Electronic Health Record Systems – A study of privacy in the region Kronoberg of Sweden
DEDICATION

To God be the glory, without you lord I could not have made it this far.

I dedicate this thesis to my late mom Mrs. Caroline Bolanle Odepidan and my brother and sisters. Boladale Odepidan, Siyanbola Odepidan and Bolajoko Odepidan, for their support and encouragements throughout my master’s period in Sweden.

God bless you all.
Abstract

This study gives a brief description of paper-based record and the adoption of ICT, which brought the introduction of Electronic Health Record System (EHRS) in Sweden, the challenges facing EHR in the health care sector around the world and what immigrants and newcomers who just arrived in Sweden knows about the privacy, rights and the policies that protect their privacy and data system, these could cause them not having enough confidence in electronic health record system, they could also be worried about their information been exposed or disclosed by their healthcare providers, this call for the confidentiality, security and privacy of EHR System. The aim of this study is to explore immigrants and newcomers as users of electronic health record system by setting interview questions and focus group to help the researcher to understand their knowledge of what they know about the privacy of EHRS and what they know about the policies health care providers follow to protect patient’s privacy and data. It is very important for them to know their rights and the rights that protect their privacy and data from been shared or disclosed.

The study also talked about the existing implications facing EHRs, comparison of both systems was shown in table 1 of this study. The necessity for a proper protection of patient data was discussed and recommendation was made towards having a great and a working electronic health record system.

Key words:
EHealth, Privacy, Security, health records, Sweden, ICT, Patient, Qualitative method.
Acknowledgement

I would like to thank everyone who has helped me during the process of my research. First, I want to thank Christina Mörtberg my supervisor I am very grateful for her advices, guidance and support. She was really helpful with the interview questions and helped a lot on how to get more information about 1177 and health care providers in the Region kronoberg. Secondly I would also like to thank Karin Hedström who was a guest lecturer at the university towards the end of my course she thought us more about information security, which gives me more idea and vision on my research study. A big THANK YOU to all the lecturers that thought me in Linnaeus University would not have been able to do this without your knowledge as my lecturers. Finally I want to thank all the participants who participated during the interview and the hospitals who replied to my questionnaire, if not for all the mentioned above, my research would have not been easy for me to finish.
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<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>CIA</td>
<td>Confidentiality integrity and availability</td>
</tr>
<tr>
<td>EHR</td>
<td>Electronic health record</td>
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<tr>
<td>EMR</td>
<td>Electronic medical record</td>
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<tr>
<td>GP</td>
<td>General Practitioners</td>
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<td>HIE</td>
<td>Health Information Exchange</td>
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<tr>
<td>ICT</td>
<td>Information communication technology</td>
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<td>LNU</td>
<td>Linnaeus University</td>
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<tr>
<td>NPÖ</td>
<td>National patient overview</td>
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<tr>
<td>POE</td>
<td>Physician order entry</td>
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<td>PSE</td>
<td>Patient Safety Event</td>
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<tr>
<td>PHR</td>
<td>Personal health record</td>
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<td>US</td>
<td>United states of America</td>
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<tr>
<td>SEHR</td>
<td>Shared electronic health record</td>
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Introduction

The world is now a global village where the use of digital technologies has taken over every sector of the industries, including the health sector. The storing of medical records from the traditional ways of paper-based record, which involve files of document that are stored up in cabinets and rooms has changed in many countries like Sweden, calling for the adaptation of electronic health record system (Wang, Yu and Hailey, 2015). Access to the paper–based record could be difficult when needed in an emergency; so therefore, paper-based record is disappearing to give way for electronic health records, which gives a quicker access to patient’s medical information and reduced the cost of maintaining paper-based files. In addition, scholars argue implementation of electronic health record system has reformed and improved the quality of care in the health care sector (Fernández-Alemán et al., 2013).

Practo (2014) report shows that some people get the definition of electronic medical records (EMR) as electronic health record (EHR) so therefore, I will start by defining both to give a better understanding. Electronic medical record (EMR) is the electronic record of health information of patient, which is created and managed by physicians and other health workers. Electronic health record (EHR) is a digital collection of patient health information compiled on a centralized system to give adequate care to sick patients.

Cesario et al., (2012) defined electronic health record as a digital document that contains patient’s personal and medical information that could be used for advanced eHealth services. Examples of the information stored in EHR are, patients medical data and event analysis, remote medical report access, e-prescription. Cesario et al., (2012) argue
also, that to have a great patient privacy protection of EHRS. Confidentiality, security and privacy of Electronic Health Record and Personal Health Record (EHR and PHR) are very important factors in the health care sector; depending on the system involves patient’s personal information needs to be secured and well protected. Sahama, Simpson and Lane (2013) write the term electronic in the health sector, means applying the use of information and communication technology (ICT) for delivery of different types of healthcare services in various hospitals and health care centers including: sharing and managing of medical information.

1177 Vårdguiden (2016) explained Healthcare Guide 1177 as Sweden’s national hub where patient can seek advice, information, inspiration and e-services for health and healthcare. 1177 Vårdguiden (2016) also made it known that 1177 is provided to the public by the county councils and region. 1177 is a platform that supplies information about patient across of Sweden, report made it known that this is the first of its kind in the world. The National Patient Overview (NPÖ) was lunched also, which is a portal platform that allowed physicians and health care workers to access patient records online across the country. The same report made it known that (NPÖ) has gone from strength to strength in having all patient’s record available electronically and all documentation in primary care is now electronic health record (EHR). This means all pharmaceutical prescriptions in Sweden are shared online as ePrescription.

Healthcare IT news (2009) also report the lunch of National Patient Overview (NPÖ) project, the nationwide electronic health record that was introduced to improve patient security and quality of care in Sweden. The NPÖ was lunched to allow healthcare providers to share and exchange
patient information across the twenty-one regions of Sweden. However, the county council regions are responsible for health care in Sweden.

Lehnbom, McLachlan and Brien (2013) argues that electronic health record has improved the quality of health care in Sweden, that most primary health care centers and hospitals uses electronic health record system. Healthcare practitioners enter medical information into the electronic health record system, the information somehow are made available to patients in some region of Sweden. However, according to Patient Act/Patientlagen – engelska (2016) website, the site will give patients 24 hours access to information about health and services by mid this year (2016). They report there are six regions in Sweden, and some medical centers in these region uses regionally shared EHRs. Castro (2009) argues also, that Sweden is the number one in the world with their primary care physicians using EHR system to allow better access to patient data. In addition, Sweden is second highest Nordic country with the use of electronic health record usage in their hospitals, widespread the use of IT application, to order tests and prescribing medicine electronically and telehealth programs.

Mirkovic et al (2015) made it known to us that Personal Health Records (PHRs) are health records that contain patient's health data and information related to the care and is managed by the patient. PHR allow patients to access manage and share information regarding their health with their physicians. PHR is also linked to the electronic health record (EHR) system that is used and managed by the doctors and healthcare providers across regions, so therefore this system require protection, due to the sensitivity of data involved. In the process to implement the system and the involvement of different stakeholders, they advise that it is very important to address all
relevant legislation rules and requirements during the design and development of such system.

Li (2015) argue that electronic health record has the potential for quick recovery of information when needed in an emergency, even if they are stored in different regions. The use of electronic health record system and centralizing health information has improved the quality of health care services, also the introduction of Personal and Electronic health Record system has changed the way patient communicate, manage and share information between themselves and their doctors and other health care workers. However, in the process to make the healthcare sector archive the EHRS, there have been many challenges with patient medical information, confidentiality, privacy and security of electronic health records are part of the challenges patients are facing. Medical records could be exposed or fall into wrong hands, which brings fear and panic. These could cause patients to be worried and lose confident in EHR system regarding the safety of their health information. Confidentiality in the health sector is very important as it is the obligation of professionals (Health care practitioners) who have access to patient’s records, not to share or disclose patient’s information with unauthorized parties (Senor, Aleman, and Toval, 2012).

Li (2015) also made it known that healthcare provider could mistakenly or intentionally expose patient’s information. This information is to be kept as private and confidential. Patients has confident in their healthcare provider and believe that their information are safe and secure. Privacy is another thing; patient discloses their health information with physicians and other health care workers because they trust and hope their information is safe, protected and won't be shared with unauthorized person. Security is also important in the healthcare sector, as patient’s information needs to be
protected; this is where the question of how healthcare providers protect privacy and data from loss, disclosures, theft and hacking? My research is about the privacy of EHR, so therefore I won’t go into the security aspect of the system, as it is wide and deep beyond my knowledge.

1.3 Motivation

Regeringskansliet (2009) shows that Swedish health care systems are bound by professionals and no one in the system is allowed to share patient information without their consent. Healthcare practitioners who work within the health care are governed by councils and region to oblige by professional secrecy act and those who work in the private caregiver are regulated by the rules of confidentiality stated in the Patient Safety Act. So therefore, anybody who breaks or violate the law would be charged to court or be punished by the authorities that regulate the Swedish Healthcare System.

Sweden is a developed country and ranked one among other countries on the chart with the use of ICT in the health sector, where citizen gets equal health care services and created access to their health record through the comfort of their homes. In the process to centralized patient’s medical information to give a better care services, challenges raise with patient medical records been exposed or disclosed and also patient not knowing their rights or the importance of data privacy in the health care may decrease their confidence in the use of electronic health record system.

Sweden as a country with population of 10 million and still growing by accepting immigrants and international students from all over the world. The ministry of health and social affairs has giving every person that lives in the country equal opportunity and level to health care services. So therefore, it is very important that immigrants and newcomers are
aware of their rights of privacy and the rights that protect them as a patient that uses the health care services in the country and also in the region where they live. The introduction of E-health in the country shows that centralizing patient’s information requires protection, for patients to have full confidence in the system, health care providers must inform patients about their rights and also let them know how their privacy and data are protected and the policies they follow in protecting patient’s privacy and data. International students and immigrants who just moved to Sweden will be more vulnerable since they recently moved to Sweden and are dealing with many new conditions like settling into the country and not understand the Swedish system e.g. health care and also their rights. Health care providers must educate them about their privacy rights and the policies they use in protecting their privacy and data.

1.4 Purpose and Research Questions

National eHealth (2010) pointed also the fear of sensitive personal information ending up in wrong hands, as there is a legal possibility for health and social care staffs to share patient information across health authority boundaries and organization within same municipality, which could affect the confidence of patients, to restore the confidence of patients in the system of EHR, government must educate and create awareness for patient about their rights and also let them know how their information are protected and the approaches health care providers follows.

Due to the above mentioned motivation the purpose of this research is to explore what immigrants and newcommers knows about the privacy of electronic health record system and what they know about the policies health
care providers follow to protect their privacy and data in the region Kronoberg of Sweden. From the beginning of implementation of electronic health record system patients are concerned about their medical record, they worry about health care providers losing or sharing their information with third parties, which could fall into the hands of unauthorized.

- What do immigrants and newcomers who just moved to Sweden know about the privacy of electronic health record and the policies healthcare providers follow in protecting their privacy and data?

International students and immigrants who are new in the society would be involve in my research, as they are fresh in Sweden and privacy is very important for all patients but international students and immigrants might be more vulnerable since they recently moved into the country and they deal with many new conditions and do not always understand the Swedish system e.g. health care and also their rights.

1.5 Justification

Appari and Johnson (2010) made it known that in recent years the government has been pushing for the adoption of universal electronic health record. This has made health care sector to spend more than any other sectors in recent years in most developed countries. In the planning to do this I believe there should also be awareness and lecturing for patients on how to protect their medical information and their rights to privacy, and also who will have access to their medical information. They also discussed that researchers have not done much to analyze information security risk in the health sector, despite the growing risk of security and privacy of electronic health records.
Appari and Johnson (2010) argues that medical records disclosures are one of the biggest reported breaches in the healthcare sector from the use of electronic health record system, patient information are also disclosed for research purpose in public health and health services research. They also made it known that on average of 25 million health records are lawfully disclosed for decision-making. National eHealth (2010) shows that Swedish government had invested in the health sector to promote the use of ICT and to centralized medical records. The introduction of eHealth in Sweden shows that Swedish government yearly invest into developing registry and security solutions to guarantee integrity and data protection, making new legislation to ensure the protection of patient’s data in the health and social care sector.

This shown a sign that the Swedish government cares about the protection of privacy and data of patients, which made them to invest so much into the security solutions to guarantee integrity over breach or leakage of medical information in the health sector. Though there is not any news about disclosures in Sweden or in the region of Kronoberg where my research would take place. But report and news had shown that patients around the world avoid treatment because of medical information disclosures and leaks, which makes patient to loss trust and confidence in the privacy of electronic health record, patient knowing that their health data and privacy are not secure, could lead many patients not to disclose more about their illnesses or sicknesses. Health sectors (Hospitals) need to do more to restore the confidence of patients in the system of EHR, by educating patients about their rights of privacy, how their privacy and data are protected and also creating a secure and security level for doctors and nurses who have access to patient’s data.
Fernández-Alemán et al (2013) states that according to report several countries including Sweden were concerned regarding data security and privacy of electronic health record risk. Creating a secure way of handling patient’s medical records could eradicate or reduce the risk of disclosures or medical data loss. Confidentiality, security and privacy are very important in the healthcare sector, health care workers must be aware that it is against the law to share patient’s records to third parties, leave their system unattended to when it is not protected or write passwords down. Public trust in the health sector cannot be maintained if privacy rights on medical records are weaker.

National eHealth (2010) argues the law, regulations and guidelines that govern health and social care activities; they said there is a need for safety, integrity and data protection in health sector. They also pointed out that there is a worry that sensitive personal information may end up in the wrong hands, as there is a legal possibility for health and social care staffs to share patient information across health authority boundaries and organization within same municipality. This act has made them called for urgent improvement scope on how patient information should be shared and protected.

Li (2015) argues that patient’s information disclosures could result in cybercrimes, and could have effect on the victims. So therefore, a good security measures must be put in place to make sure patient’s data are well protected. Patients are required to share information about their illnesses with health care workers (physicians) to get a better diagnosis and treatment, but if the trust is not there patient may refuses to give important information about their sicknesses as their information may be exposed or shared with third parties, which may affect them mentally. Let us think of someone living with
HIV been expose online, this would cause social stigma or discrimination in the society to the victim. Li also argues how important it is to protect and secure patient’s health data in electronic health record system due to the amount of information that flows in and out of the system. Li gave examples of information contained in medical records as, medical conditions and histories, medications, mental health, genetic makeup, sexual behavior, lifestyle, beliefs and habits. He argued all these data must remain private and secure, because unauthorized disclosure may harm the patient who the information belong to, and also patient information has high commercial value, they are targeted by unscrupulous marketers, identity thieves and corrupt organizations. So therefore, they required security and privacy.

1.6 Delimitation

The research was done in the region Kronoberg of Sweden. In order not to go out of scope of the study and the research question, the aim of the study is to explore immigrants and newcomers experience in the region, to get their point of view of what they know about the privacy of electronic health record and the policies health care providers follow in protecting patient’s privacy and data. A lot of patients do not know their rights or the importance of data privacy in the health care, millions of patients around the world avoid treatment because of lack of trust and knowledge in privacy and because they do not know their rights and also how their privacy is protected. Health care providers need to do more by carrying patients along and letting them know if their medical information will be used for experiment or the rights that protect them as patient or if they have the option not to let their information be shared with other health care centers in the region. This study will only examine the human aspect as stakeholders (users) of electronic health record system in the society. The human aspect as the knowledge of immigrants and newcomers who just arrived in the country as students are what I will be
analyzing in this study; the human aspect of electronic health record is the stakeholders that use the system. Protecting patient’s information cannot be done alone by system security only; people’s trust is also needed to get the best out of the implementation of electronic health record.
2. Literature Review

In this chapter, I will discuss the type of health records, EHRS components, the comparison of both paper-based and electronic health record, the law and policies that protect patient’s privacy about electronic health record will also be presented.

2.1 Types of Health Record Systems

Health record systems include two major types of record systems; these are paper based and electronic health record systems. Sahama, Simpson and Lane (2013) argued that health record system has been around for over five decades, and there are two major types of health record system for keeping patients records. There are paper-based health record system and electronic health record system. Health record system is used in gathering patient’s information for adequate care. Sahama, Simpson and Lane (2013) made it known that the rapid change in information technology brought electronic health record system to the health care sector. This made communication between physicians and other health care works and patients easier, through the adoption of EHRS.

2.1.1 Definition of Paper Based Health Record System

Paper based health record systems are the traditional system used in health care. Sahama, Simpson and Lane (2013) defined paper based as the physical storage of patient health records in files and stored away in cabinets in different locations, which could be complex to reach in an emergency. Coeira
(2003) stated that paper based record has more challenges and could not be considered as a proper way of keeping patient medical records.

2.1.2 Implication of Paper Based Health Record System

Problems related to paper based health record system have been reported. Sahama, Simpson and Lane (2013) describe problems related to paper based record system e.g, bad handwriting could cause mistakes in writing; paper record files could also be difficult to save or retrieve during emergency need. This could cause medical error and lead to loss of patient life. Below are more lists of challenges reported by Sahama, Simpson and Lane (2013) facing paper-based record system.

- Difficulty in accessing patients records when needed in an emergency
- Sharing patient medical information among other health care providers won’t be possible, access would be difficult
- Difficulty in organizing patient records and double recording of same records may occur.
- Error in prescriptions and medications could happen due to bad handwriting.
- Recovery of medical information may not be possible if files are lost due to fire or flood (backup)
- Difficulty in monitoring of staffs in case of data disclosure (Breach of patients privacy).
- Lack for storage space (Files might be too much beyond storage space).
2.2.1 Definition of Electronic Health Record System

Electronic Health Record System (EHR) is defined by Campanella et al (2015) as a systematic electronic collection of patient health information such as medical history, laboratory results, radiology reports, physicians and nurse’s notes; see Figure 1 below for the diagram. They also pointed out that EHR could also include a decision support system (DSS) which provides medical knowledge, reminders and helps doctors and other health care workers in health related decision-making. All these were archived through the introduction of eHealth. This introduction has reduced the error in handwritten prescription of medicines, it has also reduced the cost of maintain paper documents and it gives quick access to electronic health record when needed.

**Figure 1: Picture of Electronic health record system.**

![Electronic health record system. (Practo, 2014)](image)
2.2.3 Implication of Electronic Health Record System

There are many challenges with patient data stored in electronic health record system, confidentiality, privacy and security of electronic health records are major challenges patients are facing, and medical records could be expose and fall into wrong hands. Sahama, Simpson and Lane (2013) argue that medical data must be secure against, misuse, loss and from unauthorized access for illegal modification. They raised a concern about security of information in terms of maintaining three characteristic of information, which are: confidentiality, integrity and availability (CIA). Confidentiality, integrity and availability can be explain in a simple way as confidentiality as making sure unauthorized disclosure of medical information does not occur. Integrity is keeping the level of trust on high and making sure patients information is accurate and cannot be modified. Availability is ensuring that medical information is available when needed to authorize users (Sahama, Simpson and Lane, 2013).

2.3 The Comparison of Paper record Vs Electronic Health Records

Due from the previous research presented above, I will compare a paper based record system with electronic health record system in table 1 using Sahama, Simpson and Lane (2013).
<table>
<thead>
<tr>
<th></th>
<th>Paper record</th>
<th>Electronic Health record</th>
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<tbody>
<tr>
<td><strong>Storage</strong></td>
<td>• Files are locked up in rooms and it takes up space</td>
<td>• Electronic health record has more storage and could be accessed forever</td>
</tr>
<tr>
<td></td>
<td>• Paper record will decay somehow in the long run</td>
<td>• Big data, Storage space becomes smaller and cheaper</td>
</tr>
<tr>
<td><strong>Access</strong></td>
<td>• Paper record could only be access from one clinic at a time</td>
<td>• Electronic record could be access from multiple hospitals</td>
</tr>
<tr>
<td></td>
<td>• Difficult and complex to access</td>
<td>• Quick to access in an emergency</td>
</tr>
<tr>
<td><strong>Security</strong></td>
<td>• Unauthorized individual could break into the storage room</td>
<td>• Hackers can hack they system</td>
</tr>
<tr>
<td></td>
<td>• Record could be lost to fire or flood without recovery</td>
<td>• Difficult to access by unauthorized individual because they are password protected</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• It could be inaccessible due to power failure or system crash</td>
</tr>
</tbody>
</table>

**Explanation of the table above will follow below.**

*Storage:* This is how files are saved in paper based system; files are saved up in a room or cabinets, which take up spaces and would decay as time goes. Electronic health record system is more of the modern technology; hard drives are becoming small with bigger memory space. Files are saved in the cloud and can be access anywhere in the world with easy access.
Access: In the case of an emergency paper based system could be difficult to access; they are files and will need time to go through so much to get patient’s record. Electronic health record system, patients information could be access from different hospitals in the region or within the country, also records are quicker to retrieve in case of an emergency.

Security: Paper based record with are locked up could be access or go through by unauthorized individual, also in the case of flood or fire files will be completely destroyed. Electronic health records are safer and protected. It can also be inaccessible due to power failure or system crash.

Sahama, Simpson and Lane (2013) compared paper based health records with the electronic health record system. Paper-based is more of the physical document stored up in storage and locked up in different location, access to information in an emergency could be complex and difficult to reached, it is not centralized, medical information will be difficult to share with other hospitals, also in case of disaster like fire or flood all data might be loss and might not be recover. However, electronic health record system gives quick access for recovery and information searchable, performance reporting and public health surveillance; also health information could be exchange.

2.4 Components of Electronic Health Record System

A good electronic health record system should have the power to store patient medical information and data for a longer period of time, great interaction system between physicians, other health care works and patients, and support patient to manage and share their information. Nøhr (2006) argues that electronic health record is subdivided into components or modules, which make each component, handle different functionalities. Below are the most

- **Clinical documentation**, this side handles progress on all patients, notes and texts are entered into the system; this could be structured notes or free text.
- **Physician order entry (POE)** these entries are used for ordering diagnostic test and medication, they also use these entries to monitor drug interactions and patient allergy.
- **Booking services**, this allows patients and clinicians to be able to book appointments.
- **Communication system** this allows interactions between all stakeholders (hospitals, general practitioners (GP), pharmacies, laboratories and patients).
- **Result management** there should be a warning or an alert for abnormal result signal.
- **Clinical practice guidelines** there should be a module that manage and maintain clinical guidelines.
- **Disease management**, this system supports or manages chronic diseases, like diabetes, HIV and so on.
- **Management of security issues**, there is no complete electronic health record system without a proper security platform in place. There must be a special security measure to manage the authentication and authorization of user’s access.
- **Billing services**, electronic health record system makes it easier to track patients bills by the services provide to them by the health care providers.
2.5 Benefits of Electronic Health Record System

Scholar discuss also the benefits of EHRs, for example Fernández-Alemán et al (2013) explained that electronic health records provides many benefits, which includes reduction in cost, improved quality of care, the promotion of evidence based medicine and record keeping and mobility. There will not be a good health record system without the privacy and security of patient’s health record, to archive all this benefits EHR systems must create security measures to protect patient’s health information against loss, theft and hacking. Passarani (2013) argued that if patient do not trust the electronic health record system they might refuse to disclose all relevant information needed for their treatment and this could lead to sudden death.

Rezaeibagha, Win and Susilo (2015) explain also the potential advantages of EHR as a system that provides efficient and real time services to patients, flexibility and patient safety. They argue also that EHR create improvements in quality, easily accessible, and it is possible to share information. With all this potential benefits, there are also a number of challenges related to EHR. One example is that patient medical information requires security and privacy. Because, information is no long resides in one organization, but can be shared with third parties. This increase since most of the data is stored on servers that belong to third parties. Peel and McGraw (2013) suggested that health IT system must be reengineer to archive the full benefit of technology, prevent bad health outcomes and prevent discrimination based on health information disclosures.

2.5.1 Improved Care Quality

Improved quality depending on the use of EHRS has also been reported in research. For example Sahama, Simpson and Lane (2013) gave the potential
of electronic health record system as a system that monitor public health such as health information exchange (HIE). It has improved the quality of patients care, enhanced productivity and efficiency, also reduced the cost of patient visiting the hospital.

Electronic health record system changed the way physicians and other health care workers can access patient’s data that is quick data access to health information, reduction in medical and prescription errors, which were one of the paper-based record system problems. It also reduces the waiting time of test results. The implementation of EHRS has improved the way health work is done at the hospitals, e.g. workflow solution saved physicians from doing the same work repeatedly and gives the relief of work done where it was left the day before without losing any information. It also improved data intake and reduced labor cost (Sahama, Simpson and Lane 2013).

2.5.2 Enhance Productivity and Efficiency

Productivity and efficiency are other benefits of EHRS. Physicians that work with paper based record system find it difficult to go through loads of patient files and they spend more time completing paper work and reports. The adaptation of electronic health record system has reduced the time spent in searching for patients files. Electronic health record has giving a better access to patient chart, it also improved clinical decision making and disease management, gave health care practitioners quick access to patient medical record, it has also eliminated the need for paper chart (Sahama, Simpson and Lane 2013).
2.6 Challenges Facing Electronic Health Record System

In addition to benefits of EHRS there are also challenges to be considered. For example, Sahama, Simpson and Lane (2013) argued that, the major implication of electronic health record system is related to use with a specification on information security and privacy. They argue that the challenges are significant in sharing of medical information between health care providers and the patient, which is called shared electronic health record (SEHR). Shared electronic health record is when patient information record is no longer with one healthcare provider and the safety of the information relies on many organizations or hospitals. Soceanu et al (2015) explained the use of telemedicine and the use of smart devices for collecting and recording health information about patients raise serious challenges. These smart devices might get lost and fall into wrong hands. That is, disclosure of patient data shows the necessity for security and privacy in the health care sector. Soceanu et al (2015) discuss about privacy protection of electronic health records (EHR) where Doctors and other health care workers and patients share information between themselves. However, mobile devices are not designed to provide privacy and security for data in motion. That is, information that is shared on mobile devices is not protected against loss.

Fenz et al (2014) write about electronic health record system and the necessity of privacy and anonymity due to the potential misuse of patient data. Patient agreeing to the use of electronic health record system use and disclosing their information required privacy and trust. Muhammad, Hydari and William (2015) discuss also how the benefitting electronic health record is and how much the U.S healthcare had invested in the health information technology. They made it known that Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 has spent billions to promote
Electronic health records (EHRs) in the U.S healthcare sector to digitalize patient records. By implementing this system, they came up with a question of what is the effect of EHRs on patient safety. Muhammad, Hydari and William (2015) shed light on Patient Safety Event (PSE) related to EHRS. This means patient being harmed or unnecessarily placed at risk of harm, medical errors, system flaws, medical mismanagement and patient privacy are all concerns for EHR system risk.

Appari and Johnson (2010) explain how the US health have improved and reduced cost in the health sector by using Electronic Health Record (EHR). The US argues EHR gives healthcare quality and fast access to patient’s medical information, compare to the old paper based record system. The paper-based system could not fulfill the complicated requirements during emergency. The use of ICT devices such as smartphones has changed the means by which medical records could be accessed. Appari and Johnson (2010) highlight also the negative side of EHRS, which require adequate security measures; if care is not taking, it could leave patients exposed to economic threats, mental anguish and social stigma if their medical records are exposed to the public.

Li (2015) explain the importance and risk of electronic health record system. EHRS is a system that gives patients the opportunity to store, manage and share their personal health information for personal health maintenance and healthcare, EHRS also offers opportunities for personalized healthcare management which comes with the risk of privacy and confidentiality, where patients are worried about what could happened to their data or where it could end up? Li (2015) said for patients to have confident in EHRS researchers must address both technical and legal challenges to prevent unauthorized access and use of personal and electronic health records. As we, all know
medical record consist of personal information that could cause damages to reputation or financial losses if not well protected.

Fernández-Alemán et al (2013) made it known that health information is one of the most confidential type of personal information, therefore protecting this confidentiality is very essential if the privacy of care are to be maintained. Health care providers could seriously threaten security and privacy of electronic health records (EHR). In this case, security measures must be put in place to protect these records against theft or careless handers, who can mistakenly or intentionally exposes the information for monetary benefits or to damage the hospital reputation.

Peel and McGraw (2013) also discuss about the consequence of lack of privacy in healthcare sector. They argue EHR systems in US are not controlled by patients, but by the holders like insurer, data clearinghouse, hospitals, physicians and technology vendors. This means patient’s data could be shared with third parties without the patient’s admission. They also made it known that patient-physician relationship prevent patient from controlling the use of their own health information. For this reason patient may lack trust in physicians and this had caused over 40 to 50 million patients their health and lives every year by not disclosing their health problems to their doctors due to lack of trust of privacy.

Security and privacy related to EHRS are also discussed by Sahama, Simpson and Lane (2013) the primary concern in the aspect of privacy, which they referred to as ‘‘information privacy’’ p249. They explain it to be the ability for individual to exercise control over their personal information held by others. Information privacy concerns the collection, maintenance, use and disclosure of personal records. Who should have access to this
information? Health information are sensitive subset of personal information which they gave a list of security measures and regulation in protecting privacy and who should access the EHRS. They listed, European Data Protection Directive (EDPD) 95/46/EC and the use of technical policies like symmetric key or asymmetric key schemes, anonymity techniques in EHRS and digital signature scheme based on Public Key Infrastructure (PKI) that is staffs ID cards and keys are bound with digital certificates, which are used with PIN codes or biometric. One in eight of patients withheld information about their health because of privacy concern (Peel, 2013). He argues that allowing patient to control information they share on their EHRs could give patient some ability to decide what information they would like to share on the electronic health record system.

Appari and Johnson (2010) proposed the use of contextual access criteria on the level of information disclosures throughout national health information network. They also argued that interactive efforts are needed to provide privacy safeguards, industry-wide protection and an established national data protection authority, all this are needed to protect electronic health records against unlawful disclosures.

Senor, Aleman, and Toval (2012) made it known that protecting information privacy and security of electronic health record is very crucial and necessary in the health sector. Electronic health record system still lacks some policies to protect patient’s data, which is the primary concern of this study. From this research, I understand that legal authority that designed the electronic health record satisfies their own rights by setting up the privacy and security policies that protects the system and not so much for the stakeholders. Senor, Aleman, and Toval (2012) argued that electronic health record system designers must see beyond addressing security concerns only, they must seek
by law a personal data protection to protect every stakeholder that uses electronic health record system.

Peel and McGraw (2013) argued that it is very important to let patients decide on what information should be in their electronic health record and what medical information should be shared or give access to, especially the high sensitive ones. In other hand, Mirkovic et al (2015) argue that there are potential risks in letting patients manage their own record, as there could be self-disclosures as the result of sharing medical information with their general practitioners or other health care workers or by the use of their mobile devices. They made it known that there is high risk when patients shared data between their physicians, so therefore there is a need to let both stakeholders to know the ethical, legal and social responsibilities of using electronic health record.

Sahama, Simpson and Lane (2013) also made it known that information security is not only a technical problem, it also involves all the stakeholders, this means all electronic health record users. So therefore, technology alone cannot be used to address the issue. The threats could be the interaction between people and information systems. They made it known that there are few aspects to this interaction of information security, which are policy and practices of information management, education, training and awareness of all users of electronic health record system. They also gave information security framework that should be applied when using electronic health record system to ensure all security aspects are covered, see figure 2 below.
Applying this framework in Figure 2 while using electronic health record could help understand how medical data should be handle, also who should have access to the medical record and what level of access should be granted to each health care practitioner, who works at the hospitals. Some maybe granted read only access, while others may be allowed to read and modify records. Education and training for all healthcare practitioners using electronic health record system is necessary, to make sure confidentiality, integrity and availability (CIA) of medical records are not breached by their actions. Policy or law/acts must be implemented and physicians and other health workers must be aware of their actions. That if information is breached or disclosed, they must be aware of who will be held responsible for this actions, traceability will be needed to know which staff commits the breach. The authentication of all staffs will also be needed to enable accountability (Sahama, Simpson and Lane 2013).
Mirkovic et al (2015) also made it clear that to have a quality electronic health record system, it is a very important role to protect patient privacy and give confidentiality to patient’s health records. Millions of patients around the world avoid treatment because of lack of trust in privacy and because they know, health data is not private. As a researcher, we need to restore the confidence of patients in the system of EHR, by creating a secure and security level for doctors and nurses who have access to their data. Li (2015) also talked on how to protect personal health records; he said maintaining data consistency and integrity of EHR system will require mechanisms that protect the system as a whole. He also pointed out to have a good EHR system; EHR Information must be available to those who legitimately need it and be strictly protected from the unauthorized personnel.

2.7 Policy and Laws that Protect Patient’s Privacy and Data

Hedström et al (2011) paid attention to confidentiality, integrity and availability (CIA) of electronic health records and how important it is to protect patient personal information in the health care sector. They went further to explain CIA according to international standards ISO 27000-series (ISO/IEC, 2005) standard. They refer confidentiality to be the process that ensures information should only be access by those who are authorized to access it. Integrity as protecting patient’s information and make sure it is accurate and cannot be modified by unauthorized and integrity of electronic health records must be protected to ensure patient’s data are safe and protected. Availability is making sure the information is accessible whenever it is needed by authorized personnel.

Regeringskansliet (2009) also argues that there are exceptions to confidentiality of patient information in some cases where confidentiality can be broken without patient’s permission. Riksdagsförvaltningen (2014) state
the main purpose of Patient Data Act (1998:204) is to protect the privacy of patient against unlawful use of their personal data. This act also gives power to the authorities in decision making, to make patient data public if a crime is committed or in case of investigation. A court, law enforcement, or tax authority can demand to know if a patient is receiving treatment, also the Swedish Transport Agency may need patient information to review their suitability for having a driver’s license, or if information is needed during a forensic investigation.

Riksdagsförvaltningen (2014) argues that Patient Data Act (2008:355) was designed to protect, maintain patient data and to ensure secure and efficient handling of patient personal data while providing adequate care. The act allows digital access to patient’s electronic health record by health care provider and protects patient privacy, by letting patient decide who to access their data. The act also gives patient the right to access their own medical records; it also gives patient the right to control their data and the option to withdraw from participation, asking their data to be removed from the national registry.

According to Patientsäkerhet (2016) socialstyrelsen the national board of Health and welfare (Socialstyrelsen) is a government agency under the Ministry of Health and Social Affair, they have argued that it is necessary to hide cells values in protecting patient’s privacy and data. They argued further and quote according to chapter 24 §8 of the Principle of Public Access (2009:400) that cell values between one and three will never be disclosed. That is, patients information will not me disclosed and must be censored or marked (x).
2.8 Summary

I have featured a lot of theories, framework and factors that are relevant to the study of electronic health record system. Stated that the topic is about what immigrants and newcomers know about the privacy of electronic health record system and the policies health care providers follow in protecting patient’s privacy and data. I have covered many frameworks like types of health record systems and the components of electronic health record system, also the benefits of electronic health record system, challenges facing the implementation of electron health record and the policies and laws that protects patient’s privacy and data in Sweden in general. All these factors will be used to answer the research questions based on the output of interview and focus group results.
3. Research Paradigm, Methodology and Methods

In this chapter, I will present information about the methodological framework research paradigm, and the methods for collecting empirical data and analysis. In addition, the ethical consideration related to the study would be presented.

3.1 Research paradigm

The aim of this research is to explore immigrants and newcomers experience and what they know about the privacy of electronic health record system and the policies health care providers in the region Kronoberg of Sweden follows when protecting patient’s privacy and data. The interpretive paradigm focuses on understanding of people and their experiences, this approach will be use to perform this research. The paradigm helps to produce and understanding of the context of information system and the process whereby the information system influences and is influenced by the context (Myers, 1997). Interpretive research will give depth understanding about the patient’s experience, what they know about the privacy of electronic health record and the approaches their health care providers follow in protecting the data collected. The assumption of people having their own individual or groups beliefs to the meaning of where they live and came from would also help to give more depth understanding of how patient feels about electronic health record system and the people who have access to the information. The information gathered after the interview and focus group would be analyzed and use on the research on how to improve patient confident on electronic health record system and their health care providers.
3.2 Research Methodology

My research is based on the study of people (patient) and what they know about the privacy of EHRS and how their privacy and data are protected. Knowing these acts/laws could help to increase their confident in using electronic health record system. Qualitative research is designed to help researchers to understand people in their social and cultural contexts within which they live (Myers 1997). In addition, (Ingham-Broomfield 2015) defined qualitative research as a strategy that could be used to examine subjective human experience by using non-statistical methods. Stoop and Berg (2003) also explained qualitative method as excellent suited for understanding a phenomenon from the point of view of the respondents and in its particular social and institutional context. Qualitative in this research will give meaning to what patients knows about how their privacy and data are protected, when they tell their experience about electronic health record, knowing how important health information is and how easy it could fall into wrong hands, so therefore I will like to know what patient really knows about the privacy of EHRS and also if they know the policies the health care providers follow in protecting their privacy and data. The result gathered will give me the knowledge to know if respondents truly understand the use of electronic health record, who have access to the information and if the health care providers in the region Kronoberg are doing enough to promote the use of electronic health record and the use of 1177 platform. Quantitative research is best when collecting data in the field of research and also from more numbers of participants, the more findings the more quantity of samples, the more the quality of the result will be.
3.3 Data Collection Methods

Myers (1997) gave several methods of collecting data while doing qualitative research. Examples are: Interview, focus groups, observations, questionnaire and many more. I would use two methods for this research and they will be interview and focus group to collect information needed to answer the research questions.

3.3.1 Participant

Medicinenet (1996) defines patient as a person under health care or a person that makes use of health care services either for minor or serious issues. We are all as a whole a patient and we all use the hospital one way or the other.

The participants in my research are international university students and immigrants who study Swedish for immigrant (SFI). I choose them because international students are from different countries and background, also they are new in the Sweden and privacy is very important for all patients but international students and immigrants might be more vulnerable since they new and they deal with many new conditions trying to settle in and do not always understand the Swedish system e.g. health care and also their rights.

I have chose both male and female students between the ages of 25 -38 were selected to take part in the interview and focus group. Participants were selected based on their knowledge in the use of ICT and also they are residents and have lived in the city between six months to two years. I have selected the best among them by screening the ones who have better knowledge of Information Technology (IT) systems and services. All participants have or use the health care centers in the region.
Table 2: Data Collection methods

<table>
<thead>
<tr>
<th>METHOD</th>
<th>PURPOSE</th>
<th>SCOPE AND TIME</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus group</td>
<td>• In-depth understanding of what patient knows about the privacy of EHR</td>
<td>• 5 international students</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 60 minutes</td>
</tr>
<tr>
<td>Interview</td>
<td>• To understand what patient know about the privacy of electronic health record and the policies health care providers follow to protect patient’s privacy and data</td>
<td>• 10 semi structured questions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 45 minutes on each respondent</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 10 participants</td>
</tr>
</tbody>
</table>

3.2.2 Focus Group

The Focus group session was used to generate more empirical data from the respondents. A topic of discussion was developed by me as the group leader to collect information on the choosing topic, where participants were asked to talk about what they know about the privacy of electronic health record system and the policies health care providers follow in protecting patient’s privacy and data. Barbour (2005) defined focus group as a method which can be used to ensure that the discussed topic are easily understood by the participants and are relevant. Through focus group session, I met with group of five participants to discuss what they know about the privacy of electronic health record. Notes were taking by me as the leader of the group, through the discussion I realized that some of the respondent did not really have so much knowledge about EHR and
did not know their rights, especially when it comes to the policies health care providers follow in protecting their privacy and data. We went further to discuss who have access to this information, to my surprise some were not even sure who have access to their record.

3.3.2 Interviews

Myers (1997) made it known that interview can help researchers to be aware of participants thoughts and feelings are. Interviews are methods of collecting data while using the interpretive paradigm and qualitative research method. A semi-structured interview would be put together for the participants to get quality and firsthand information for the research. Interview would help me to find out participant’s thought and feelings, their view on the research. Interview is not naturally occurring, it is constructed by researchers and do not provide direct access to the experience of the participants (Silverman, 1998).

A semi-structured interview questions were developed to investigate patient’s knowledge about the privacy of electronic health record (EHR) and also to explore if they know the policies health care providers follow in protecting their privacy.

The interview was carried out on the 19th September 2016 and lasted for about a week. Also about 45mins time, scope was spent on each participant. Qualitative interviews were performed on 10 participants; six were males and four females from the Swedish for immigrant (SFI). Focus group was also carried out with five international male students from Linnaeus University. All respondents are students, aged between 26 -38. It was face-to-face interview and focus group. In total, I have 15 respondents and because of anonymity, I will refer to them as respondent 1 - 15.
The interviews were documented respondents wrote their answers on papers provided for them by me, also notes were taken to keeps focus on the questions and not to miss any important information due to limited time and impatient respondents. The interview started by giving each respondents the inform consent form to read, so that they can be familiar with the research topic and the goals of the study by asking each respondent if they are willing to participant in the interview. This was followed by warm up question of an introduction of knowing each participants, their age, country, occupation and how long they have lived in the city. When I noticed they are more comfortable then I moved to the next question to know the participants who are familiar and have the knowledge of how to use smart devices and internet. By knowing this I can begin to select and decide who to choose and who are qualified as respondents.

3.4 Method of Data Analysis

Lichtman (2013) explained that analysis is an ongoing process during a research. She made it known that though serious analysis could only start when all necessary data are gathered, but as soon as a researcher begin to take notes, s/he has started the process of analysis. Before a researcher can conduct analysis on qualitative research the six steps (6) procedure must be followed as Lichtman (2013) as pointed out that qualitative research do produce loads of words and data, so therefore researcher must be very careful not to lose any important points. The researcher must follow the procedures listed by Lichtman (2013) for a quality data analysis.

Lichtman (2013) argued that during preparation and organizing data lots of important points will be made so therefore it is very important for researcher to take notes as not to miss any valuable points during the
interview process. She also suggested that the interview results should be transfer into Microsoft word on a computer where one can easily read and understood them better, this method is called transcribing. He also advised that research results must have a backup copy on another drive or device in case of loss.

Lichtman (2013) also made it known that to give a meaning to data gathered on the field of research is to obtain the key concepts from the data. To archive the key concepts researcher must follow the process of coding and identifying themes. He explained that through content analysis researcher can identify important themes from coded empirical findings.

Lichtman (2013) also talked about coding analysis as an approach that help researcher to analyze the data collected from the respondents into text in other to define the similarities and differences that gives a better knowledge of the research questions or gives an answer to it. They made it known that one way of knowing that data collected are accurate is by coding, which means researcher could go back into the research field to rechecking with the respondents by checking if the themes, argument or assertions gathered from the codes are accurately matches their statements, which in my case I checked using the literature review and also check on the internet to confirm the results I got from the hospitals are accurate.
Lichtman (2013) gave six (6) steps to coding

- **Step 1: Initial coding.** I read through the results thoroughly at a time and started marking the important ones with the comment section since I have transferred it on to a computer for it to be easier to read and understand. I started to represent the important parts with phrase. Once I’m done with one, I move to the next one, till I was done with all.

- **Step 2: Revisiting initial coding.** This stage, I went back to the initial coding again, I re-read it to reduce redundant by rename all the similarities of words to one matching word, also to improve the first codes.

- **Step 3: Develop an initial list of categories.** After the previous step of modification of words (codes). I started arranging them into categories, in well-arranged manner.

- **Step 4: Modify initial list based on additional reading.** After categorizing the codes, I realized some are less important or with two similar phrases, which can be modify to one or remove as they are unnecessary to be there.

- **Step 5: Revisiting your categories and sub-categories.** After combining similar words and categorizing them, I checked again for the irrelevant ones for redundant and to removed, making sure all unnecessary similarities are out and only important codes are left.
• **Step 6: Moving form categories to concepts** *(Reflecting the meaning you ascribe to your data).* Finally, at this stage I need to define concepts from my categories. I begin to identifying the concept that has more meaning to the data I collected, just as Lichtman (2013) discuss that coding could be arranged from 80 to 100, which could later be arranged into 15 to 20 categories and could end up being 5 to 7 concepts or themes. She said the concepts must be defined they are the original findings from the analysis and the foundation of the discussion of a research. For my research to be more meaningful and also to have good concepts I would be using information from the literature review to enrich my data. Here is the list of concepts I emerged during my analysis - Policies and acts of protecting privacy, lack of knowledge, limited awareness of e-health services, lack of confidence, language barrier, trust and security.

### 3.5 Trustworthiness of the Research

This study involves conducting interview and focus group on respondents which will produce somehow loads of data, these data would be analyzed and used to answer the research questions so therefore the trustworthiness of this research must show that data gathered are right and not wrong. Also in qualitative research the trustworthiness of data collected is very important. A researcher must be neutral and hold no bias throughout the research (Johnson, 1997). There have been issues with validating qualitative research, it cannot be verified if the researcher has done the research the right way as the respondent and social setting changes as time goes by. Shenton (2004) also, talked about informant strategy, this strategy was performed by choosing a random respondent to whom that gives the results researcher is expected to be collected and addressed. Shenton (2004) argued that a random sampling
strategy provides the greatest assurance that those selected are representative of the larger group; the verification of identifying similarities of comparing the result with previous research is a very useful strategy. For example in my research higher similarities shows trustworthiness of my results.

### 3.6 Ethical Considerations

The purpose of the study is to explore the experience of patient related to what they know about the privacy of electronic health record and the policies and laws that protect patient’s privacy and data. The study does not involve medical field work, that is, it does not involves patients with health issues or serious illness, so therefore I was not invading into high sensitive part of the respondent’s privacy. But in order to carry out a qualitative research, it is very important to consider all ethical aspect. The identities of participants were protected by not listing their names in the study; they were referred to as respondent or informant 1 and so on. Smith (1995) discuss about ethics in focus group that qualitative researchers must follow and obey the rightness and wrongness of our actions in relation to the lives of participants we are studying, also the importance of these actions in relation to those who are participating. He also made it known that focus group is based on human interaction and if care is not taking participant could get too comfortable and disclose vital information.

This study will obey the ethical rules of research. I informed the participants about the research and an inform consent form was given to each participant to read and signed, see Appendix A. They were all willing to participate freely, without any force. I kept their identities and information private, during the interview and focus group session. Their information is considered highly sensitive and has been handled with great caution. They reserve the rights to withdraw the agreements of participating in an
interview, also to the information collected by me. Rock and Hoebek (2014, p.189) states that informed consent is very important when conducting a research; researchers must inform the participant of the research and what the research is involved. Failure in obtaining consent from participant may result in liability claims and risk of being sued. For these purposes, all respondents involved in the study were adequately informed of the aim of the research and made clear that they could withdraw at any time as the participation is voluntary.

3.7 Summary

In this chapter, I have chosen to use interpretive research paradigm and quantitative research methodology. Interpretive research was used because it gives a depth understanding of what the immigrants and newcomers who just moved into the society of Sweden knows about the privacy of electronic health record and the policies their health care providers follow in protecting their privacy and data. In addition, focus group and interview methods were use in collecting empirical data from the participants. In addition, the trustworthiness of the research was discussed followed by the ethical consideration of the participants, on how I kept their identities private by not mentioning their names, by informing them what the research was about and how they have the right to withdraw at any time.
4 Empirical Findings

In this chapter, I will present the empirical findings based on the methods used in collecting the data. Analysis on the research will also be presented.

In this section, I will present the findings of my research based on the empirical material gathered from the interview and focus group. These two methods were used in this study, through the methods many data were collected, and were organized and analyzed according to Lichtman (2013) six (6) steps. After analyzing theses data, they were later transformed into categories and concepts that gave answers to the research questions. The answers to the research questions will be presented together below.

4.1 Empirical Findings

The research questions were set up to get quality information from the respondents; their answers will give a better understanding and solution to what they know about the privacy of electronic health record system in general and also if they know how their privacy and data are protected by health care providers, if they ever use 1177, If they know how to manage or request for their medical information and also if they would like to know how their privacy and data are protected.

Below I will present the concepts found after the analysis of empirical materials. The concepts are listed in phrase and not in words so that the reader could have a better understanding of the main categories which was found in the study. I have managed to refined and reduce the concepts to: Approaches
and acts of protecting privacy, lack of knowledge, limited awareness of E-health services, confidence, language barrier and trust and security. The empirical findings will be presented according to these categories and concepts.

Table 3 Concepts Identified in the Empirical Material

<table>
<thead>
<tr>
<th>Categories</th>
<th>Concepts</th>
</tr>
</thead>
<tbody>
<tr>
<td>• They don’t know the protection acts</td>
<td>• Policies and acts of protecting privacy</td>
</tr>
<tr>
<td>• They do consider security and privacy</td>
<td></td>
</tr>
<tr>
<td>• Not sure how they store their information</td>
<td>• Lack of knowledge</td>
</tr>
<tr>
<td>• Not sure how their privacy is protected</td>
<td></td>
</tr>
<tr>
<td>• They don’t know their rights</td>
<td></td>
</tr>
<tr>
<td>• They don’t know if their medical information is available to access or manage</td>
<td></td>
</tr>
<tr>
<td>• They don’t access their health record</td>
<td>• Limited awareness of E-health services</td>
</tr>
<tr>
<td>• They don’t even know it is available in the region</td>
<td></td>
</tr>
<tr>
<td>• They don’t use 1177</td>
<td></td>
</tr>
<tr>
<td>• Possibility of medical records discloses</td>
<td>• Confidence</td>
</tr>
<tr>
<td>• Medical staffs having access to very high sensitive information</td>
<td></td>
</tr>
<tr>
<td>• Most important information are in Swedish</td>
<td></td>
</tr>
<tr>
<td>• Immigrants need more time to learn the language</td>
<td></td>
</tr>
<tr>
<td>• The use of multiple passwords</td>
<td>• Language barrier</td>
</tr>
<tr>
<td>• Policy and privacy laws reminder</td>
<td></td>
</tr>
<tr>
<td>• System security is not enough</td>
<td>• Trust and security</td>
</tr>
</tbody>
</table>
Policies and acts of protecting privacy: It is not only health care providers that should care about protecting medical records; it is the duty of all stakeholders, which are the users of electronic health record including the patients. They must be educated about how they should secure their privacy when using their devices. From the results of the interview, it shows that the majority of the respondents are familiar with the use of internet and ICT, because all the selected respondents use smart phones. They use the internet to search for difficult words, watch movies, read and send emails, read news. Unfortunately, the majority of the respondents do not use the internet for any medical related services, due to the lack of knowledge that such exist in the region Kronoberg. Only one respondent had visited 1177.se site to change his address and it was unsuccessful.

The results shows that majority of the respondents consider security and privacy when they are using the internet. Hence, this shows they care about their privacy by making sure the websites they visit are secure. One of the respondents explained:

‘‘I do really consider security and privacy when using the internet especially on social media, due to numbers of news and the hacking in incidents that happened everywhere off recent made me to worry about the sites I visits. I always make sure my anti-virus is on and also make sure the website I am visiting is encrypted over a secure connection.’’ – Respondent 8

A patient knowing the policies and acts/laws of which the hospitals use in protecting their privacy is very important. In addition, providing patients with the information of how their records are protected could increase their confident on the use of electronic health record system. Untrustworthiness of
patients about the hospital and the system could be very dangerous and result into so many health related issues, patients may not disclose or open up enough for their doctors and this may result in untimely death.

Riksdagsförvaltningen (2014) shows that health care, hospitals in Sweden follow the use of Data protection, and hospital rules in protecting the privacy of patients. Riksdagsförvaltningen (2014) had also showed that health care providers in Sweden follows Publicity and Secrecy Act (2009: 400) privacy rules, which are Sekretesslagen (Swedish data act) and Patientlagen (patient data act). Which means hospitals in the region does not discuss about patient to third parties. They are not allowed to look at other patient journals, than the patient they are working with, only if approved by medical principals and Etiska Kommittén (ethics committee).

The hospital has shown strength in the approaches they follow in protecting patient’s privacy. Also as part of approaches the hospital follows in protecting patient’s data and privacy, staffs logs and activities are traceable, so therefore, every activity of each staffs could be monitor and every staffs will be responsible for their act. Also, judging from the literature review it shows that former employee’s security key and passwords are deactivated when they stop working for the hospital, so therefore they do not have access to patient record once they are working for the hospital.

As it shows above the hospitals need to do more to get information about electronic health record across to every patient, it is very important for patient to have access to their records and also let them know how their data and privacy are been protected.

Lack of knowledge is an additional concept that emerged during the analysis. The majority of the respondents does not know their rights or are sure of those
who have access to their medical information and are not sure of the type of information stored on electronic health record system because they have never requested for their medical records before or ask from their hospitals what information they have about them. The majority of respondents do not know they have the rights to manage or access their records, simply because they were not advice by their hospitals, they do not even know the information is accessible.

In addition, the majorities of the respondents have never heard or knew about 1177 service until they started language school, where they were thought just the basic about it. They had never visited the site or called the number before. Even though the average of the respondents selected has lived in the city for 6 months, they do not know how to use the site or make an enquiry on it before. So the majority of the respondents do not know about the service of 1177 and they were not sure what they could do on it, because they have never visited the website. One respondent explained:

‘‘I have heard of 1177, I tried using it to change my address, but I could not get it done, it was not easy to navigate the site. I have also called to ask questions when I was sick, they were too quick to get off the phone.’’

Respondent 4

A third concept identified in the empirical material is limited awareness of E-health services. The awareness of 1177 and the privacy of electronic health record system are low according to the data gathered from the respondents during the interview. It is very important for patients to know their rights and the law/acts that protect them, which is the duty of the health care providers to let patients know their rights and the rights that protect their privacy and data. This could increase the confident of patient and could also make them to open
up more to their doctors on the issues of high risk sicknesses, it would also help them to receive adequate care they deserve once they trust and can open up to their doctors.

Another evident show that respondents were not informed or told how to manage or access their records when they join or register at the hospital. These things are very important, as it is the rights of every patient to know how to request or manage their medical record. In addition, the majority of the respondents do not know the type of information their health care providers save on electronic health record system about them. Below is an illustration of what one of the respondent told:

‘‘I was not informed about my rights to privacy and data when using the hospital for the first time. I was not informed on how to access my records and who have access to them.’’ –Respondent 3

Hence, the result shows that the majorities of the respondents is not sure or know how their privacy and data are protected. Respondents also do not know how to manage their records; they do not know how their privacy is protected by their health care providers.

Healthcare Guide 1177 was provided to public by the county councils and regions, for patient to read and make enquires about e-services for health and healthcare. But most of the respondents do not know how to use or if the web platform does exist in region Kronoberg hospitals via internet, Vårdguiden 1177.

The empirical findings had made it clear that the health care providers are not promoting E-health enough or the awareness is not reaching everyone in the
region especially those who are new in the country and region. There are platforms and facilities in some hospitals provided by the health care providers for patients to have access to their records, but not everyone knows about it. Therefore, the health care providers are not doing enough to educate patients about the use of electronic health record and their right to privacy.

Results from the interview shows that respondents do care to know how their privacy and data are protected, due to the negative news about health record disclosures and leaks. Below is a respond received from one of the respondent when asked if they care to know how their privacy is protected?

“‘Yes I would like to know how my privacy is protected, it will increase my confident and would make me not paranoid when talking to the doctor whenever I visit the hospital. There is a lot going on in the world right now, did you hear about the footballer who is HIV positive and didn’t know, he signed a new contract and did blood test it came back positive, the result was released to public and his contract was terminated.’” – Respondent 9

**The fourth concept identified in the empirical material is lack of confident:**
In the system of electronic health record, also patients not knowing what information health workers save about them could affect the confident of patient as general practitioners and other health care workers are dealing with high sensitive information belonging to patients, therefore patient confident is really needed in this situation, medical staffs could mistakenly or intentionally disclose patient’s information. Patients must trust medical staffs for them to open up about their sicknesses, for them to receive adequate treatment; if the trust is not there many patients might hide the trust and may not tell or visit the hospital to receive proper treatment. Confidentiality in health sector is very important, Physicians deals with very high sensitive information about
patients which requires adequate protection. Patient’s medical record could mistakenly or intentionally be exposed or disclosed by health care providers. So therefore patient confident is required, as they need to share information about their health freely with their doctors and nurses, so that they can get necessary treatment they deserve, but if the trust is not there patient may refuse to give important information about their sicknesses. They may think their information may be exposed or shared with third party, which may affect them mentally, because they are not sure or inform how their privacy or data are protected. A question was asked how respondents would feel if the system fails and their information was disclosed without their permission. Majority of the respondents had answered they would be disappointed and sad if the system failed. Below is a reply from one of the respondents.

‘‘I wont be happy and would never use the use the hospital again, I might even sue the hospital.’’ – Respondent 10

This responds showed that respondents will really be disappointed if their medical information is exposed or hacked and reveal to the public without their permission.

The fifth concept identified in the empirical material is language barrier:
I realized respondents are from different countries, many have lived in Sweden for over two years and could not read or write Swedish language, this could also be a problem, patient could receive important information which they cannot read and just ignore it due to the fact that they can’t read or translate it. Medical information is vital and important; patient must be able to read this information for them to know the proper way to go about getting the best care they deserve.
Sweden is one of the European countries who accepted many migrants, which most of them don’t speak Swedish or English. Patients would like to know how their privacy and data are protected and how they can manage and access their medical information but due to the language barrier it would be difficult for them to read or understand. Even if the information is available how do they read or understand these information, also because they were not informed by their health care providers on how to access or request for their record. It is impossible for them to know their rights of privacy, how they store or what information is stored about them. Health care providers must educate patients on to access or manage their record; also it is very important to let every patient to know their rights of privacy. Some of the respondents are international students who are new in Sweden and in the region Kronoberg.

This analysis had shown that international students and immigrants who just moved to the city do not know so much about their rights and the services of 1177. Health care providers in the region are not doing so much in promoting 1177 services to the new international students and the immigrants, so patients were not informed or told about how their privacy is protected when they use the health center for the first time.

The majority of the respondents knows there is a general law/acts that protects privacy in Sweden but do not know about patients data acts/laws, as they were not informed at their hospital where they receive treatment.

**The sixth concept identified in the empirical material is trust and security:** Security and trust are major crucial acts in the health sector; if patient do not trust the system or health care practitioners, or doubt that their medical information is not secure, they may not disclose the serious part of their
illnesses, which could cause untimed death. This research has focus more on the issue of (security) trust and data disclosure which has made some patients to have low confidence in the implementation of electronic health record system (E-health).

4.2 Summary

Here I have presented the empirical findings from the interview and the focus group methods, I explained further on how I selected the participants based on their knowledge. I have also presented what the participants knows about the privacy of electronic health record system and the policies health care providers follow in protecting patient’s privacy and data. In doing this, I have followed the six (6) steps proposed by Lichtman (2013). I have also presented a table of categories and concepts that answered both research questions, followed by the analysis of the concepts and supported by the quotes of the participants. I have presented the concepts in phrases for easier understanding.
5. Discussion

In this chapter, I will discuss my findings and also discuss the strengths and weakness of the hospitals from the analysis. The discussion will be based on the concepts from the analysis.

The outcome of this research will be discussed and compared with the literature reviews. This will give a better understanding of the concepts. The discussion would include results from the interview, focus group and from the data analysis that answered the research questions.

The purpose was to explore what immigrants and newcomers knows about the privacy of electronic health record and what they know about the policies their health care providers follow in protecting their privacy and data. From the literature review, I presented the problems facing implementation of electronic health record system and how it affects the confidence of patients across the world.

The study is about privacy of electronic health record and the policies health care provider’s follows in protecting patient’s privacy and data in region Kronoberg of Sweden. Sahama, Simpson and Lane (2013) made it known that privacy is the primary concern in the context of electronic health record system. Information privacy is the ability of a patient to have control over their personal data and medical information held by their health care providers. Information privacy could also be a problem in the process of collection, maintenance, disclosure and use of patient information. With patient information, unauthorized personnel could
identify an individual with their health information details. So therefore, privacy is required in the use of electronic health record to protect patient information as they use the system. The government had set up privacy laws to protect patient privacy and data. According to The Swedish Parliament act of law (1998) Data Act (1998:204) protect patient privacy and data against unlawful disclosure information. Electronic health record must be secured and protected against theft, disclosures, loss and also for patients to have more confident in their health care providers, that their medical record are safe and secure patients must know how their privacy and data are protected. Riksdagsförvaltningen (2014) also protect patient’s privacy and data from been share or disclosed with third party.

**Policies and acts of protection:** Patients are interested in knowing how their privacy and data are protected, it gives confidence to every patient how to know how and who has access to their information. The problem of patient not knowing the approaches their health care providers follow in protecting their privacy and data will lower their confidence. During the interview, majority of the respondent do not know how their privacy and data are protected and the personnel who have access to their medical information, which is very important.

Datainspektionen, (2008) made it known that health care providers in the region uses data protection acts and hospitals rules approach in protecting patient privacy, and also they have privacy rules which are total silence about patient privacy, Sekretesslagen (Swedish data act) and Patientlagen (patient data act). National eHealth (2010) also made it known that former employee’s security key and passwords are deactivate once they do not work at the hospital anymore. Also, health care practitioners use different security
level to access patient’s information. This means security access is based on position, which means senior staffs (doctors) have more security access to certain information about patient more than nurses do. Also, traceability of health care staffs is very important, this way every activities of each staffs are traceable, this will make the staffs comply and obey the policy of privacy, they are aware that if they break the rules surely it can be monitor and trace back to who or where the act was done. Sahama, Simpson and Lane (2013) talked about access level, they said access level should be based on position, where junior staffs should have read only access and seniors could have read and modify access level. They also made it known that educating staffs on how to create and change passwords are very important that sharing passwords is wrong (password management).

Hedström et al (2011) argued that some medical centers still use multiple passwords in their hospital. Multiple passwords will be very difficult for health practitioners to remember and this could lead to them writing it down on a piece of paper, which could eventually fall in the hand of unauthorized person. Single password system for all hospitals across the region would be the best option as it will reduce the risk and also stop health practitioners from writing passwords down. National eHealth (2010) explained the implemented of smart workplace which makes login into multiple computers in the hospital very straightforward and easier for staffs to remember one password that works with all the systems in the hospital, this development won’t be a bad idea also in the region Kronoberg.

The protection and security of medical records is critical in the health sector, Information and Communications Technologies have caused the challenges in which patient’s health data are confronting new security and privacy threats and security measures are required. Health records
contain personal information like name, date of birth and address. If there are no proper law regulatory and security to protect this information, it could lead to financial loss or social stigma for the victims. Li (2015) made it clear that patients are concern and losing confidence in electronic health record system, regarding the safety of their health record. For these reasons, maintaining patients trust, privacy and security are very important and also to have a successful electronic health record system, adequate security measures must be put in place by the ministry of health.

In the approach of protecting patient’s privacy and data the use of multiple passwords shows the weakness of the health care providers in the region. This could cause security breach in the hospital, staffs may not be able to memorize more than three or four passwords, and multiple passwords may result in staffs writing the passwords down on a paper, which could get lost or fall into a wrong hand, which could give unauthorized person access to patient information. In addition, the duration it takes the management to remind the staffs (health practitioners) of the policy and regulation of privacy and data acts, seems too long when dealing with high sensitive information such as patient’s medical information. In the case of people working with high sensitive information like medical records that contain patient’s personal information and diagnoses, I believe constant reminder and constant education awareness about this policy regulation on how to handle patient data should be priority of the health care providers. Also, integrating policy acts into staffs everyday activates is every important, finally, letting staffs be part of the policy making will bring them more closer to practicing it. Once a year reminder is too long and it is very risky in this type of industry. Doctors and nurses are there to save lives, in the field of their duty they may forget or work under pressure and mistakenly breach privacy.
**Lack of knowledge** is another problem facing the implementation of electronic health record system, immigrants and newcomers not knowing how their privacy and data are protected and the policies their health care providers follow to protect their privacy and data, also them not knowing who have access to their information or if they could access their medical record, all these could affect their confidence. The majority of the respondents lack knowledge on how their health care providers protect their privacy and data, also how to access or manage their medical record. Peel and McGraw (2013) made it known that it is very important to let patient have access to their health record and also decide on what information their health care providers should keep about them, especially the high sensitive ones, this will allow patients to know the types of information their health care providers keep about them.

**Lack of confidence** is another big major problem to immigrants and newcomers when it comes to confident, possibility of medical record discloses could affect patient confidence. Senor, Aleman, and Toval, (2012) made it known that confidentiality in the health sector is very important, as it the obligation of medical staffs (health care practitioners) to secure and protect patient’s privacy and data. According to the results of the interview majority do not know how their privacy and data are protected because they were not informed by their health care providers. Educating patients about how their privacy is protected and carrying patient along could increase their confidence. Appari and Johnson (2010) made it known that over 25 million patient’s information is lawfully disclosed for the purpose of health service research and decision-making. Every patient deserves the rights to know what their information is used for or will be used for, and give the chance to decide if they want to be part of it or not. Mirkovic et al (2015) also argues
that millions of patients around the world avoid treatment because of lack of trust and privacy, it is very important to let patient know who are authorized to access their data, how their privacy and data are protected, this would increase or give confidence to patient.

National eHealth (2010) in this aspect of increasing patient’s confidence, talked about the law, regulations and guidelines that governs health and social care activities must provide the safety, integrity and data protection in the health sector for all patients. This shows that the government is putting so much effort to increase patient’s confidence in the implementation of electronic health system in Sweden. Report also had it that the government invest so much in developing registry and security solutions to guarantee the integrity and data protection of electronic health record to ensure the protection of patient’s data and privacy are secured.

*Limited awareness of E-health and its privacy* is another factor affecting patient’s knowledge about electronic health record system. To increase patient’s confidence, they must know how their privacy is protected; they must also know what information their health care providers have about them. For all these to be possible the hospitals need to do more by educating each patient about the laws/acts of privacy that protect them when they join the hospital. By them knowing that they are protected, it could give them more confident to disclose more about their health condition without holding anything back, this way patient could receive adequate treatment they deserve.

*Language barrier:* Apart from the concepts related to the research question, another issue that was found having strong implication was language issue, most of the respondents were international student and
migrants from other countries who does not speak or understand Swedish language. Health care providers must provide more alternative languages on the use of electronic health record. Even though this service was available via 1177.se website, majority still did not know it exist. I will suggest maybe a welcome package should be send to each patients based on the language they speak or understand, this can be done by checking their ethnicity on the system or when they join the hospital. Another suggestion is to include health care in the syllabus of SFI.

**Trust and security:** Some of the major problem of electronic health record are security and privacy, electronic health record consist of important information about patient, which require proper security measure for protection. Senor, Aleman and Toval (2012) made it known that health care providers must protect patient’s information and privacy. Which means the protection of patient’s data is crucial. They made it known that electronic health record system designers must see beyond the issue of security system alone and must involve all stakeholders in the process of securing privacy and data. Health care providers must educate patients on how their privacy and data are protected in order to increase their confidence and to make patients trust the system of electronic health record.

Hedström et al (2011) also pointed out on how health care providers should educate and involve doctors and nurses in policymaking as a way of integrated security issues in their daily activates. Hedström et al (2011) also made it known that security policies and regulations are employees expressions of values and majority of breaches are caused by insiders, internal staffs are the most significant threat to information systems, workers can mistakenly or intentionally expose patient’s data. Workers must respect and comply with policies. Take the hospital for
instance, doctors and nurses are there to save lives and are under pressures at times, this leaves them to forget or ignore the policy of privacy and security, constant awareness about ethics, privacy policies must be thought periodically. Health care provider’s management must remind their staffs about policy and regulation of privacy and data acts, which is done yearly in most hospitals in the region. The idea of yearly reminder is too long to remind the staffs about the policies, due to how important and sensitive patient medical information is, constant educational awareness of the policies and acts are very important.

5.3 Limitations of this Research

The study focused on what immigrants and newcomers knows about the privacy of electronic health record and what they know about the policies health care providers follow to protect patient’s data and privacy. As a student and a patient myself, I tried not to influence the study and let the respondents take control of the research by answering the questions in their own unique ways.

Firstly, the respondents had shown that they lack knowledge about what they know related to the privacy of electronic health record and the policies health care providers follow to protect patient’s privacy and data. It would have been better if they know or informed on how their privacy is been protected, this would have a bit impact on their confidence. The aspect of their confidence drives the study a bit toward into IT security, which would have pushed my study out of its main scope. IT security is quite wide and under the IT securities, we have computer security and communication security, which I do not have knowledge about. My study has covered the human aspect of IT and electronic health record stakeholders. I have made it known in this study that stakeholders can not only rely on the system security alone, people’s trust are
also needed to get the best out of the implementation of electronic health record system.
6. Conclusion

In this chapter, I would present the conclusion of my research; the depth and extensive reading have done about electronic health records, the theoretical contribution and suggestions for future research.

This study has followed the normal required sections and format that was asked in the guideline, it was carried out in the region Kronoberg of Sweden; aiming to explore immigrants and newcomers knowledge related to what they know about the privacy of electronic health record (EHR) and the policies health care provider follow in protecting patient’s privacy and data. I have introduced electronic health record followed by the history on implementation of electronic health record in Sweden, have listed and explain the components that formed electronic health record system. Also in chapter 2, Table 1 of this study, I have compared the differences between paper-based record and electronic health record, to give depth knowledge of the benefits and implications of both systems.

I have also shown that today healthcare providers have involved information and communication technology (ICT) in centralizing Personal and Electronic Health Record to improve the care giving to patients. There are few challenges facing the implementation of the electronic health record system. Because of the vital information, involved, health care providers must provide adequate protection for patient health information and privacy.

The outcome of my research shows that the immigrants and newcomers who just moved into the country lack knowledge about their rights and the
policies their health care providers follow in protecting their privacy and health information. So therefore, health care providers should educate international students and immigrants who just arrived in Sweden about their rights and policies, which they follow in protecting their privacy and data. This will give them more confidence and let them be more open to their doctors and other health care workers about their sickness, which will help physicians and other health care workers give adequate care to them.

Despite all the challenges faced during this research, there were still several interesting things about the research, learnt a lot from the study, it is an eyes opener for me, I can now discuss about electronic health record system to someone who does not know about it. Through my findings, the majority of the respondents care to know how their privacy and data are protected. Health record confidentiality is very important; government should be strict about the law and policy that protects patient’s privacy. In addition, health care providers should create more awareness and educate immigrants and newcomers more on how their privacy and health information are protected. They should also reduce the reminder of their staffs about the policy of privacy, and reduce or introduce one password system in the region.

6.1 Research Contribution

There has not been previous research conducted on this same study, so therefore there is no study to compare this research with. In general, I believe this research has covered most aspect of the research questions within the privacy of electronic health record in the region Kronoberg. This research contribution has been made known what do immigrants and newcomers know about the privacy of electronic health record and the policies health care providers follow in protecting their privacy and
data. It is very important for immigrants and newcomers to know their rights, how to access and manage their records, who have the rights to access their record and also the policies the health care providers follow in protecting their privacy and data. Through this study, health care providers can now see the reason international students and immigrants do not know their privacy rights.

Another contribution of this research, is an eyes opener for anybody that doesn’t know much about electronic health record, after reading this research, they should be able to discuss about electronic health record system to someone who does not know about it and also know their rights and the policies hospitals follow in protecting patient’s privacy and data.

### 6.2 Future Research

The purpose of this study has been to explore what immigrants and newcomers knows about the privacy of electronic health record and the policies the health care providers follows in protecting patient’s privacy and data. The result of this study can be used as a foundation for future work or it can be used as a further research on information security or use as a follow up on patient confident on electronic health record system, . Future researcher could also improve the interview questions and work with more female respondents to gather more results. Future researcher could extend his/her work on national or be used in another country.
7. Reference


Castro, D., (2009). Explaining international IT application leadership: Health IT, SSRN Electronic Journal


Haahr, A., Norlyk, A. and Hall, E.O., (2013). Ethical challenges embedded in qualitative research interviews with close relatives, Nursing Ethics, 21(1), pp. 6–15


National eHealth., (2010). The strategy for accessible and secure information in health and social care S2011.023


Appendix

Appendix A

Informed Consent Form for Master Thesis

**Topic**
Exploring immigrants and newcomer’s experience of what they know about the privacy of electronic health record system and the policies health care providers follow in protecting patient’s privacy and data in the region Kronoberg of Sweden.

**Researcher**
Mojeed Adetayo-odepidan, Master’s Program in Information Systems, Linnaeus University.

**Research Purpose**
The purpose of this research is to explore what immigrants and newcomers know about the privacy of electronic health record system and the policies the health care providers follow in protecting patient’s privacy and data.

**Research Project Description**
Interviews would be conducted on respondents in order to gather empirical materials based on patient’s experiences about what they related to privacy of electronic health record system and the approaches health care providers follow on how they protect patient’s rights and privacy in region Kronoberg.
Research Benefits
As a researcher, this research will give me a better understanding about the privacy of electronic health record system and the policies health care providers follow to protect patient’s privacy and data. It will also show if the international students and immigrants who just moved to Sweden knows their privacy rights and how health care providers in the region protect their privacy and data.

Risk
There will be no risk for participant in this research, as the study does not involved in any medical elements; I am just here to explore respondent’s experiences, so I will not be collecting names. For example, sharing of your personal information with third parties is forbidden. The interviewee will remain anonymous throughout the interview and any material that may identify the interviewee or his/her affiliations in this research. Participants names will be replace with fictitious names and it will not resemble the real names. Age and gender will only be listed in the research if necessary.

Rights of Participants about Interview, focus group
Participant’s rights are reserved. S/he has the right to refuse or withdraw from the interview, focus group and questionnaire. The Interview, focus group and questionnaire are volunteer, participants can refuse or withdraw at any time s/he wants without any explanation.

Access to Empirical Material
Empirical materials will be limited to the researcher only, upon request it could be shared with the supervisor and the examiner of the research. Materials gathered during this research that may identify the participant will not be shared with any third parties.
Questions about the Research

In case, there is any question to be asked about this research or your role. Please do not hesitate to contact Mojeed Adetayo-odepidan, by email: (ma223jd@student.lnu.se).

Confidentiality

I understand and agree to the above context.

Yes □ No □

I understand my participation in this research is volunteer and I can withdraw from it any time without any explanation.

Yes □ No □

I understand my data can be requested to be deleted any time without explanation.

Yes □ No □

By signing this document, I agreed to participate in this research and permit you to use the data and information in your master thesis.

Yes □ No □

By signing this document, I agree to participate in the research A study of privacy in the region Kronoberg. Information shared with me would be used in my master thesis.

I want to remain anonymous □

Date of interview: ______________________ Place: ______________________

Participants Name: _____________________________________________

Participants Signature: _________________________________________

Researcher Name: _____________________________________________

Signature: ___________________________________________________
Appendix B

Aim of Interview and Focus Group

The interview and focus group questions were developed to explore what immigrants and newcomers know about the privacy of electronic health record system and the policies their health care providers follow in protecting their privacy and data in the region of Kronoberg. The interview and focus group questions will give a depth understanding of what respondents know about the privacy of electronic health record system, if the respondents know their rights, how to access and manage their records. Finally, if they know how their data and privacy are protected.

Interview Questions

1. Could you please state your age, country and your occupation here in Sweden and also how long you have lived in växjö?

2. Could you please explain if you use the internet and what you use the internet for, e.g. social media? Do you consider security and privacy when using the internet?

3. Please explain if you use any services related to health care services online? What type of device do you use in accessing health data? Is your mobile device password protected?

4. Could you please explain if you know or have you heard of the 1177 or have you called 1177 number before? Could you explain what you used it for or if you have an idea of what it is?
5. When using health care for the first time in the region Kronoberg were you informed about your rights of privacy and data? Were you also informed how to assess your information on electronic health record system or how to request for your medical record?

6. Please explain if you are aware that some health care providers offer patients to read their records and how to request for their medical records?

7. Please explain if you know how the health care workers (doctors and nurses) stored information about you? Do you know the type of information stored about you? Do you know who have access to the information stored in the electronic health record system?

8. Please explain if you care to know how your privacy and data held by health care providers are protected? Due to the issues of privacy on social media and other data disclosures issues across the world?

9. Different countries and organizations have different policies and laws regarding sensitive data and privacy issues. (Facebook has privacy policy, banks and other organization also uses privacy policies). Do you know how your privacy and data is protected by your health care provider?

10. Can you explain how you would feel if the system fails and your medical information exposes or leaked to public without your permission.
Declaration

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Did you do the thesis alone or in cooperation with someone? Tick one of the boxes

✔️ I am the sole author of the thesis

I declare that in my thesis, I Mojeeed Adetayo-odepidan

1. Did not re-use my previous work without referring to it
2. Did not use other work without referring to their work (e.g. course literature, scientific publications, other types of articles, web sites or lecture material)
3. Use the references and quotes in a proper way
4. Included all references and resources in a references in a correct way may be considered as plagiarianism.

I am aware that not citing and using references in a correct way may be considered as plagiarism.

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<td>M. Adetayo-odepidan</td>
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