English.

### 3.5.2 Observation

In this research, I 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, s/he could not speak Swedish. The observations could help the researcher to understand what happened and how it happened (Bricki and Green, 2017). I selected this method because it was useful to see what the patients and healthcare personnel say and do. According to Bricki and Green (2017,p.23):

"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."

On the 15th of August 2017, the 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 me 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. That can help me to get answers to my research questions about how the data can be stored and how the patients can be motivated to use the EHRs and increase their accessibility. As I mentioned I will investigate just the diagnosis part in EHRs due the short time I have for this study.

### 3.6 Data analysis

Data analysis starts when the data is gathered. It means that when I started to take notes, the analysis starts. (Lichtman, 2013). There are six steps the researcher must follow to do data analysis in qualitative research. That type of analysis starts with words, and therefore, it is very important to write all points and words during data collection. The goal of analyzing the words is to make them available for thematic analysis in qualitative research (Lichtman, 2013).

According to Lichtman(2013), 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. The data can be gathered by interviews, documents, observations or journals.(Lichtman,2013). When going from raw data to meaningful concepts I will follow Litchman's model "The three Cs: Coding,

Categorizing and Concepts" which is explained in the following figure (figure 2):

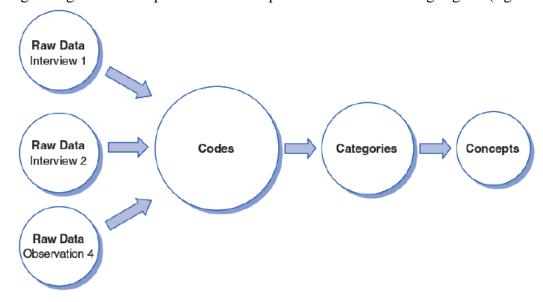


Figure 2 Three Cs of data analysis: Codes, Categories, Concepts, Lichtman, 2013, P.26.

I will use thematic analysis and follow the six steps, according to Litchman (2013):

- Initial coding: The codes can be words or phrases. In this step, I read my results and I wrote notes. It then gave every part a code. I did that with the whole text.
- Revisiting initial coding: I re-read my codes to reduce or rename them. That improved the codes.

Initial listing of categories: After step 2 I reworked the codes to categories.

- -Modifying the initial list: In this stage, I re-read my categories several times to remove those which were not important or had similar words.
- Revisiting categories: After removing less important words, I read once more to reduce and remove, and to make sure that I had only important codes.
- From categories to concepts: At this stage, I gave my categories themes then I defined them.

The data which I collected by interviews and observations, was analysed by using thematic analysis. Through a detailed and careful examination, the gathered data got themes from my interviews and observations. The themes were identified and analysed to get the answers for research questions. After that the answers were examined to get answers and suggestions regarding my research problem. During the interviews and observations I transcribed all the data.

The first step was to read the transcribed data carefully so I didn't miss an important word in gathered data. After reading several times, I started finding codes. I did this until I finished reading it all.

The second step was to convert the codes into categories. It was time- consuming step. I thought hard about the relationship between the codes and the relationship between them and the categories.

The last step was to read the categories several times, examined which categories were less important, or two categories became one, etc. Then the final categories converted into themes. I thought about the relationship between the categories and themes. That resulted in set of themes which were established through the process then I started to translate from Arabic and Swedish into English because the gathered data was in Arabic

and Swedish and this research should be written in English. After that I started analysing them.

### 3.7 Validity and reliability

Reliability means testing or evaluation (Golafshani, 2003). In order to get a high quality in qualitative research, the research should be evaluated. The reliability and validity are the foundation for the trustworthiness of the study, and the researcher can influence them to increase them (Golafshani, 2003). In this research, all data will be written to be analysed, and results from this research will be evaluated when the patients and medical will assess the suggested improvements. The researcher will send a mail to all participants six months after using the suggestions, and asking them about the situation after using the improvements. If the problem disappears after using the solution in the study, this means that the research has high validity and reliability.

### 3.8 Ethical Considerations

Sparkes (2014) discussed the ethics of qualitative research. Participants must be informed about the research they have right to choose either to participate or not. Sparkes (2014) also discussed qualitative anonymity in research. With anonymity has to be respected human rights and privacy.

In this research, the researcher will use Sparkes' (2014) guidelines for qualitative research:-

- 1- *Culturally*: respect to participants' culture. (Sparkes, 2014)
- 2- **Relational**: respect to researchers, researched and respect to their job and their society.
- 3- Reflexive: a researcher should respect the participants ' privacy, safety and anonymity.

And the researcher will present their research in order to be understood. (Sparkes, 2014).

The research shall respect all participants including researchers and researched. The research should be presented to show what are outcomes and how has the researcher arrived at the result.

Participants were informed about the study. It is optional for all participants in the study to be interviewed. No names will be written in the research for the all participants. Home countries, disease, age and number of years in Sweden, the role for healthcare professionals, and the name of the hospital will not be written in the research. All referenced material will be properly sourced. All participants will be called "participant x", where x is a number.

### 4. Empirical Findings

This chapter presents the findings from the data that was collected in this research. The chapter presents each finding in detail.

The purpose of this study was to explore if the EHRs can be improved to stimulate patients without Swedish language to use EHRs and to that end, the information was collected to answer the research questions for this study. Through thematic analysis and following Lichtman's (2013) recommendations, the following themes were identified:

- Theme 1: EHRs is a communication and information system
- Theme 2: Patients haven't enough information about EHRs
- Theme 3: EHRs in Swedish prevents patients to use it
- Theme 4: Referring patients to use EHRs when they need the medical information
- Theme 5: Better instructions about EHRs
- Theme 6: ICT can present medical information in diagnosis part in EHRs in other languages
- Theme 7: ICT can present medical information in diagnosis part in EHRs by sound

Interestingly, through these themes we found answers for the research questions. Through in-depth study and discussion, the researcher found that the first research question can be answered by the first two themes and the second question can be answered by the next three themes and the third question can be answered by the last two themes.

#### Theme to RQ1

RQ1: How do refugees and healthcare professionals as users perceive the use of EHRs?

Table 1. Refugees' perception of EHRs by themes

| RQ1 | How do refugees and healthcare professionals as users perceive the use of |
|-----|---|
|     | EHRs?   |
| 1   | The EHRs is a communication and information system                        |
| 2   | Patients haven't enough information about EHRs                            |

#### Themes to RQ2

RQ2: How can computer literate non-Swedish speaking refugees be motivated and enabled to take increased access to the diagnosis section of EHRs, according to healthcare professionals and refugees?

Table 2. Motivation of patients to use EHRs by themes

| RQ2 | How can computer literate non-Swedish speaking refugees be motivated and        |
|-----|---|
|     | enabled to take increased access to the diagnosis section of EHRs, according to |
|     | healthcare professionals and refugees?  |
| 3   | EHRs in Swedish prevents patients to use it                                     |

| 4 | Referring patients to use EHRs when they need the medical information |
|---|---|
| 5 | Better instructions about EHRs  |

#### Themes to RQ3

RQ3: How can patient medical information be organised in the diagnosis part of EHRs to enable access and understanding of records for patients, according to healthcare professionals and refugees as providers?

Table3. The organisation of medical information in EHRs by themes

| RQ3 | How can patient medical information be organised in the diagnosis part of     |
|-----|---|
|     | EHRs to enable access and understanding of records for patients, according to |
|     | healthcare professionals and refugees as providers?                           |
| 6   | ICT can present medical information in diagnosis part in EHRs in other        |
|     | languages   |
| 7   | ICT can present medical information in diagnosis part in EHRs by sound        |

### 4.1 Empirical findings for RQ1

RQ1: How do refugees and healthcare professionals as users perceive the use of EHRs?

The main themes of the Research Question 1 are show as below:

- The EHRs is a communication and information system
- Patients haven't enough information about EHRs

### Theme 1: EHRs is a communication and information system

The EHR is used as a communication system between healthcare professionals and patients, and can also be used as information system where the patients and healthcare professionals can get the information they need about treatments, labs and test result in EHRs.

Participant 4 responded: "I knew that EHRs can present to me and my family our medical information about our diseases"

Participant 5 responded: "I was informed by a friend I can read the information in the diagnosis part in EHRs, I could see what I and my doctor discussed about, I hear I could also see my medicine in EHRs"

During observation, it was clear that healthcare professionals used EHRs as an information and communication system when the nurses used the information in EHRs to inform the patients when they called, and then they wrote in EHRs to inform the doctors about patients and potential reasons for calling.

#### Theme 2: Patients don't have enough information about EHRs

The patients cannot use EHRs because they didn't get information about EHRs or the information stored in EHRs.

Participant 1 responded: "The healthcare professionals weren't actively informing the patients when they need the medical information or when they visit the healthcare facility."

Participant 2 agreed with participant 1.

Participant 3 added: "The patient must know because the information about EHRs found in internet, e.g. in 1177 homepage, healthcare professionals haven't time to inform the patients about ICT"

Participant 4 responded: "I just heard that I could read my medical information in EHRs, and this information I got from my friend who use the EHRs. I didn't get more information about it."

Participant 5 agreed with participant 4.

Participant 6 said: "I never got information about a system I can use to read my medical information. I usually use the 1177 homepage and other health websites; however these sites don't present my own information or my discussion with the health care facility." Participant 7 responded: "I don't know what EHRs means or which information I can get. I saw the nurses read and answer me when I visited the healthcare facility but didn't believe I could read that information by myself at home" Participant 8 agreed with participant 7.

### 4.2 Empirical findings for RQ2

RQ2: How can computer literate non-Swedish speaking refugees be motivated and enabled to take increased access to the diagnosis section of EHRs, according to healthcare professionals and refugees?

This question will be answered by the following themes:

- EHRs in Swedish prevents patients to use it
- Referring patients to use EHRs when they need the medical information
- Better instructions about EHRs

#### Theme 3: EHRs in Swedish prevent patients from using it

Patients cannot use EHRs, because they don't understand the information stored in the EHRs. The information is stored in Swedish and the language is difficult, especially the medical information. The patients cannot allow their own relatives or friends who can read Swedish to read their information in EHRs.

Participant 1 said: "The patients don't use EHRs due to difficulties with the Swedish and the medical information is also hard to understand."

Participant 2 said: "There are many reasons to why patients cannot read the EHRs and one of them is it being written in Swedish."

Participant 3 agreed with participant 1 and added: "The medical information isn't difficult only for refugees, but it might be difficult for Swedish people as well. Not all Swedish people understand what healthcare professionals write in EHRs."

Participant 4 responded: "I opened my EHRs but all information was stored in Swedish. I can speak English but that didn't help me to use EHRs. I thought to use Google translate, but it was all wrong. I use other healthcare sites in my native language."

Participant 5 responded: "My friend who told me about EHRs can speak Swedish but I cannot allow him to read my EHRs. My health problems are my private matter. No, I don't allow anybody to read my EHRs but I cannot read it now. I must learn Swedish to use it."

Participant 6 said: "I can't get the benefits of EHRs use because it's written in Swedish and I can only read my native language. When I need my medical information, my

friend calls the healthcare facility to ask them if I get it. They send it to me on paper in Swedish also".

Participant 7 answered: "There is no reason to get information about EHRs if it is just written in Swedish and I am a new refugee here, and can just speak a few Swedish words."

Participant 8 responded: "It is a big problem if I read a medical information system but I cannot read Swedish, I might translate it wrong."

Theme 4: Referring patients to use EHRs when they need their medical information

The patients must be referred to medical information stored in EHRs to motivate patients to use it, to try learning and reading. They must know that some of the nurse's answers can be found in EHRs and the healthcare professionals must inform the patient that S/he can read the information related to the last visit in EHRs if needed.

Participant 1 answered: "The health care doesn't say that the medical information is found in EHRs and don't inform the patients when they are calling healthcare. The patients might use it if the healthcare professionals refer them to EHRs"

Participant 2 and 3 answered as participant 1.

During observation, it was very clear that the patients were not referred to their EHRs when they contacted the healthcare.

#### Theme 5: Better instructions about EHRs

Patients need instructions about EHRs because it is a new system that is not easy to understand for refugees when they are new in Sweden. Vårdguiden1177 doesn't have information or instructions about EHRs in other languages that can decrease EHRs use by refugees.

Participant 1 answered: "The patients didn't get instruction about how they can use it, the healthcare facility didn't send any information about that to patients."

Participant 2 said: "The patients must get better instructions, today they must know that by themselves."

Participant 3 answered:" It would be helpful if the 1177 write instructions for use of EHRs in different languages that could maybe motivate them to read their EHRs"

Participant 4 responded:" Refugee patients need guiding for use of EHRs, the patients might solve the problem in language by using a dictionary"

Participant 5 answered: "It is in Swedish so I cannot know under which part the medical information related to my last visit is stored. Healthcare must inform and guide us more to use the EHRs."

### 4.3 Empirical findings for RQ3

RQ3: How can patient medical information be organised in the diagnosis part of EHRs to enable access and understanding of records for patients, according to healthcare professionals and refugees as providers?

This question will be answered by the following themes:

- ICT can present medical information in the diagnosis part in EHRs in other languages
- ICT can present medical information in diagnosis part in EHRs by sound

Theme 6: ICT can present medical information in the diagnosis part in EHRs in other languages

The diagnosis part could have a translate function to other languages. Today the diagnosis part is written just in Swedish and all study participants wish that diagnosis

the part could be shown in other languages by using the new technologies. Google translate didn't give them the right translation, and using dictionaries requires more time to translate the content in the diagnosis part.

Participant 1 answered: "It could be very nice if we could see the diagnosis part in other languages, so the patients can click and choose which language S/he wants."

Participant 2 said: "If the patients can read a little of their EHRs, they can offload healthcare professionals, but they cannot read or be motivated if they cannot read it in the language they can speak. There are many websites today that everybody can read because the people can choose in which language they want to read the information."

Participant 6 said: "I don't prefer the learning of EHRs use if it is written in Swedish and the patients cannot read it. To teach people a new information system need time but it is no use if the patients cannot use it after the teaching. I prefer that the language problem be solved first. Perhaps by using a translation technology for translating into English in the beginning, since there are many refugees can read their native languages and English"

Participant 7 said:" The patients get the medical information with the help of an interpreter. Why can s/he get the same information with same language but I can't read my EHRs? The interpreter can write the interpreted information on a paper and the healthcare professionals can scan it in my EHRs."

Participant 8 had the same idea for participant 7.

Theme 7: ICT can present medical information in diagnosis part in EHRs by sound The participants proposed that it would be very helpful if the last visit could be recorded in audio in EHRs. They mean that the last visit can be recorded and then saved in the diagnosis part in EHRs, allowing the patients to listen to it when needed.

Participant 1 said: "It is not bad to better EHRs by adding sound."

Participant 3 said:" There are many patients who cannot read when they have eye disease so they need sound in their EHRs."

Participant 4 said: "The patients get an interpreter at the last visit, so it will be very easy if the dialogue between the patient and healthcare professionals could be recorded and saved in EHRs."

Participant 5 said: "It is easier to remember what everybody said at the visits when the patient hears the sound file in the EHRs. That will both motivate patients to use EHRs and enhance the EHRs."

Participant 6 said: "Sound in internet always increases the page's access e.g. YouTube, I use YouTube to get the information I want in the language I want".

## **4.4 Overview of Empirical Findings**

The results of the analysis are summarized here in the table below. The table represents the themes and their findings:

Table 4.A summary of findings per theme

| Themes             | Findings   |
|--------------------|--|
| 1. EHRs is a       | - Patients can read about their medicine, disease and health |
| communication and  | information.   |
| information system | - Healthcare professionals use EHRs to get patient's medical |
|                    | information or to inform patients and healthcare             |
|                    | professionals.   |

|   | - Healthcare professionals use EHRs to communicate with others by typing patient's medical information.   |
|---|---|
| 2. Patients haven't enough information about EHRs   | <ul> <li>Health care wasn't active to inform patients about EHRs.</li> <li>There is no information in other languages about EHRs in vårdguide 1177.</li> <li>Patients knew about EHRs from their friends.</li> </ul>  |
| 3. EHRs in Swedish prevents patients to use it  | <ul><li>There is no idea to inform patients about EHRs when it is still in Swedish.</li><li>Patients can't read the EHRs because it is in Swedish.</li></ul>  |
| 4. Referring patients to use EHRs when they need the medical information  | <ul> <li>Patients don't be 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 don't be referred to read their information when they contact the healthcare and have questions which are answered in EHRs.</li> </ul> |
| 5. Better instructions about EHRs   | <ul> <li>Patients don't know how they can use EHRs.</li> <li>Patients haven't idea about which information is found in their EHRs.</li> <li>There are no instructions in other languages about EHRs on vårdguide 1177.</li> <li>Patients don't get instructions from healthcare professionals.</li> </ul>   |
| 6. ICT can present medical information in diagnosis part in EHRs in other languages 7. ICT can present medical information in diagnosis part in EHRs by sound | <ul> <li>The last visit can be typed with patient's native language and scanned in his/her EHRs.</li> <li>There is need to have translate function in EHRs to translate the information stored in EHRs to other languages.</li> <li>The last visit can be recorded at the time the interpreter interprets and added in EHRs.</li> </ul>                                 |

Some participants described the EHRs as an information and communication system. EHRs function as information system when they are used to help patients read their medical information and help healthcare professionals get patients' medical information to discuss the treatments and test results. The EHRs function as a communication system when they are used for communication with patients or healthcare professionals. Patients who described the EHRs as a communication and information system knew about them from their friends, not from the healthcare facility.

Some participants mentioned that they didn't hear about EHRs from healthcare professionals at all and that it is difficult to know about healthcare systems in Sweden as new-coming refugees and that because of this, they couldn't use it. Some participants got information about EHRs from their friends, but all participants said that the patients don't get information from the healthcare facility about EHRs use. Healthcare professionals don't inform patients that the medical information is found in their EHRs, which causes the patients to have no idea about EHRs and prevent their involvement in

EHRs. The participants also highlighted that the Swedish language is very difficult and it is a big problem when they want to read their EHRs. They might translate wrong and get inaccurate information about their health. All participants said that they wouldn't use the EHRs if continued to be in Swedish only.

Patients should be motivated to use the new technologies and try to learn it if they are informed about it. At a first step, the patients must know that their questions might be answered in their EHRs when they are calling healthcare after last visits. This information must be communicated to patients at the visits, e.g "if you need this information later, you can read your EHRs". This would promt the patient to ask more about EHRs and try to use them. They can then also learn the disadvantages of being unable to use it due to the language, and they can then tell the healthcare professionals to find a solution for those themselves. It will help the healthcare to know why the patients cannot use their EHRs. The patients didn't get instructions about EHRs from health care professionals nor the Vårdguiden 1177 homepage. There is a lot of information and instructions in other languages in the 1177 homepage, but nothing about EHRs although all patients have same rights for health in Sweden.

All patients in this research used internet and health sites, but they did so in those languages they speak. All participants desire a translate function in EHRs from Swedish to another language. They suggest that the information from the last visit could be written by the interpreter who translates it at the visit and it was scanned into the diagnosis part of the EHRs by healthcare professionals. The patients would be informed about that at the visit so they can read their EHRs if needed after the visit.

Another suggestion was that the information related to the last visit would be recorded in audio and saved in the diagnosis part in EHRs. That will solve the language problem with EHRs for refugees who can use ICT and have knowledge about EHRs. The healthcare system's role is to inform patients about EHRs, give patients instructions about it and to hear the patient's difficulties and comments about it in order to motivate the government to improve the EHRs based on patients and healthcare professionals' requirements.

The observation method in this research showed that the patients don't get information that their medical information are stored in EHRs or that they can read them when they need it and the patients were not referred to their EHRs when they contacted the healthcare. Since the patient does not know about the EHRs, they don't ask about them and thus cannot learn to use it. They return to the healthcare facility when they have questions, the answers to which are already stored in their EHRs. The observation method further showed that healthcare professionals used the EHRs as information and communication system when they documented the information or health problems about patients and used the information in EHRs to answer patient's question.

### 5. Discussion

This chapter presents the discussion on findings, the answers for the research questions and also how the findings relate to the previous literature.

### **5.1 Discussion on findings**

The aim of this case study is to investigate how EHRs might be improved to stimulate computer literate non-Swedish speaking refugees to use EHRs. That is covered by RQ1, RQ2 and RQ3 with corresponding themes.

#### 5.1.1 Discussion of RQ1

RQ1. How do refugees and healthcare professionals as users perceive the use of EHRs?

The findings for the research question 1 were explained by two different themes, EHRs is a communication and information system, patients haven't enough information about EHRs

EHRs is a communication and information system:

The outcome of this research showed that" EHRs is a communication and information system". I found that patients use EHRs to know about their medicine or diagnosis. Healthcare professionals use it to inform patients and other healthcare professionals when the patients contact healthcare. Healthcare professionals use EHRs to communicate with others when they type in EHRs about patient's health.

In reference to the existing literature, according to Ambinder (2005) and Campanella et al (2015) EHRs can be used by patients, healthcare personnel, hospitals, clinics, laboratories and pharmacies. They use EHRs for communication, management, visit procedures, laboratory test, referrals and support.

The patients who told me that they knew about EHRs ant its benefits they don't use it but they got this information from their friends who have been in Sweden many years and can speak Swedish. The patients didn't get this information from healthcare. They also refer the use of EHRs to the Swedish language. They said their friends use it and they can Swedish. Might they mean it is possible for them to get information about EHRs if they can speak Swedish.

This theme shows that healthcare professionals use the EHRs continuity both to inform other healthcare professionals and patients and to communicate about patient's health while they type the information that patients inform.

It is clear that healthcare professional use it as information system when they inform others about patient's health problem. And they use EHRs to communicate with other healthcare professionals when they write the notes about patients.

Patients haven't enough information about EHRs:

The empirical findings show that patients haven't enough information about EHRs. There is no information in their native languages on 1177. The healthcare professionals weren't active to inform the patients about EHRs. I found also that patients get information about EHRs from their friends. To get the EHRs in use by patients they must get information it to use it.

It was clear that patients haven't enough information about EHRs. They didn't get information about use of EHRs from healthcare professionals who can the EHRs best. The patients got the information from their friends or they didn't get any information about it. That agrees with Wu and Raghupathi (2012) who found that the patients must be informed about new technologies to use it.

### 5.1.2 Discussion of RQ2

RQ2. How can computer literate non-Swedish speaking refugees be motivated and enabled to take increased access to the diagnosis section of EHRs, according to healthcare professionals and refugees?

The findings for the research question 2 was explained by three different themes, EHRs in Swedish prevents patients to use it, referring patients to use EHRs when they need the medical information, better instructions about EHRs

#### EHRs in Swedish prevent patients to use it:

The empirical findings showed that the patients don't prefer to be informed about EHRs when it is still in Swedish. They cannot use it because it in Swedish. They feel the language prevents them from EHRs use. I found here the difficulty of the language is one of the difficulties that the patients can get. According to Ennis et al. (2011) who found that there are many difficulties with accessing ICT, but they also found the relation between empowerments and patient's access to EHRs.

#### Referring patients to use EHRs when they need the medical information:

This theme is outcome from both interviews and observation. I found that the patients don't be referred to check their EHRs when they need their medical information. They don't be informed that they can read their EHRs. When the patients don't be referred they don't become interested to learn EHRs. They cannot be motivated to use it or to ask about it. This theme is existing with a literature by Ennis et al (2011), they found the relation between empowerments and patient's access to EHRs. That means although the difficulties with the language the patients can be empowered to access their EHRs.

#### Better instructions about EHRs:

This theme showed that the patients know about the EHRs but they didn't get any instruction about it. They were active and conducted search on 1177 to get some instructions in their languages about it. Healthcare professionals and Vårdguid 1177 have no instructions for EHRs users in other languages. According to my experience there is information and instructions on Vårdguid 1177 for EHRs users in Swedish.

To get the EHRs in use by refugees without Swedish language they should get instruction about it. That exists with literature by Wu and Raghupathi (2012) who found that the patients must be informed about new technologies to use it.

These themes showed that the patients don't want to be informed about EHRs if its content still in Swedish. The themes showed also that the patients didn't get instruction or were informed that the information is stored in EHRs. To motivate the patients it is important to inform him/her that the information they need is stored in EHRs. And as the EHRs is a new technology the patients must get instructions to use it.

On vårdguid 1177 are found instructions but it in Swedish. According to themes and findings the EHRs must be in patient's language, the patients must get instructions about it and the patient must be referred to use EHRs when S/he needs the information stored. That can motivate refugees without Swedish to use EHRs.

#### Discussion of RQ3

RQ3. How can patient medical information be organised in the diagnosis part of EHRs to enable access and understanding of records for patients, according to healthcare professionals and refugees as providers?

The findings for the research question 3 was explained by the two different themes, ICT can present medical information in diagnosis part in EHRs in other languages, ICT can present medical information in diagnosis part in EHRs by sound

ICT can present medical information in diagnosis part in EHRs in other languages:

The findings regarding this theme show that the last visit can be typed with patient's native language by the interpreter who interprets the dialogue between the patient and healthcare professionals. The interpreter can write it after the meeting and healthcare professionals can scan it as a document in patient's EHRs.

Another finding is that the healthcare can solve the language problem by adding a translate function. The translate function can translate the information in diagnosis part to patient's language.

ICT can present medical information in diagnosis part in EHRs by sound:

The last visit can be recorded when the interpreter interprets at the meeting between healthcare professional and the patient. The recorded sound can be saved in patient's EHRs.

These themes and their findings described the patients' needs to use EHRs. These themes also confirm the literature of Tuikkaet al.(2015). They conducted a study which focussed on EHRs and patient involvement. In their research, they discussed the empowerment of patients in EHRs. Their study showed that identification of needs/needs elicitation and capture should engage patients. They further identified that implementation of patient led requirements in EHRs should include patients who are beneficiaries of the work. By knowing the needs the EHRs can be implemented according to patients needs that can empower patients to use it.

### **5.2 Reflections**

The empirical findings of this study reveal that, EHRs can be improved to stimulate computer literate non-Swedish speaking refugees to access EHRs and get their medical information. The findings showed that the patients didn't get information, instruction or were referred to use EHRs. That didn't motivate the patients to use it or to be curios about EHRs.

They don't prefer that the EHRs are in Swedish but they prefer that the EHRs will be in their native language to access it. They explained that the Swedish language is difficult to learn which can take time for them. That prevents them from using EHRs. The empirical findings showed that the information in diagnosis part might be stored in other languages. By adding a translate function or the meeting can be translated, written and scanned in EHRs. The patient can access it when it is needed instead of contacting the healthcare. Another finding is to record the meeting with help of the interpreter and save it in patient's EHRs. The patient can listen to it when needed.

These findings might be considered as solutions for the problems the refugees face due to lack in Swedish languages new comers in Sweden.

To add a translate function in EHRs is not very simple solution. It might need time and other technologies as a technical solution but it is very practical. So the patients can choose a language from a list in EHRs and get the medical information translated. This solution may need an agreement from many aspects.

To record a meeting and add interpreter's sound in EHRs might be a difficult task when it comes to get the interpreter's agreement.

But to get the meeting translated, written and scanned is probably a good solution. The interpreter can write what S/he said to patients on a paper, the healthcare professionals scan this paper and save it as document in EHRs. It is important that healthcare professionals inform the patient that the last visit will be saved in their languages in their EHRs and they can read it at any time.

### 6. Conclusion and future research

This chapter presents the conclusion, suggestions for future research and the contribution of this study.

#### **6.1 Conclusions**

At a time when many people migrated from their countries to Sweden, the need for healthcare to take care of non-Swedish speakers has increased. The use of EHRs will help to improve the quality of health by involving the patients in his/her healthcare.

This study has attempted to provide answer to the question of how the EHRs might be improved to stimulate refugees in Sweden who cannot speak Swedish to engage with their healthcare. Using the interpretive qualitative research methodology with data collection methods observation and semi-structured interviews, the research study resulted in seven themes through a thematic data analysis which answered the research questions:

- 1. How do refugees and healthcare professionals as users perceive the use of EHRs? This question answered with first and second themes "EHRs is a communication and information system", "Patients haven't enough information about EHRs".
- I found that the health care professionals used it as communication and information system, the patients heard from their friends that it can be used as information system, some patients didn't know anything about EHRs.
- 2. How can computer literate non-Swedish speaking refugees be motivated and enabled to take increased access to the diagnosis section of EHRs, according to healthcare professionals and refugees?
- "EHRs in Swedish prevents patients to use it", "Referring patients to use EHRs when they need the medical information", "Better instructions about EHRs" are themes which answered the second research question.

I found that the patients didn't want to get information about EHRs when it is still in Swedish, patients didn't get instructions about EHRs and patients were not referred to EHRs when they need their medical information. It is important to inform patients that they can get their information from EHRs when they need it, solve the language problem and giving better instruction to learn patients how they can use the EHRs, that can motivate patients to access their EHRs.

How can patient medical information be organised in the diagnosis part of EHRs to enable access and understanding of records for patients, according to healthcare professionals and refugees as providers?

This research question answered by themes "ICT can present medical information in diagnosis part in EHRs in other languages", "ICT can present medical information in diagnosis part in EHRs by sound".

The findings related to these themes were that a translation function might be added in EHRs, the last visit can be written by the interpreter and scanned in patient's EHRs by healthcare professionals or the last visit can be recorded with the interpreter's sound and added in patient's EHRs.

The most suitable solution might be that the last visit can be written and saved in patient's EHRs.

To get the information in EHRs translated can increase the access by the patients even by refugees who cannot speak Swedish. The EHRs must be designed and its components must fit all its users to get the benefits of it and all must have the equal accessibility of EHRs (Rao and Edlavitch, 2010; Ennis et al, 2011; Häyrinen et al, 2008).

#### **6.2 Research contribution**

This research keenly focuses on the field of information systems development, with respect to patient's and health care professionals' perception and experience.

This study aimed to explore how the EHRs can be improved to stimulate the refugees who cannot use EHRs due to their lack of skill in the Swedish language. The scope of this study wasn't to construct a technical solution, but to outline a description of EHRs by patients, the patients' motivation for using them, and suggestions for how the diagnosis part in EHRs could be designed to improve EHRs so as to stimulate the patients to use it. It might decrease number of patients who contact the healthcare after the last visit and save time for healthcare professionals.

This research is conducted at a hospital in a region of western Sweden, but the benefits of the research are applicable in any place where people with different languages share EHRs. Based on the outcomes of this study, hospitals can strive towards providing EHRs based on patient's needs. By this study the EHRs can be improved to all refugees not only in Sweden but in other countries which have population from other countries and they cannot use EHRs due the difficulties in the language.

#### **6.3 Future Research**

This study is limited to patients who are refugees and don't use EHRs due to their lack of the Swedish language skills in Sweden. This research didn't explore the patients who are illiterate or cannot use EHRs. Those patients might be Swedish or refugees who can speak Swedish but otherwise can't use EHRs. There are many suggestions for future studies. First suggestion: a research about how EHRs can be improved for patients in other countries which have immigrant people. Second suggestion: how can EHRs be improved for people who are illiterate? A third suggestion might be about developing a technical solution for solving the language problem. Those studies might increase the population who use EHRs to get the best result by using ICT in the health sector.

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## **Appendices**

## **Appendix A. Interview Questions For Patients**

- Do you use the internet? If yes can you please mention for what do you use the internet?
- Do you have a problem when you search information on Internet?
- Do you contact healthcare after you are finished your treatments to get your medical information?
- Can you describe the EHRs and please mention where from do you get your description?
- Do you want to use EHRs? And why?
- How do you like your EHRs might be showed?

# Appendix B. Interview Questions For Healthcare Professionals

- How often does patient call the healthcare to get the information stored in EHRs?
- How do you feel about that?
- When do you inform the patients to use EHRs?
- Do you feel that refugee patients use EHRs and why?
- Do you inform patients that their medical information are stored in their EHRs at last visit so they don't need to contact the healthcare when the need the information?
- According to you experience which is the biggest problem that refugee patients have with use of EHRs?
- How can that be solved?

### **Appendix C. Informed Consent From for Master Thesis**

Informed Consent Form for Master Thesis

Date: August, 2017

Titel of the Research: Improving Electronic Health Records for non- Swedish speaking

refugees

Researcher: DuaaAbdulrazakKadhim, Master Programme in Informatics, Linnaeus

University

Email: da222iq@student.lnu.se

Phone: 0735 26 88 41

#### Purpose of the Research

To explore how the EHRs might be improved to stimulate non- Swedish speaking refugees to use EHRs.

#### Your part as participant

You will be asked to participate in an interview which can take maximum one hour. The purpose of the interview to help me to answer my research questions how do refugees perceive the use of EHRs, how can computer literate non-Swedish speaker refugees be motivated to enable and increase accessibility to diagnosis section in EHRs, how can patient medical information be organised in diagnosis part in EHRs to enable access and understanding of records for patients. The answers will help me to achieve the purpose of the study.

#### Confidentiality and Risk

All information about you as participant, such as name, professional, age, native language, home country, during and after this study will be anonymity. Your participation in this research study is free of risks.

#### How this research will be beneficial and to whom

In my research I will gather knowledge to increase the accessibility of EHRs by patients who cannot speak Swedish. That might offload the healthcare at the time with shortage healthcare professionals for offloading the healthcare.

#### Participation

You participation is voluntary but even you want to participate your contribution can be destroyed without problems or consequences. You can refuse to answer questions without saying why.

#### **Ouestions**

Please contact DuaaAbdulrazakKadhim on telephone 0735268841 or by e-mail: <u>da222iq@student.lnu.se</u> when you have questions about the research.

#### Legal Right's and Signatures

I agree to participate in the research study:" Improving Electronic Health Records for Non-Swedish Speaking Refugees" that is conducted by DuaaAbdulrazakKadhim. I have understood the purpose of the research and I allow my views to be used in this study

| however legal rights will be saved even I sign this form. I give my agreement by signing below. |
|---|
| Participant: Date:  |
| Signature:<br>Researcher: Duaa Abdulrazak Kadhim<br>Date  |