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Layperson Perceptions and Attitudes Towards a National Electronic Health Record Introduction in Saudi Arabia

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LAYPERSON PERCEPTIONS AND ATTITUDES TOWARDS A NATIONAL ELECTRONIC HEALTH RECORD INTRODUCTION IN SAUDI ARABIA

by

Jwaher Abdullah Almulhem

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ABSTRACT

LAYPERSON PERCEPTIONS AND ATTITUDES TOWARDS A NATIONAL ELECTRONIC HEALTH RECORD INTRODUCTION IN SAUDI ARABIA
by
Jwaher Abdullah Almulhem

The University of Wisconsin-Milwaukee, 2017
Under the Supervision of Dr. Timothy B Patrick

Introduction: Since patients and the general public may interact with a national electronic health record (EHR), including them during implementation of an EHR is important. Such acceptance has been documented as one of the critical areas in the development of a national EHR. However, only a few studies have considered public perceptions and attitudes regarding use of their health information in a universal EHR. This is the first study that concentrated on Saudi patients and citizens' attitudes regarding a national EHR. . **Objectives**: The purpose of this quantitative study was to understand perceptions and attitudes regarding the introduction of a national EHR among the Saudi citizenry. **Methodology**: This study used a cross-sectional survey, which was designed based on a literature review and interviews with a small subset of the target population. The final survey was distributed by hand as well as through the internet. **Analysis**: The data was analyzed by conducting descriptive, bivariate and logistic regression tests. **Results**: Most of the Saudi citizens supported the development of a national EHR system, which might be used for several services, such as healthcare, health services planning and health research. Twelve percent of respondents reported being undecided in their view and only 2% of them would be opposed to such a system. In terms of accessing health records in a national EHR, most were in favor of accessing their complete record. The study results also highlighted that more than 70% of respondents would be concerned about the security of their health record if it were to become part of a national EHR. The results also revealed significant differences in levels of support depending on sociodemographic characteristics. Working in health related jobs and level of education were important factors related to level of support for the development of a national EHR. Furthermore, it indicated that there is no significant relationship between preferences for access to a national EHR and demographic, education and health related characteristics.

Conclusion: These findings support the need for expediting the incorporation of health information technology, especially an EHR in healthcare organizations in Saudi Arabia. Making a national EHR as an optimal goal before adoption of a local EHR in each healthcare institution will help to facilitate the complex implementation. Findings of this study can be generalized and extrapolated to other societies that have similar cultural factors. Furthermore, the results potentially benefit the policy makers in Saudi Arabia.

Keywords: national electronic health record, unified electronic health record, Saudi Arabia citizens, support level, EHR requirements, EHR concern.

To my husband, Mr. Abdulaziz Aldossari,
and my parents, Mr. Abdullah Almulhem and Mrs. Fawziah Almulhem,
A special thanks to my supervising professor, Dr. Timothy B. Patrick

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LIST OF ABBREVIATIONS

EHR	Electronic Health Record
PHR	Personal Health Record
MOH	Ministry of Health
CPOE	Computerized Physician Order Entry
CDS	Clinical Decision Support
HIE	Health Information Exchange
HII	Health Information Infrastructure
CCHIT	Certification Commission for Health Information Technology
NHS	National Health System
HIPAA	Health Insurance Portability and Accountability Act
HITECH	Health Information Technology for Economic and Clinical Health
GP	General Practitioner
PHC	Primary Healthcare Center
SCR	Summary Care Record

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Chapter I: Introduction

"The practice of medicine is inextricably entwined with the management of information" (Cimino, & Shortliffe, 2006, p. xiv). Ongoing advancement of information technology and an increasing amount of medical information necessitate the adoption of electronic health records (EHR) instead of traditional paper records. However, an EHR is not an electronic version of a paper health record. The former has more functional capabilities, as presented in table 1.1 (Gillies & Holt, 2003; Shortliffe & Cimino, 2013). Realized benefits of using EHR are well documented in the literature; such as improving patient care, enhancing access to a patient's chart, and alerting healthcare professionals about potential medication errors (King, Patel, Jamoom, & Furukawa, 2014).

Table 1.1: Functional comparison between the electronic health record and the paper-based version (Gillies & Holt, 2003).

Function	Paper record	EHR
Availability	One location	Multiple
Security	Low	High
Consumer control	Low	High- if desired
Data	Difficult to extract	Should be easy to extract
Durability	Low	High
Duplication of records	Yes	No – can all be linked
Duplication of tests	Yes	Rare
Audit trail	No	Yes
Patient interaction	None	Full – if desired

The focus of this study is on the benefits of, and the need for, patient interaction with the EHR. The greatest impact of an EHR may be its potential to motivate patients' contribution in their own care. This interaction could occur in several modalities, including accessing their medical records online, learning about their health conditions, communicating with physicians, and adding more information to the record itself (Tsai & Starren, 2001). Since patients and the public in general interact with EHRs, including them during implementation is important. Acceptance of an EHR among healthcare providers and other professions has been studied considerably in the literature. However, few studies have considered patient acceptance of an EHR (Luchenski, et al. 2012).

Several countries have initiated the development of a national EHR owing to the fact that patient's healthcare is provided from numerous healthcare organizations. During development of this national project, patient and general public acceptance should be examined. Such acceptance has been documented as one of the critical areas in national EHR development (Deutsch, Duftschmid, & Dorda, 2010). Yet, only a few studies have considered public perceptions and attitudes regarding use of their health information in a universal EHR (Luchenski, et al. 2012).

National EHR System

It is important to recognize that patients usually receive health care from various healthcare providers. This necessitates linking EHR systems between different providers. Such integration is required to create interoperable EHR systems that includes a digital repository of patient health information from different healthcare organizations. Creating interoperable EHR systems will help to develop a national EHR system. According to Rashbass, "[The integrated EHR] will change the everyday practice of medicine both for the individual and the population, but it will also revolutionize clinical research" (2001, p. 1769). Having a national EHR system aids in informing consumers about their health status. Healthcare payers can benefit from such systems by decreasing duplications and errors. National EHR benefits also extend to include public health agencies and medical research (Brailer, 2005). In a recent study, Papoutsi and colleagues (2015) studied patient and public opinions regarding national EHR implementation in the UK. The ultimate benefit from most participants' viewpoint was enhancing healthcare provision and patient treatment, ranging from emergency response to chronic disease management. More specifically, they indicated that increasing information sharing would lead to greater efficiency in the diagnostic process and the avoidance of redundant information gathering such as medical histories. Chen and his colleagues (2009) examined the impact of implementing a comprehensive EHR system in ambulatory care between 2004 and 2007. The study found that the total office visit rate decreased by 26.2 percent, the adjusted primary care office visit rate decreased by 25.3 percent, and the adjusted specialty care office visit rate decreased by 21.5 percent after implementing an integrated EHR in one Kaiser Permanente region.

Several initiatives have been introduced to develop a national EHR in different countries, such as Canada (McGinn et al., 2011), the UK (Sheikh et al., 2011) and the USA (Hiller et al., 2011). All these initiatives have a common goal of "(making) elements of a patient's health record … accessible across different regions and to all authorized providers, with the ability to send messages (like reports and discharge summaries) across the system securely." However, each initiative has adopted different models to implement a nationwide EHR. In the US, a bottom-up approach has been used, which maintains existing local health systems and relies on the interoperability standards to facilitate the exchange of patient information. The opposite approach, a top-down approach, has been adopted in England. This approach aims to develop a single shared electronic record through replacing the existing local health systems with a centrally-managed system that enables healthcare providers to access and add information. A middle-out approach, which has been used in Australia, includes central support for the development of national standards, as well as motivation incentives at a local level to encourage clinical providers’ compliance with standards (Coiera, 2009, p. 271).

Personal EHR

Within the EHR concept, patients can manage their health information by using a personal health record (PHR). PHR is defined as ‘‘An electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment.” (Tang, Ash, Bates, Overhage, & Sands, 2006, p.122). PHRs may be categorized by different approaches, ranging from standalone to tethered applications. The standalone approach means that PHR is not linked with any other system and the individual develops his or her PHR by using commercial applications. On the other hand, the tethered PHR enables an individual to access his or her health information, maintained in an EHR system of healthcare institutions. Sometimes, an individual may input additional information that may or may not be included in the provider’s EHR (Tang, Ash, Bates, Overhage, & Sands, 2006). The standalone PHR approach has been suggested as a solution to solve interoperability problems between different EHR systems by developing a single source for individual health information (Henriksen et al., 2008). However, maintaining an up-to-date standalone PHR for individuals is impractical. Also, it is unreliable to consider a standalone PHR that relies only on patient input as a main channel to exchange medical record data among health care institutions (Tang et al., 2006).

A tethered PHR enables patients to access their medical records electronically. Such access has resulted in several benefits; such as, increasing patient knowledge about their own health care and relevant medications. Also, patients can enhance accuracy and completeness of their medical information by checking the accuracy of available information and implement modifications if errors have been identified. Providing appointment scheduling and screening reminders helps patients stay current with their health status (Pyper, Amery, Watson, & Crook, 2004a). Other potential benefits are improving communication between patient and healthcare providers and enhancing healthcare decision-making (Pyper, Amery, Watson, & Crook, 2004b). In a randomized controlled trial, congestive heart failure patients had electronic access to their medical records. The findings indicated that this access was correlated with an adherence to physician advice and led to overall satisfaction with doctor-patient communication (Ross, Moore, Earnest, Wittevrongel, & Lin, 2004).

Saudi Arabia and EHR

In Saudi Arabia, the adoption of local EHRs has increased considerably. However, there are variations in the rate and level of EHR adoption between hospitals and between regions. In Riyadh, Aldosari (2014) surveyed 22 hospitals and found that 50% of the hospitals had adopted fully-functioning EHR systems, eight hospitals (36%) had systems that could be described as works in progress, and three (14%) had not implemented EHR system at all. Furthermore, the Saudi Ministry of Health (MoH) launched an e-Health Strategy which involves creating interoperable, patient-centric health records, available at any point of care, to authorized users (Ministry of Health, 2011). In order to create an e-Health strategy, the MoH allocated 4 billion Saudi Riyals (1.1 billion USD). In 2011, an Information and Communication Technology team selected by the MoH to create a 10-year e-Health strategic plan aims to enhance the Saudi healthcare system and its services (Hasanain, Vallmuur, & Clark, 2014).

Statement of the Problem

Involving patients and the general public while implementing a national EHR is critical because they will play an active role in accessing, entering and managing their health information. However, several studies have concentrated on physicians' and other professions' acceptance of EHR. These studies have considerable results within the profession, but the public has not been considered sufficiently. In fact, general population acceptance was recognized as one of the critical areas in national EHR development (Deutsch, Duftschmid, & Dorda, 2010). Only a few studies have considered public perceptions and attitudes regarding the use of their health information in a universal EHR (Luchenski, S. et al., 2012). Such studies will be important to understand public expectations and needs in a national EHR, which may help in the successful implementation of future national projects. Moreover, it is vital to recognize patient and citizen perceptions and concerns in advance to facilitate EHR implementation by informing policy makers about such studies' findings (Hoerbst et al., 2010).

Furthermore, it is important to understand that physicians, other health care professionals, administrators, and patients have distinctive perspectives on the EHR development process that should be taken into account. Participation of end-users in the selection and planning phase has been mentioned as a unique factor among physicians. Other healthcare professionals focus more on factors such as: evidence regarding the benefits of EHRs, support and promotion of EHsR by colleagues, and various ethical matters. On the other hand, autonomy and patients' attitudes and preferences towards EHRs were uniquely cited by patient studies. Also, the most cited factors affecting EHR implementation are different depending on user group. With physicians and other healthcare professionals, studies mostly cite design and technical issues, cost, and perceived usefulness. On other hand, perceived usefulness, privacy and security concerns, accuracy, risk-benefit equation, motivation to use EHR, and patient and health professional interaction were cited as factors in patient studies (McGinn et al., 2011).

Hoerbst, et al. (2010) analyzed citizens' knowledge and expectations about the concept and contents of an EHR among Austrian and German populations. This study found that both populations had a positive attitude towards the introduction of an EHR, but shared certain concerns such as data protection. Chhanabhai and Holt (2007) examined the public's perception of electronic systems security and reported how their perceptions potentially shape the building of stronger systems in New Zealand. The findings of the study indicated that the consumers were prepared to accept the EHR; however, they were highly concerned about the security and privacy of the EHR system.

Maintaining patient privacy and confidentiality is crucial within the patient—physician relationship. Before revealing sensitive information, the prospective patient has to be certain that his or her information will not be disclosed to unauthorized users. Otherwise, patients may not reveal such information or may not seek medical treatment (Sankar, Mora, Merz, & Jones, 2003; Whiddett, Hunter, Engelbrecht, & Handy, 2006). According to Whiddett and colleagues (2006), three main factors have affected the patients' attitudes toward sharing their information. Regarding the identity of the receiver, which is the first factor, the patients were expected to share their information among health professionals; however, they were reluctant to distribute it to other parties, such as administrators, researchers or other government entities. The second factor is the level of anonymity. Type of information has also effected the respondents’ attitudes. Respondents, perhaps understandably, were more willing to share unidentified information. The study indicated that respondents were unwilling to share their sensitive information with anyone other than their healthcare provider.

The Need for the Study

As mentioned above, the Saudi MoH has considered launching a nationwide EHR as a part of the Saudi eHealth Strategy. Also, several studies have been conducted to illustrate physicians’ and other health professions’ attitudes toward an EHR and its acceptance in Saudi Arabia (Alharthi, Youssef, Radwan, Al-Muallim, & Zainab, 2014; Asiri, AlDosari, & Saddik, 2014; El Din, 2007; Khudair, 2008). However, perceptions and attitudes of EHR among future users, are, by definition, unknown. Although some studies have been conducted among specific populations, such as the Austrian and German ones, the Saudi population has different social and cultural factors that may have an impact on public perceptions of national EHR and privacy concerns.

To the best of our knowledge, this is the first study that focused on national EHR perceptions and attitudes among Saudi patients and citizens. Findings of this study can be generalized and extrapolated to other societies that have similar cultural factors. Furthermore, the results will potentially benefit the policy makers in Saudi Arabia. Implementation of a nationwide EHR should be carefully construed to address and alleviate any public concerns.

Purpose of the Study

The purpose of this quantitative study was to understand perceptions and attitudes regarding the introduction of a national EHR among the Saudi citizenry. The objectives of this study were to:

- Investigate public knowledge regarding national e-Health strategy.
- Identify the support level of a national EHR among patients and the general population.
- Identify public acceptance about accessing their own records in a national EHR
- Specify association between support level and demographic, health, education characteristics.
- Determine association between Saudis who want to access their record and support level, demographic, health, education characteristics.
- Recognize needed EHR functionalities from a public perspective.
- Determine public concerns and fears.
- Determine relationship between security concerns and degree of support for a national EHR.

Definition of Terms:

Electronic health record (EHR): repository of electronically maintained information about individual's health status and health care, stored such that it can serve multiple legitimate uses and users of the record (McDonald, Tang, & Hirpcsak, 2014).

Personal Electronic health record (PHR): an electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment (Tang et al., 2006).

National Electronic Health Record: an electronic health record that stores everything about individual's health and the healthcare received from birth until death. Electronic health records would bring together all separate files into one record, whether stored on paper or a computer, in all of the different locations where healthcare is received (Luchenski et al., 2013).

Complete electronic health record: an EHR that includes detailed health information (Luchenski et al., 2013).

Summarized electronic health record: an EHR that includes specific purposeful documents such as prescriptions, medications, and test results

Partial electronic health record: an EHR that includes only information limited to a specific purpose which helps healthcare professionals to provide needed healthcare.

Attitudes: the probability that a person will show a specified behavior in a specified situation (Schwarz & Bohner, 2001).

CHAPTER II: Literature Review

Nationwide EHR Development:

According to the Healthcare Information and Management Systems Society (HIMSS), EHR is defined as "a longitudinal electronic record of patient health information generated by one or more encounters in any care delivery setting" (n.d.). Some researchers have considered EHR systems as a trans-institutional digital repository that contains individual health data from birth to death (Hoerbst, A., et al. 2010; Shortliffe, & Cimino, 2013). Comprehensive EHR systems have five components, including; a unified view of patient data, computerized physician order entry (CPOE), clinical decision support (CDS), access to medical information resources, and reporting and communication tools (Shortliffe, & Cimino, 2013). However, CDS, CPOE, and health information exchange (HIE) are the main functionalities that have the potential to simultaneously improve healthcare quality and decrease cost (Menachemi & Collum, 2011). CDS is a computerized system which aids healthcare providers in decision-making regarding care provided to patients by providing up-to-date medical knowledge that is relevant to a patient's condition, reminding healthcare providers about any possible drug interactions and adverse events, as well as presenting patient information along different viewpoints that facilitate decision-making. CPOE helps to reduce errors and costs by enabling healthcare providers to enter orders electronically instead of manually writing them. HIE is the process of making patient information accessible to different healthcare institutions (Menachemi & Collum, 2011; Shortliffe, & Cimino, 2013).

Benefits of using EHR have been documented considerably in the literature. The realized advantages may be categorized as clinical, organizational, and societal outcomes. Enhanced adherence to evidence-based clinical guidelines has been realized from using EHR systems that are particularly integrated with CDS tools. Also, EHR helps to reduce waste of resources such as redundant diagnostic testing. Both CDS and CPOE have decreased the number of critical medication errors. From an organizational perspective, using EHR has resulted in increasing revenue and improving cash flow in terms of facilitating charge capture in a timely manner, decreasing billing and coding errors, and reminding patients of their appointments, routine examinations and tests. Enhancing organizational efficiencies also can result from decreasing the number of personnel to maintain paper records, costs of paper record supplies and chart pulling. Having patient data in electronic format helps also to conduct medical research and improves public surveillance of population (Menachemi & Collum, 2011).

On the other hand, implementing EHR has created several disadvantages among healthcare organizations. Financial challenges usually have been associated with EHR implementation. Implementation cost not only involves purchasing the EHR system, but also buying and installing of hardware, converting currently used paper records to electronic format, and training end-users. The cost of an EHR system also includes ongoing maintenance costs in terms of replacing hardware, upgrading software, and continuing training of users. Short-term losses of user productivity resulting from the learning of new systems and disruptions of work-flows are other drawbacks of EHR implementation. Since patient information can be shared electronically, privacy and confidentiality breaches have become a concern for patients. To reduce this burden, congressional legislation has made such violations more difficult; such as the Health Insurance Portability and Accountability Act (HIPAA). Other unintentional negative outcomes have also resulted from using EHR; such as a rise in medical errors because of inadequately designed user interfaces or improper end-user training (Menachemi & Collum, 2011).

Since patients receive medical care from different healthcare institutions, continuity of care may be affected when each institution employs its own EHR system. Continuity of care is defined as the providing of continuing health care in several health care settings (Anderson & Helms, 1993). Warner (1995) and his colleagues indicated that continuity of care can be implemented by developing a complete EHR that linked the University of Utah hospital with 30 specialty and subspecialty clinics. The goal of this project was "to provide common access to data on any patient needed to provide continuity to the care process where ever it occurs" (p.152).

Initiating health information infrastructure (HII) is an essential enabler that helps healthcare providers to access up-to-date and complete information regarding each patient. This facilitates making informative decisions about provided care. The ultimate vision of HII is "comprehensive patient information when and where needed" (Shortliffe & Cimino, 2013. p. 423). Two main architectures have been proposed, including; institution-centric and patient-centric approaches. Institution-centric architecture is illustrated in Figure 2.1. This approach is most commonly used when each record is stored where it is created. As a result, a central index about where to find particular patient information should be developed. This approach works in the following way (Shortliffe & Cimino, 2013):

1. The clinician EHR system requests all the patient records from HIE. The index stores information about this request for future query.
2. Queries are sent to all EHRs based on prior care locations generated from the index.
3. All prior care EHR systems respond by sending patient's record to HIE.
4. All returned records are assembled and transmitted to clinician EHR system.
5. New information about the patient is maintained only in clinician EHR.

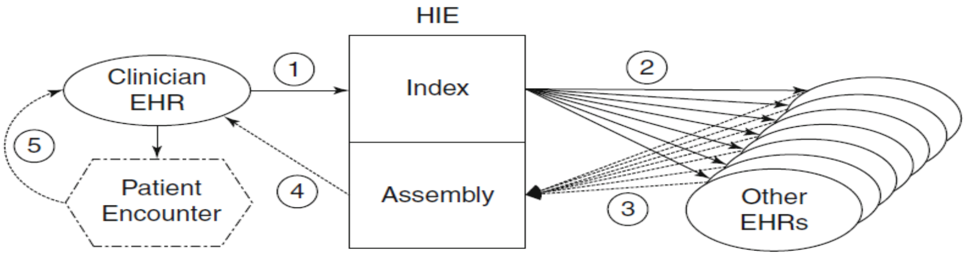


Figure 2.1: Institution-centric architecture of HII (Shortliffe & Cimino, 2013).

The second architecture is a patient-centric or health record banking (HRB) approach, which is simpler than the first one. A health record bank is an independent institution that is responsible for developing a protected repository used to collect and preserve a person's health and medical records from several healthcare organizations along the course of a lifetime. Also, it enables individuals to have full control over his or her records. This architecture solves many problems in implementing HII and offers many more advantages in terms of cost, simplicity and privacy compared with institution-centric architecture. A comparison between two approaches is presented in Table 2.1. The workflow of this approach, which is presented in Figure 2.2, includes (Shortliffe & Cimino, 2013):

1. Clinician EHR system sends a query to HRB prior to a patient's visit.

2. HRB sends all prior requested patient's records to clinician EHR.
3. All new information about patient is stored in clinician EHR and sent to HRB after each patient visit.

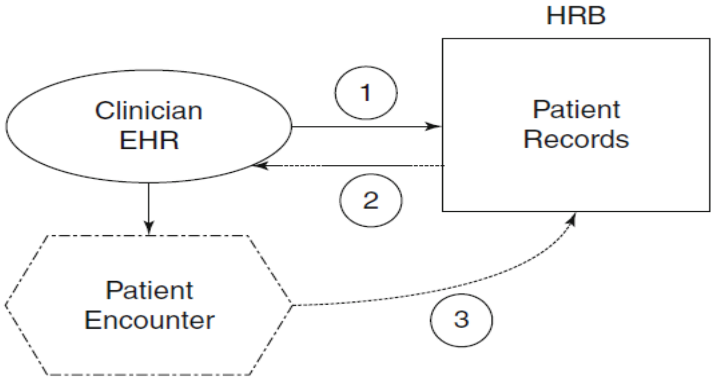
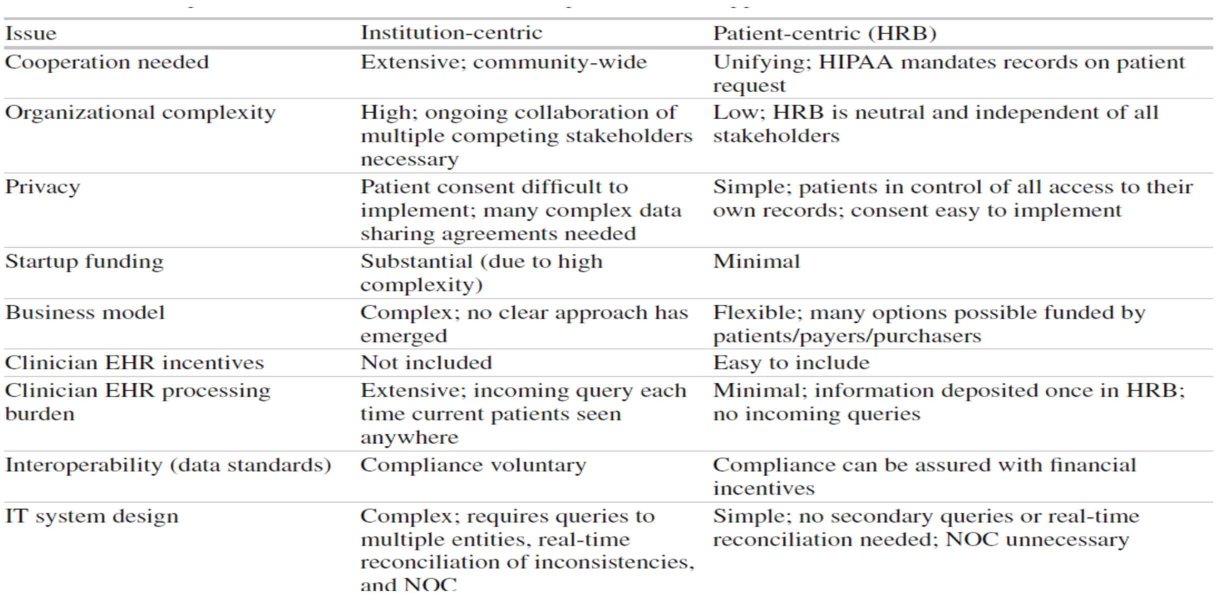


Figure 2.2: Patient-centric architecture of HII (Shortliffe & Cimino, 2013).

Table 2.1: A comparison between institution-centric and patient-centric architectures (Shortliffe & Cimino, 2013).



Issue	Institution-centric	Patient-centric (HRB)
Cooperation needed	Extensive; community-wide	Unifying; HIPAA mandates records on patient request
Organizational complexity	High; ongoing collaboration of multiple competing stakeholders necessary	Low; HRB is neutral and independent of all stakeholders
Privacy	Patient consent difficult to implement; many complex data sharing agreements needed	Simple; patients in control of all access to their own records; consent easy to implement
Startup funding	Substantial (due to high complexity)	Minimal
Business model	Complex; no clear approach has emerged	Flexible; many options possible funded by patients/payers/purchasers
Clinician EHR incentives	Not included	Easy to include
Clinician EHR processing burden	Extensive; incoming query each time current patients seen anywhere	Minimal; information deposited once in HRB; no incoming queries
Interoperability (data standards)	Compliance voluntary	Compliance can be assured with financial incentives
IT system design	Complex; requires queries to multiple entities, real-time reconciliation of inconsistencies, and NOC	Simple; no secondary queries or real-time reconciliation needed; NOC unnecessary

Models of Developing a National EHR

Several countries have developed nationwide health information infrastructures. The goal of these approached is to enable EHR to be accessible to all authorized providers across different regions in the country and sending health data securely between different providers. Improving the efficiency of healthcare organizations is one of the expected benefits of implementing a national EHR by improving data-sharing, availability, security, and quality. Also, it has the potential to increase patient involvement and saves worker time. Two opposite approaches have been developed in the USA and England. A bottom-up approach has been used in the USA, while England has applied a top-down approach (Coiera, 2009; Morrison, Robertson, Cresswell, Crowe & Sheikh, 2011).

In the bottom-up approach, healthcare organizations can use any EHR system, however, they are required to ensure that what they used and any newly acquired systems meet interoperability standards. Regional HIE is formed by cooperations of different healthcare providers' systems in a specific geographical area. These regional HIEs are predicted to form the nationwide HIE. HIE provides virtual views of patient records through collecting records from regional systems. This approach satisfies the local need for healthcare providers, and avoids the costs of purchasing new systems and training employees (Coiera, 2009; Morrison et al., 2011). One of the possible barriers of this model is the risk of acquiring an EHR system that does not comply with interoperablility standards to support the exchange of data between different healthcare settings (Morrison et al., 2011). This problem has been addressed by the Certification Commission for Health Information Technology (CCHIT), which is an independent, not-for-profit organization. The main responsibility of CCHIT is to develop credible, efficient and sustainable certification programs for EHRs (Health Information Technology | CCHIT, n.d.).

Since the English National Health System (NHS) is a nation-scale, single-payer health system in the UK, the top-down model that involves centralized management has been used. Within this model, the nationwide EHR is implemented by creating a single-shared EHR that is centrally maintained. This system will enable all healthcare providers to add or read information from each other. Implementing this approach requires exchanging the local EHR system, which did not meet the national standards, with a new one that complies with these standards. However, the new system may not meet all the local needs of a healthcare setting which require additional cost for employee training, and necessitate additional effort to modify the workflow (Coiera, 2009). The large scale of nationwide implementation, the various stakeholders' interests, and healthcare organizations' variable preparedness for change have resulted in a slowing down of the national EHR implementation in England (Robertson et al., 2010).

A third model that is sandwiched between these two polarized approaches is the middle-out model. This approach has been adopted in Australia. In this model, the role of the government does not include requiring immediate standards compliance; however, it is responsible for paying the development process of national-scale standards. Furthermore, the government offers incentives and support that motivate healthcare providers to install standard-compliant EHR systems. As a result, healthcare providers are able to incrementally make their EHR systems comply with national standards. The cost for implementing this model is quite possibly equal to the cost of bottom-up HIE implementation; however, the end result is the enabling of more information sharing. According to Coiera (2009), “the middle-out approach seems the only rational way to do” the national scale EHR (p. 273). It is important to recognize that countries currently adopting top-down or bottom-up models can convert to the middle-out model at any time in order to accomplish national EHR systems. For example, the Health Information Technology for Economic and Clinical Health (HITECH) Act has been introduced in the USA in order to offer motivation payments under Medicare and Medicaid for eligible professionals and hospitals when they install, upgrade, or prove meaningful use of a certified EHR system. The beneficiaries of the incentive payment received up to $43,720 over 5 continuous years under the Medicare EHR Incentive Program beginning in 2011. Under the Medicaid EHR Incentive Program, eligible professionals may obtain up to $63,750 over 6 years (CMS, 2015).

Patient’s Right to Access EHR

Currently, patient access to their healthcare data has been facilitated through increasing adoption of health information technology systems. Using traditional paper records may limit patient access to their healthcare data because each access requires obtaining authorization (Ferreira, et al. 2007). Increasing the adoption of EHR may help to simplify patient access to their records (Cimino, Li, Mendonça, Sengupta, Patel, & Kushniruk, 2000; Masys, Baker, Butros, & Cowles, 2002). Patients’ accessing medical records has been regulated in several countries such as the USA and the UK. HIPAA gives the patient the right to view and obtain copies of their records, and request amendments (Department of Health and Human Services, 2001). In the UK, persons, or their authorized representatives, have the right to request access to specific personal data held about them, including health records under the Data Protection Act 1998

(DH Policy and Planning Directorate, 2010). Lack of knowledge about this right and difficulty in the requesting process have led to a reduction in the number of people obtaining copies of their records (Fowles et al., 2004).

Since 1973, Shenkin and Warner recommended that patients should regularly be given a “…complete and unexpurgated copy of all medical records, both inpatient and outpatient [that is] issued routinely and automatically to patients as soon as the services provided are recorded.” (Michael, & Bordley, 1982, p. 432). However, several healthcare organizations provide PHR portals, which may not include the full medical record. These portals usually include the following information; problem lists, procedures, main diseases, allergy data, family history, immunization, medications, social and lifestyle history, and laboratory tests (Tang, 2006). Furthermore, it may include protected communication tools such as appointment scheduling, prescription refills, and secure emails (Pagliari, Detmer, & Singleton, 2007). Endsley and colleagues (2006) have clarified that there are three types of PHR, including: provider-owned digital summary, a patient-owned program, and a portable digital file. The first form can be read by the patients, however the healthcare provider supplies, controls, and maintains the information provided to them. A patient-owned program allows patients, or healthy individuals, to register, control and maintain their own health information. This type of program contains health information such as patient concerns, problems, symptoms, and emergency contact information. A portable digital file involves designated, clinically related health data that can be managed, secured and transferred by using devices such as smart cards and cellular phones.

Patient Attitudes about National EHR, and Accessing Their Health Record

Assessing patients' attitudes regarding national EHR and ability to exchange health data between several healthcare providers is very important because patients and the public in general are part of the potential users of such a system. A recent study explored patient and public opinions in the UK about the national EHRs utilized in healthcare, research and policy. The results showed that the majority of respondents expressed their overall support, 27.9 % of them were undecided and only 9.6% were not supportive of the national EHR. When the participants were asked about the use of the national EHR for specific purposes, the level of support increased. Almost 90% of them preferred to use their data for healthcare purposes. Approximately 80% of participants supported using it for health services policy and planning, and 81.4 % wanted use for research purposes. It is important to note that 59.7 % and 67.1 %, would like to eliminate their personal identifiers for health policy and research, respectively (Papoutsi, 2015). Hoerbst and colleagues (2010) conducted a study to explore Austrian and German citizens' knowledge and expectations about the concept and contents of an EHR, which was considered as "trans-institutional". The majority of respondents had positive attitudes regarding electronic exchange of health-related data between health care providers, which is one of the essential functionalities of an EHR. A study explored patients' perceptions regarding electronic sharing of their health information as part of a community-wide electronic health information exchange. The results showed that 88% of participants would agree to participate in the system of health information exchange (Simon, Evans, Benjamin, Delano & Bates, 2009).

Since patients have the right to access their EHR, several studies assessed patients' attitudes regarding this issue. Hassol and colleagues (2004) conducted a study to evaluate patients' values and perceptions regarding web-based communication with their primary care providers within the context of accessing their EHR. This system permits patients to access certain parts of their EHR and communicate electronically with their healthcare providers. They concluded that patients' attitudes were positive about the use of web messaging and online viewing of their EHR. The majority of respondents believed that the system was easy to use and that their medical record information was complete, accurate, and understandable even among adults whose education was limited to four years of high school or less. Honeyman, Cox, and Fisher (2005) conducted a study to examine the attitude of patients attending a primary care setting regarding their access to EHR. The study found that patients were more interested in accessing their electronic than their paper record. Another study indicated that most patients who accessed their EHR described navigation between sections of EHR as a very easy process and the EHR content was easily understood. However, a very brief verbal explanation was necessary for patients who had little or no computer experience (Pyper, Amery, Watson, & Crook, 2004a). Patients' attitudes regarding the provision of access to their doctors' notes was studied by Delbanco and colleagues (2012) in a quasi-experimental trial. Before and after the intervention, patients were keen and almost all of the respondents suggested that this opportunity should continue.

In fact, PHR portals usually do not include clinical notes due to the fact that patients may need more explanation in order to understand these notes. Also, these notes could include physicians' comments which are not meant to be read by patients (Halamka, Mandl, & Tang, 2008). In a study conducted by Hassol and colleagues (2004), the clinicians indicated that patients' accessing clinical notes would require them to be clearer in documentation of patient problems and conditions. Also, clinicians were concerned about the language and the content of their notes which could annoy patients. Consequently, clinicians should be careful in the use of language, particularly when documenting sensitive issues such as obesity and depression. The need for clearer documentation was also mentioned by heart failure patients who had access to the clinical notes. The patients stated that the use of medical terms was a barrier to the information. The participating patients reported using medical dictionaries, online references, friends or family members' assistance who were medical professionals, and their doctors or nurses for clarification (Earnest, Ross, Wittevrongel, Moore, & Lin, 2004). Delbanco and colleagues (2012) conducted a quasi-experimental trial of primary care providers and patients to assess the impact of patient access to visitation notes over protected internet portals. Both participating and nonparticipating physicians expressed concerns about granting patient access to visitation notes prior to the intervention. After the intervention, the workload concerns had reduced remarkably. In fact, a small number of physicians reported increasing duration of visits or time to answer patient questions outside of their scheduled visits. Also, a minority of the responding physicians stated that they modify documentation content and/or took more time writing notes. However, a sizable minority reported that they changed the manner in which they reported some issues such as substance abuse, mental health issues, cancer, and obesity. Most of the responding physicians indicated that "making visit notes available to patients online is a good idea" (p. 467). A few respondents stated that they would not desire continuing to provide access to their notes at the end of the year-long intervention period. Kind and her colleagues (2011) conducted a study to explore whether healthcare providers write visitation notes differently when they are aware that their patients have easy, online access to visit notes. They concluded that dictation style seemed relatively unchanged over time with or without online patient access to visitation notes.

Benefits and Drawbacks of Patients' Accessing Their EHR

Despites clinicians' concerns, patients accessing their EHR, or part of it through patient portals, has resulted in several benefits. When patients access their EHR, problems related to accuracy and completeness in EHR may be solved since patients will be able to recognize and highlight deficiencies in their records. Furthermore, healthcare providers will be motivated to chart more carefully with the knowledge that patients are able to view their own medical records and discover any errors (Hassol et al., 2004). The majority of the participants in another study, which investigated the effect of patients accessing their EHR on the doctor–patient relationship, indicated that having access to their EHR would 'help break down barriers between them and their doctor' (Honeyman, Cox, & Fisher, 2005, p. 58). In addition, this opportunity would help them to better understand their health status and become more confident in their healthcare providers. Pyper, Amery, Watson, and Crook (2004a) interviewed 100 patients to understand their views after accessing their EHR for the first time. From the patients' point of view, accessing EHR helped them to be better informed about their own health and health care, which enhanced their relationship with their doctors. Since patient access helps to recognize errors and omissions in patient records, accuracy and completeness of the electronic patient record would be enhanced. This would also help physicians when records are complete and accurate. In another study, heart failure patients were given access to their records (Earnest, Ross, Wittevrongel, Moore, & Lin, 2004). After interviews, the participants believed that accessing their records assisted them in increasing their education of their own condition. Coordinating their care was a secondary benefit reported by the responding patients in terms of viewing lab results, adjusting medications, and providing copies of tests and laboratory results to their other healthcare providers. Such access also helped heart failure patients to remember all of the information given to them during appointments, such as medication doses and test results. Furthermore, accessing medical records helps patients to enhance their contribution to provided care and facilitate the process of getting information, such as normal test results. In a quasi-experimental study, the vast majority of participating patients indicated that accessing primary care providers' notes for one year would impact their future decisions when looking for care (Delbanco et al., 2012). The perceived benefits reported by the vast majority of them included; an increased sense of control, comprehension of their medical conditions, improvement in remembering their care plans, and enhancing planning for upcoming appointments. This access also had a positive effect on medication adherence. Cimino, Patel, and Kushniruk (2001) concluded that both patients and their physicians believed that use of the system, which provided patients access to their own medical records, improved the patients' understanding of their illness and enhanced their communication with their healthcare providers.

Patient access to their electronic records has several advantages; even though some studies found negative impacts. For example, Palen, Ross, Powers, and Xu (2012) examined health care utilization by both patients who had and did not have online access to health records. The results of this study suggested that patients accessing their online record, which includes secure email messaging with healthcare providers, resulted in increased use of most in-person and telephone clinical services. Patients with such access had higher rates of all around utilization in terms of office visits, telephone encounters, and acute care services, when compared with patients without online access. These results were similar for both younger and older patients and for patients who with and without chronic diseases. However, this result was inconsistent with another study that assessed the effect of patient access to EHR with secure patient–physician messaging on primary care (Zhou, Garrido, Chin, Wiesenthal, & Liang, 2007). The result showed that such access was related to a decline in the rates of primary care office visits and telephone contacts.

To sum up, a recent systemic review study, which covered studies from 1970 to 2013, concluded that patients accessing health records seemed to improve patients' perceptions of control and either decreased or had a neutral effect on patient anxiety (Giardina, Menon, Parrish, Sittig, & Singh, 2014). Also, the authors stated that "our review found no current evidence to substantiate any negative patient outcomes resulting from access to health information" (p. 739).

My Health Record is an example of providing patient access to the national EHR in Australia, which was introduced nationally in July 2012. This system provides a digital summary of a patient's health records which can be viewed by both the patient and healthcare providers anywhere and anytime. After patient approval, patient information can be shared with the Department of Human Services. Healthcare providers can add clinical documents such as discharge summaries and imaging reports. Patients can also enter information about their personal health, such as emergency contact details, allergies and medications. This system includes shared health summaries that involve an overview of a patient's healthcare status written by his or her general practitioner (GP). Patients are responsible for controlling the access of their record by creating access lists and sorting documents as either general or restricted documents. Furthermore, patients have the ability to view who has accessed their record through access history. If patients discover that someone accessed their record without authorization, they can call the help line immediately. Patients' privacy is protected through the Personally Controlled Electronic Health Records Act 2012 and the Privacy Act 1988, which specify penalties for unauthorized access (My Health Record, 2016).

Public Fears and Concerns Regarding Development of a National EHR and Access to Their Records

Patients and the public in general expressed several concerns when they were given the opportunity to access their EHR either at a national or institutionally provided levels. One of the main concerns is security and privacy since patients having access to an integrated EHR will inevitably lead to new security threats. These threats would result from an increase in access levels that include several healthcare organizations. Security vulnerabilities might give rise to the disclosure of patients' data to unauthorized individuals or companies. Consequently, patients' data should be protected against manipulations, unauthorized accesses, and abuse (Fernández-Alemán, Señor, Lozoya, & Toval, 2013). Although the English public at-large and patients in particular showed their support to the development of national EHR in the study conducted by Papoutsi and colleagues (2015), the majority of the participants reported that they would be concerned about the security of their health record if it were included in a national electronic records system. During the time of the study, 71.3 % expressed concerns regarding the ability of the NHS to ensure the security of EHRs. During focus group discussions the participants indicated that they were concerned about hacking, identity theft and unauthorized access. They were more worried about insurance companies, employers and people outside the NHS who would be able to access their records. It was unexpected to find that 55 % of the participants who worried about security expressed their support of the national EHR development, 32.6 % were uncertain, whereas only 12.3 % would not be supportive of national EHRs. This pattern was also noticed among the respondents who believed that the NHS would be incapable of protecting EHRs. Hoerbst and colleagues (2010) also asked Australian and German citizens about their fears and other barriers regarding the sharing of EHR between healthcare providers. Many respondents were concerned about the privacy of their data and one of them stated that "This will lead to the 'transparent citizen" (p.87). Simon and his colleagues (2009) discussed electronic exchanging of health information between different healthcare providers with 64 patients in a focus group. Some participants were concerned about privacy and security— that included issues such as providers who will access their health information, the types of sensitive health information that would be exchanged, and unauthorized access risks. However, other participants showed a considerable level of trust in the security of the system and they were unconcerned about the sharing of sensitive information between different healthcare providers. One of them stated, "Yeah, but the doctors [already] ask you about all that stuff anyway, right? This isn't really that different" (p.3).

Possible security breaches, which should be considered, also have been mentioned in several studies that concentrate on providing patient access to their records at an institutional level. In a study conducted by Delbanco and his colleagues (2012), one third out of 5,219 patients who accessed at least 1 visitation note and finished a post intervention questionnaire had privacy concerns. Pyper, Amery, Watson, and Crook (2004a) asked 100 patients about their opinion before and after their access to EHR. The authors found that 47% had concerns over security prior to viewing their electronic records. However, most were comforted by the use of biometrics, passwords and NHS numbers, and only 4% were worried about confidentiality after using the system. Among the participants who did not want to access their EHR in this study, three were patients who work as health professionals or administrators and had previous experience with health records. These three participants reported that their main reason was confidentiality concerns because they were skeptical of computers and system security. However, the respondents in other studies hold opposing opinions about this issue. The majority of respondents in a study, which assessed patients' perceptions regarding having access to their EHR, had no concern about their confidentiality and the security of their information (Hassol et al., 2004). This finding has been confirmed in another study, which was conducted by Honeyman, Cox, and Fisher (2005), where 78 respondents out of 101 were "not concerned" or only "a little concerned" about the security of their electronic record.

Another concern that has been expressed by patients is potential exploitation of a profit-oriented use of the EHR. In a study the patients were concerned about using health data outside of healthcare provisions by non-medical staff, other patients, employers, insurance companies, pharmaceutical companies, the government, police, social services, and computer hackers (Pyper, Amery, Watson, & Crook, 2004a). However, using health data in research or epidemiology was considered reasonable and acceptable when they were informed prior to usage. This concern was also stated by the participants in the focus group that discussed the development of a national EHR especially when health records would be shared with private organizations (Papoutsi, 2015).

Also, getting new information about his or her health status was one of the concerns of many patients, particularly if the information contained abnormal results or bad news (Pyper, Amery, Watson, & Crook, 2004a). Although getting bad news may raise the level of patient anxiety, this has not been found in a quasi-experimental study conducted on breast cancer patients. The results indicated that providing access to personal health information reduced anxiety levels among patients (Wiljer et al., 2010a).

Since national EHR will be shared between several healthcare providers, some participants, who discovered errors in their EHR, were concerned about sharing inaccurate information. When that happens, diagnosis and treatment decisions will be affected negatively. Another concern highlighted by ethnic minority participants was that health professionals might "make character judgments." In one study, a participant stated that "I know it could lead to negative labelling, definitely. And it just comes down to the human level, with the nurse, the GP dealing with patients, how it will affect their treatment of people, I'm sure it will have an influence on that. There will be someone down the line that will react negatively, there's no doubt about it" (Papoutsi, 2015, p.9).

Difference between Attitudes of Physicians, Administrative Staff, and Patients

Although several studies, which are mentioned above, clarified that patients have positive attitudes regarding having access to their EHR, physicians may have different opinions due to several reasons. An early study that examined physicians' attitudes toward patients' requests to read their hospital records was conducted by Bernstein, Andrews and Weaver (1981). The results showed that 28% of participants believed that patients reading their record is necessary, but not a desired part of their work. Although 62% of responding physicians considered the patient request as an opportunity for education or treatment, 83% of the respondents felt such reading would harm patients due to an absence of medical knowledge. Differences between physician and patient opinions has also been questioned by Fisher, and Britten (1993). They explored cancer patients and physicians' attitudes about offering access to medical records. The results indicated that all 21 participating physicians reported negative attitudes towards patient access to records. They held negative opinions because they worried about several issues, such as harming patients, patients' misunderstanding of written information and the required time to explain medical terms. However, 20 out of 32 participants chose to access their records. Their motivation was that hearing the truth would be therapeutic when dealing with the stresses of cancer. Also, this result was confirmed by a newer study conducted by Ross, Todd, Moore, Beaty, Wittevrongel, and Lin, (2005). This study revealed that physicians were significantly more likely to expect worries than patients. Furthermore, physicians were significantly less likely to predict that patient access to medical records would be more empowering for the patients than were the patient participants. The authors also asked about the potential consequences if patients gave access to their records. The majority of the respondent physicians predicted that their "workload would increase substantially," and almost half of them estimated that they "would document things differently in the medical record" (p. 5).

Another stated reason was the negative impact of informing patients about abnormal test results. In a study, system administrators and physicians were worried that patients might become concerned about test results that they could access online, especially if the results were abnormal and if they had not been previously discussed with a provider (Hassol, et al., 2004). However, patients were not concerned about this issue. All patients were enthusiastic to view more online test results. Administrators also worried if confidentiality and security of patient online medical information would be an issue of contention. Most of the respondents from the patients group had little or no concern about security and confidentiality. In fact, the respondents who had a high school education or less were somewhat more concerned about this issue than patients who had attended college. Another disagreement was regarding preferred communication, patients preferred e-mail communication for several interactions such as requesting prescription refills, as well as getting general medical information. However, the patient respondents favored in-person communication when explaining treatment instructions. Although physicians chose telephone as a preferred communication channel with patients, telephone or written communication was never a favored communication channel from the patients' perspective.

A study conducted by Earnest, Ross, Wittevrongel, Moore, and Lin (2004) assessed the experiences of patients and physicians in a clinical trial regarding patient-accessibility of their EHR. Before the trial patients' attitudes were more positive than the physicians in expecting that such access would increase patient empowerment. However, physicians were more likely to predict some concerns, such as increasing patient worry and confusion regarding laboratory and x-ray reports. Also, the physicians were concerned that giving patients access to their records would lead to them bypassing physicians as their main source of information. They felt that such access could give an impression that patients should determine their own clinical plan. Furthermore, they indicated that it might disrupt them from addressing more critical issues in their medical record. However, other physicians believed that it might lead to enhanced trust in the doctor–patient relationship and an increased contribution of patients in their care. Regarding patient education benefiting as a result of such access, the participant physicians also had two opposing points of view. Some indicated that it might lead to confusion among patients more so than educating them since the record is not designed for educational purposes. The second group believed that it might be an educational tool that teaches patients about their illness and the complexity of the care provided to them. The impact of reading sensitive information was another concern of physicians which might upset patients and have a negative effect on the patient-doctor relationship. As in other concerns, some physicians felt that they should be honest with their patients and that the record was “not a place for secrets.” After the trial period none of the previously mentioned concerns were mentioned again by the participating physicians. In fact, the physicians did not feel it impacted their workflow or the relationship with their patients. Regarding documentation style, only three out of seven participant physicians felt that they had modified their documentation style in order to make it more comprehensible to the patients, but no one indicated that as being problematic. Actually, this led to an increase in the level of preciseness in documentation.

Urowitz and his colleagues (2008) asked Chief Executive Officers of Canadian public and acute care hospitals about organizational readiness for providing patients access to their medical records. Regarding providers’ and patients’ attitudes, less than 25% of the respondents thought that patients would like access to their full EHR and only 16% believed that patients would like access to their lab results. Also, less than 10% of the respondents believed that health care professionals would wish that patients view their full EHR.

Needed EHR Requirements from a Public Perspective:

From a public viewpoint, several necessities should be considered during development of a national EHR because they will be among the future users. Papoutsi and colleagues (2015) asked the public and patients about their views regarding the development of a national EHR. In the focus group discussion, participants favored providing full access to their record for specific professionals such as general practitioners. However, limited access could be provided to professionals who were not participants in their healthcare provision. Hoerbst and colleagues (2010) presented a list that included several EHR functionalities to Australian and German respondents. The most required functionalities selected by the respondents were the electronic vaccination record, online information on doctors and hospitals, and the administration of appointments and reminders.

When patients were given access to their EHR, they requested several requirements to be considered in the development of a national EHR. In a study conducted by Honeyman, Cox, and Fisher (2005), the respondents were excited about the idea of editing the record themselves when they were asked the question “if you had the opportunity to add to your record yourself, how much would this interest you?”. Another study found that many patients, who had accessed their EHR for the first time, asked for explanations of medical terms, abbreviations and acronyms, and information on tests or results that would help them to better understand their conditions (Pyper, Amery, Watson, & Crook, 2004a). Also, the participants requested the inclusion of online services such as prescription refills, appointment booking, and results requests. Additional requirements stated by the participants included; further health record information inclusion; such as blood type, reasons for medications, and previous medications, more information entered by them about self-medication, living wills, and consents regarding serious illness care. In this study, the authors also discussed the consent issue with patients in the focus groups. The majority of the patients indicated that they should have the right to either provide or restrain consent for professionals to access their EHR. The respondents have three opinions based on healthcare professional type. Most of them wanted to allow access to all health professionals. The second group, which was a few participants, wished to provide general consent for physicians; however, they wanted to give specific consent to other health professionals, for example nurses and physiotherapists. The third group, which was a very small number of participants, wanted to limit access to specifically named health professionals. In case of emergency, the majority of them agreed to override limitation on access, however they felt the access should be restricted to specific parts of the record, which include; for instance, mental health, sexual health or termination of pregnancy.

Another potential concern expressed by patients was receiving bad news about their health conditions when they accessed their EHR. Pyper, Amery, Watson, and Crook (2004a) discussed that with the patients in focus group. The majority of them would desire to be informed of any bad news by a health professional before getting the result by EHR. Patients given the opportunity to access the clinical notes had some difficulties in understanding medical terms. To address this challenge, some patients wanted access to a record that was specially modified to decrease the number of medical terms. Another suggested solution was a means that enabled them to find definitions of medical terms quickly. In this study, the patients also suggested providing hyperlinks to explain medical terms and methods for patients to mark their records when they discover any errors. Several participants recommended inclusion of assistance that would help to understand laboratory and other diagnostic tests (Earnest, Ross, Wittevrongel, Moore, & Lin, 2004).

In addition to medical issues, Wiljer and colleagues (2010b) studied which ancillary issues should be considered in order to provide applicable patients access to health information. The results showed that most of the support contacts was related to technical support, such as registration problems, password reset, and results access. Also, only 2% of support contacts were categorized as clinical or educational support.

Saudi Arabia Context

- ### Healthcare System in Saudi Arabia

The healthcare system in Saudi Arabia has received a lot of attention from the government. “Although many nations have seen sizable growth in their health care systems, probably no other nation [other than Saudi Arabia] of large geographic expanse and population has, in comparable time, achieved so much on a broad national scale, with a relatively high level of care made available to virtually all segments of the population” (Gallagher, 2002, p.182). In 2014, the total budget provided to the Ministry of Health (MoH) was 59,985 billion SR, which is equivalent to 7% of the total government budget (MoH, 2014).

MoH is the main provider of health care services which affords 60% of healthcare services to citizens and expatriates working for the government as presented in Figure 2.2. All healthcare services levels including; primary, secondary and tertiary are provided free of charge by MoH. Creating and managing health policies is the responsibility of MoH, which also is in charge of monitoring healthcare services provided by the private sector. The remaining services are provided by other bodies such as, National Guard Health Affairs, Ministry of Higher Education hospitals, and ARAMCO hospitals. These bodies are independent from MoH in terms of their budget and employing their personal. They also provide all levels of healthcare services, but only for their employees and their families. However, they sometimes provide medical care to the public in complex cases, such as cancer treatment. The last part of care is provided by the private sector for a fee. In fact, the share provided through private healthcare organizations is insignificant compared with the government sector (Albejaidi, 2010; Alkhamis, 2012). The overall structure of the healthcare system in Saudi Arabia is shown in Figure 2.4 (Alkhamis, 2012).

In 2014, the total number of hospitals had reached 453 (an eight hospital increase when compared with the previous year). The total number of beds was 67,997 and MoH's hospitals included 40,300 beds. Also, the primary healthcare center (PHC) numbers increased from 2,259 in 2013 to 2,281 in 2014. The total number of physicians was 81,532 and the rate of them among the general population was 26.5 per 10,000 (MoH, 2014).

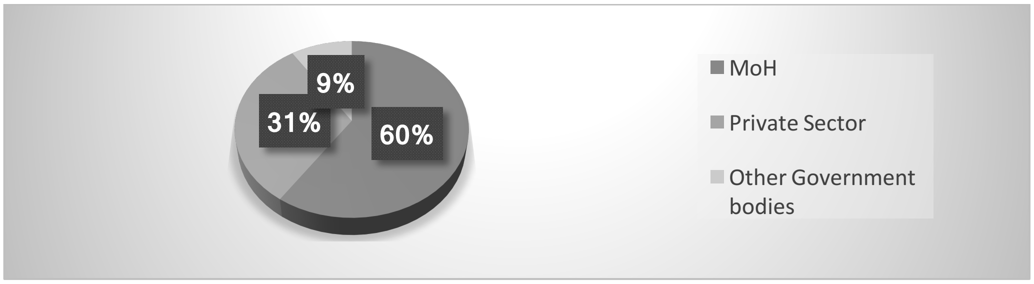


Figure 2.3: The number of hospital services provided by different health care sectors in Saudi Arabia (MoH, 2014).

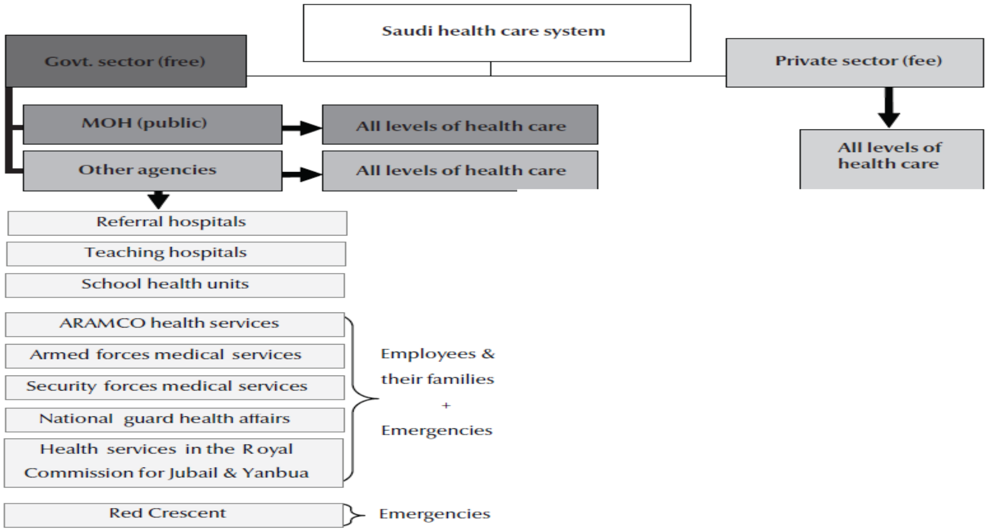


Figure 2.4: The overall structure of the healthcare system in Saudi Arabia (Alkhamis, 2012).

- **Saudi Arabia e-Health Strategy:**

In 2011, MoH launched an e-health strategy, which is defined as “the unified usage for information technology and electronic communications in the health sector.” This strategy consists of two, five-year phases. This was developed by MoH with the guidance of IBM Middle East FZ-L.L.C. The ultimate vision of this strategy is "safe, efficient health system, based on the care centered on a patient, standard-oriented, and supported by the e-Health,” which is presented in Figure 2.4. To achieve this vision, more than 70 projects have been identified. As a result, a roadmap has been created to organize project implementation. In order to realize both business and clinical values, the strategy was created based on MoH Business Strategy. For example, one of the MoH strategic objectives is to, "develop e-health, ICT and management information system." This objective is aligned with one of e-health strategy objectives, which is to "integrate and connect." MoH recognized the complexity of this nationwide project, which involves tens of thousands of physicians, nurses, pharmacists, other system users, and the public who are served by MoH. Consequently, a highly organized governance model has been formed which includes the Strategy and Change Management Office. E-health strategy has six guiding principles, two of which are related directly to EHR adoption. The first one is "quick win, high clinical value," which requires healthcare providers to adopt EHR as fast as they can. The second principle is "broad, then deep, standards based approach," which necessitates adoption of core EHR functions first, then the adoption of increased functionalities in phases (MoH, 2013).

From MoH's point of view, "A significant e-health benefit is the immediate availability of complete data, for clinical decision making, health system management, and research and trend detection". The foundation of this e-health strategy is the interoperable EHR, which will be developed by using standardized clinical terminologies and secure communication standards. This standardization will enable accurate automated communications between various systems. An interoperable EHR will include admissions and demographic data, ancillary departments' orders, diagnostic test reports, radiology and other images, progress notes, discharge summaries, health history, prescribed medication, allergies, and immunizations. To facilitate interoperability and increase competition, MoH selected three different vendors who will provide EHR software. Then, three earliest adopter sites will select the appropriate solutions from the vendors (MoH, 2013).

According to MoH, e-health strategy will benefit patients, healthcare providers, and health system managers. Patients will gain advantages through accessing their health information anytime and anywhere, entering new information about their health status that will be useful to healthcare providers, decreasing the time required to receive healthcare in different locations, and speeding up the diagnostic process. Also, MoH will protect their privacy by maintaining patients' records in centralized datacenters and providing access to authorized providers after obtaining consent from patients. Furthermore, patients can place any (privacy) restrictions on their record to guard their sensitive information. These datacenters will be linked to all hospitals, PHC's labs, specialized clinics, and all MoH offices by a secure, high performance telecommunications network. This connection will be improved to include private sector and other non-MoH organizations. e-Health strategy will also benefit healthcare providers in several ways; such as accessing patient data at any time and any place, reducing the time required to perform redundant tests and procedures, saving wait time for patient tests which will be available electronically, reducing waste of time in diagnosing patients who already have been diagnosed, and finally, by decreasing medical errors and adverse events by use of decision support tools and up-to-date evidence based knowledge systems. Administrators' work will be facilitated through the e-health strategy since all performance indictors will be current and available to them on dashboards. This also will help them to compare their performance with other healthcare organizations in the same or different regions. Electronic communication with other healthcare organizations, either within MoH or through other facilities, will be conducted easily. Furthermore, mangers will be notified about any emerging trends about healthcare services and patient health status (MoH, 2013).

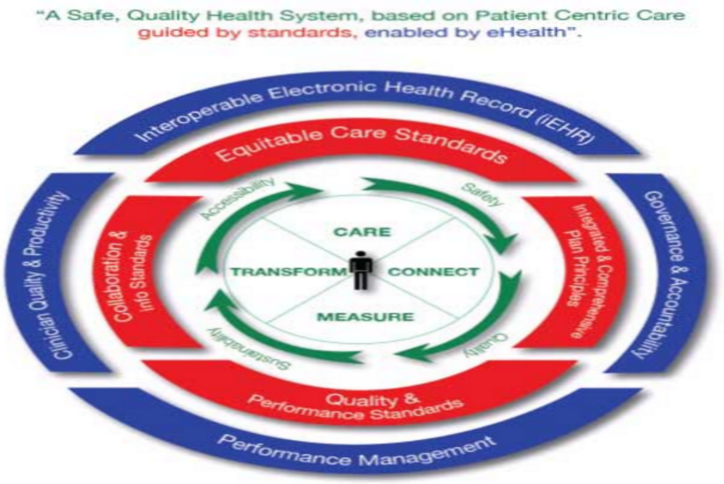


Figure 2.5 The complete vision of e-Health strategy in Saudi Arabia (MoH, 2013).

- **EHR Adoption in Saudi Arabia:**

To identify healthcare organizations progress toward the e-Health strategy, a couple of studies have been conducted to examine the rate of EHR adoption. Bah, Alharthi, and El Mhalli (2011) studied the rate of EHR adoption among government sector hospitals in Eastern Province, Saudi Arabia. Only 3 of 19 hospitals adopted EHR. They implemented the same EHR system which includes three main modules; laboratory, radiology, and pharmacy. A recent study conducted by Aldosari (2014) examined EHR system adoption in Riyadh, Saudi Arabia. As mentioned above, the study found that 11 of the hospitals had implemented fully functioning EHR systems, eight had systems in progress, and three had not adopted a system. This study showed more progress in adoption however; 16 different systems were being implemented among the 19 hospitals. Adoption levels were positively correlated with hospital size. Also, tertiary hospitals were more likely to be farther along in their adoption of EHR systems than are secondary hospitals. In a recent study, Mahalli (2015) assessed the level of EHR functions used among three governmental hospitals which have adopted EHR in in Eastern Province, Saudi Arabia. She found that all hospitals had underutilized all functionalities. This study showed more progress in adoption, however; 16 different systems were being implemented among the 19 hospitals. However, the results reveled that there was no utilization of any communication tool with other providers or with patients, such as "allowing patients to use the Internet to access parts of their health records" (p. 4).

The e-Health strategy launched five years ago. As a result, it is important to recognize why slow EHR adoption has characterized healthcare organizations in Saudi Arabia. From a nurse's prospective, Mahalli (2015) indicated that the most often cited barriers were lack of accessing patient records when computers stop working, deficiency of continuous training and support, and increased data entry time. Furthermore, nurses reported that EHR systems were not customized according to their needs. Khalifa (2013) identified the main barriers that affected the adoption of EHR among healthcare professionals in two hospitals. The study showed that the human barriers, which were associated with beliefs, behaviors and attitudes, and financial barriers were the major challenges that faced them. Another study reported challenges from health informatics professionals' viewpoints. Three main categories were identified, which included: organizational and behavioral, technical and professional, and privacy and confidentiality challenges. Regarding organizational barriers, some participants stated that "bureaucracy" of healthcare organizations interfered with the goals of projects, which led to a delay in a project's progress. Finding the qualified health information professionals, who have experience in e-Health standards and system architecture, was one of the main difficulties of e-Health implementation in Saudi Arabia. One of the suggestions stated by the participants was giving all patients the ability to access e-Health services, such as accessing their medical records, prescription refill services, and being able to communicate with healthcare providers (Alsulame, Khalifa, & Househ, 2015).

Altuwaijri (2011) introduced the successful implementation of EHR at National Guard Health Affairs (NGHA), which resulted in receiving the Middle East excellence award in EHR in 2010. NGHA consists of four hospitals and 60 primary and secondary health centers distributed around Saudi Arabia, which serves more than 2.5 million out-patients and around 60,000 in-patients every year. One of the implementation challenges was multi-site involvement. As a result, they adopted the phased model, which began with one hospital acting as a pilot site. This study suggested several factors which should be considered during EHR implementation, including:

- The implementation should be presented as a “business project” rather than an “IT project”.
- Project’s vision must be stated clearly to project team which helps to avoid stakeholder resistance.
- The implementation process is not finished with the "Go-Live" day, since discovering all issues that concern users take some time.
- Appropriate training is an essential success factor. "Train the trainer" approach has been used to train more than 8,000 employees in this implementation.

Alnuem, Samir, Youssef, and Emam (2011) presented a model of a national EHR in Saudi Arabia with concentration on integration, security, and uniqueness of the patient identifier issues. After surveying several hospitals in Saudi Arabia, the authors determined two significant elements required for integration that are absent in Saudi Arabia's healthcare organizations including; patient unique identifiers and summary care record (SCR). They suggested the use of a Universal Patient Identifier that consisted of: eight digits of birth date, two digits of region, and three digits of letters to distinguish between same date and region born individuals. SCR is a summary of an individual's record that should be extracted from hospital databases and loaded into the centralized national SCR database. The authors also proposed a workflow to inquire about the SCR, which is presented in Figure 2.4. When a patient enters, the system should check local databases for any available record. If the system finds it, it should obtain it and check the national database for any extra information to be added. If the system does not find a patient's record in the local database, it should check the national database. If a patient has a record in the national database, the record should be obtained. If there is no record, a new one should be created in both the local and the national databases.

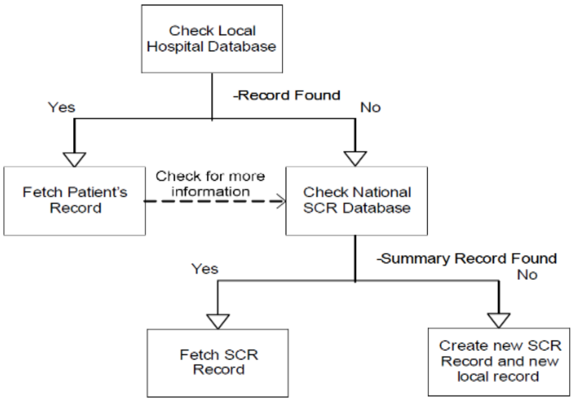


Figure 2.6: SCR Inquiry Procedure (Alnuem, Samir, Youssef, & Emam, 2011).

CHAPTER III: Methodology

Research Questions

1. Are Saudi citizens familiar with national e-Health strategy?
2. Do Saudi citizens support the development of a national EHR?
3. If a national EHR were developed, would Saudi citizens have interest in accessing their medical records?
4. Is there a significant relationship between the support for a national EHR and demographic, health, and education characteristics among Saudi citizens?
5. Is there significant association between Saudis who want access to a national EHR and support level, demographic, health, education characteristics?
6. What functional aspects of an EHR interest Saudi nationals the most?
7. What concerns do Saudi nationals have with regard to the introduction of a national EHR?
8. Is there a relationship between security concerns and degree of support for a national EHR?

Design Appropriateness

The focus of this cross- sectional study was to describe Saudi nationals' perceptions and attitudes toward a national EHR. A quantitative approach using a survey method was chosen. According to Creswell, survey research is most appropriate for the provision of numerical descriptions illustrating trends, attitudes, or opinions of specific populations (2009). Since the present study evaluated the support level for national EHR among Saudi citizens, a quantitative design was most appropriate (Marshall, 2005). Also, survey design is most suitable when data about attitudes or beliefs is collected directly from study participants. Another reason to use a survey is that data can be gathered by using structured questions that can be answered through one-word options (Vogt, Gardner, & Haeffele, 2012). This study necessitated collecting data from a large number of participants. As a result, a survey approach is most appropriate because it can be distributed and analyzed within a reasonable timeframe (Choy, 2014). Furthermore, use of a questionnaire is argued to provide "high quality usable data, achieve good response rates and provide anonymity", which helps to obtain truthful answerers from respondents compared with other methods, such as interview (Marshall, 2005). Choy (2014) indicated that, "numerical data obtained through this [survey] approach facilitates comparisons between organizations or groups, as well as allowing determination of the extent of agreement or disagreement between respondents" (p. 101). To objectively reflect reality, a quantitative design is used to collect data that is independent of researchers (Williams, 2011). The present study determined if there was a relationship between Saudi nationals' support level for a national EHR and citizens' desire to access their record and demographic, health, and education characteristics. In fact, one aim of the quantitative design is to evaluate the relationship between independent and dependent variables, as stated by Hopkins (2008) as well as Edmonds and Kennedy (2012). Furthermore, reliability of study results can be met with a quantitative approach, when data are analyzed correctly (Choy, 2014).

The present study could not use a qualitative design because, "[qualitative approach] findings cannot be extended to wider populations with the same degree of certainty that quantitative analyses can. This is because the findings of the research are not tested to discover whether they are statistically significant or due to chance", according to Atieno (2009, p. 17). Another reason suggesting the inappropriateness of a qualitative approach for the present research question is that a qualitative approach provides detailed description and does not calculate frequencies and "shoehorn the data into a finite number of classifications." (2009, p.17). Also, the number of research participants included in a qualitative design is usually small and the study sample is selective because of the depth of data collection and the analysis procedures (Carr, 1994). However, this study required collecting data from a large number of participants in order to generalize the results. Since qualitative approaches tend to be more time consuming in terms of the data collection process, the present study relied on a quantitative design method (Choy, 2014).

The mode of distribution for the study survey was a self- administered questionnaire. Since the ability to read and understand the content of the survey was one of inclusion criteria, using other modes, including face-to-face and telephone surveys was not required since face-to-face and telephone modes are recommended to be applied when respondents cannot read. This mode was also used to prevent the influence of the researcher on the participants' answers (Vogt, Gardner, & Haeffele, 2012). This study proposed to collect data from a large number of participants and involve participants from different regions of Saudi Arabia in order to be generalizable and reflect real attitudes of citizens. Self- administered questionnaires were thought to be the most efficient option, compared to other modes, in terms of time, cost and effort (Vogt, Gardner, & Haeffele, 2012).

Study Design and the Sample

This study used a cross-sectional survey to investigate the Saudi citizens' attitudes toward introduction of a national EHR in Saudi Arabia. All Saudi laypersons were eligible to participate in the study. The total Saudi Arabia population is 31,742,580, which includes Saudi and non-Saudi individuals, with 20,081,582 being Saudi, according to the Central Authority for statistics (2016). The unique advantage of selecting this sample is the ease of access to the data since the researcher is from Saudi Arabia. The survey was distributed on different days, at different places and at different times.

The required sample size was calculated with the formula suggested by Kotrlik, & Higgins (2001). Since the study variables are categorical, the Cochran's sample size formula is:

$$n_o = \frac{(t)^2 * (p)(q)}{(d)^2}$$

Where n_o is the required sample size, t is the alpha level value of .05 in each tail = 1.96, (p)(q) = estimate of variance = .25, d = acceptable margin of error = .05

$$n_o = \frac{(1.96)^2(.5)(.5)}{(.05)^2} = 384$$

The applied values in the sample size equation are based on acceptable and commonly used values in scientific research. The alpha level usually applied is either .05 or .01. The researcher used .05 in the above equation. Regarding the margin of error, 5% of marginal error is suitable for categorical data. To estimate variance in the population and maximize the sample size, the researchers must select .50, as the estimate of variance (Kotrlik, & Higgins, 2001). According to Israel, the necessary sample size of a population sized more than 100,000 is 400 for precision of ± 5% (1992). In this study, the analyses included logistic regression to determine two relationships. According to Green (1991), the sample size should be greater than 50 + 8 m (where m is the number of independent variables). The study included 17 independent variables. Based on this rule, the sample size should be greater than 50 + 8 (17) = 186 participants. Another rule to determine appropriate sample size when using multiple regression is 30 participants per independent variable. Accordingly, 30 x 17 = 510 participants (VanVoorhis, & Morgan, 2007).

To increase sample size, oversampling is suggested by Kotrlik, & Higgins (2001). They recommend four methods in order to estimate the response rate, which include; (1) take the sample in two separate phases, (2) apply pilot study results; (3) use response rates from a similar population in previous studies or (4) estimate the response rate. Accordingly, oversampling was used after conducting a pilot study to evaluate the response rate. Then, the researcher increased the sample size based on the following calculation:

$$n_1 = n_0 / x$$

Where n_1 is adjusted sample size, n_0 is preliminary sample size and x is response rate from a pilot study.

$$n_1 = 510 / .96 = 531.25 \approx 532$$

Due to increasing the number of participants who would like to fill out the survey, particularly the online- based surveys, the sample size was expanded to than 1000 participants. In fact, increasing the sample size led to increased power and precision of the study (Rusticusc&

Lovato, 2014), (Mackinnon, 2013). Since this study determined the public perception, the researcher recruited the largest sample from the population within the constraints of the study.

The inclusion criteria of the sample included:

- All Saudi citizens, gender (male, female)
- First time filling in the instrument
- Able to understand the content of the survey

The exclusion criterion of the sample included:

- Individuals who were less than 18 years old.

The Instrument

In order to identify all important aspects regarding a national EHR from the public perspective, the development of the distributed survey was conducted in five phases. Phase one involved conducting a literature review to identify what has been included in other studies that assessed the same issues. Phase two involved conducting interviews based on open-ended questions used to recognize any missing areas that have not been indicated in other studies. Phase three was the first pilot study that included a semi-structured survey. It was distributed to a small sample size. A second pilot study was conducted as phase four. Phase five involved creating the final survey that included the close ended questions, which has been distributed to the target population and two open-ended questions. Phases of developing the distributed instrument is shown in Figure 3.1.

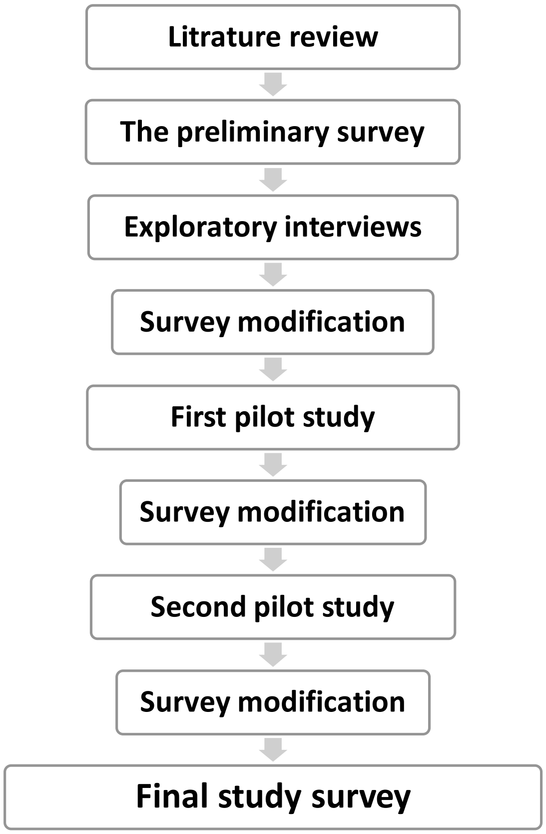


Figure 3.1: Phases of developing distributed instrument

Phase I: The Preliminary Survey

The first stage required conducting an extensive review of the literature to recognize the factors that might affect the general attitudes of those potentially impacted by a national EHR, the associated required functionalities of a national EHR, and their concerns and fears of other populations (Hoerbst, Kohl, Knaup, & Ammenwerth, 2010; Luchenski, et al., 2013; Papoutsi, 2015). The preliminary survey items were based on questions from previously conducted surveys (Luchenski et al., 2013, Hoerbst et al. ,2015) and some items generated by the author according to the literature review. They are grouped in the four following sections: Section A – Demographic and health information, Section B – National Electronic Health Record, Section C –

Required functionalities of national electronic health record, and Section D – Concerns and fears of introducing a national electronic health record.

The variables that may affect attitudes were included in the first section of the preliminary survey. This section asked participants about demographic data, computer proficiency, and whether they worked in a health-related job. Also, this section included questions about if the participant has any chronic diseases, if he/she takes care of any ill persons, and the frequency of his/her use of healthcare services.

The second section aimed to identify public support for the potential development of a national EHR. In the beginning of this section, the researcher defined the national EHR as a single record that collects all health information about individuals electronically instead of having several health records distributed among different healthcare facilities. This single record can be accessed by different healthcare providers in various healthcare organizations (Luchenski et al., 2013). This definition was also stated on the cover page of the preliminary survey to inform participants about the purpose of the study. The first question asked about public familiarity with a national EHR. To determine degree of support, the survey included two questions: whether they prefer the development of a national EHR, and whether the participants would want their health record to be part of a national EHR. To answer the second question, the participants had three options: yes for complete record, yes for part of the record, and no. The complete record is defined as, "all of your detailed health information (i.e., complete health history)." The partial record is defined as, "information … limited to a specific purpose (e.g. prescriptions, allergies, etc.)", as defined by Luchenski and colleagues (2013). Also, the survey asked the participants more specific questions about using their health record in research and policy making. Since public identification may affect use of health information in research and health service planning, options to answer these questions included: yes with existence of identification, yes with name and address excluded, and no. The last question in this section related public desire to access their record if it is part of a national EHR. All questions of this section are from a questionnaire developed by Luchenski and colleagues (2013), in a study that aimed to enhance understanding of patient and public views about the development of universal patient EHRs and their willingness to share their personal records in a national EHR system.

The third section is related to participant attitudes regarding the necessary national EHR functionalities. Providing full access for specific professionals was one of the public requirements (Papoutsi, 2015). Item 17 asked the respondents about their opinion to give record access to the following professionals: physicians and nurses, pharmacists, emergency department, receptionist, and other healthcare professionals. Respondents answered this question by selecting between: complete record, partial record, and no record. This question was also examined by Luchenski et al. (2013). Item 18 lists several functionalities that could be provided in a national EHR. These functionalities should be rated based on their importance from the public perspective using a 5-point Likert scale. These functionalities were studied by Hoerbst et al. (2015) to explore Austrian and German citizens' knowledge and expectations about the concept and contents of an EHR. This section asked further questions about other functionalities such as: adding more information (e.g. emergency contacts and over the counter medication) and providing access consent. The final item is an open-ended question inquiring about additional functionality interests that the participant might have.

The last section of the preliminary survey focused on the possible concerns and fears regarding introduction of a national EHR. These potential concerns included: security, profit-oriented exploitation of health information, receiving bad news when accessing their record, and sharing of incorrect health information between different healthcare providers. These questions use a dichotomous yes/no response option. The last item in this survey was an open-ended question inquiring about additional possible fears and concerns that were not amongst the given options. The preliminary survey consisted of 28 questions (Appendix A).

Phase II: Exploratory Interviews

The second stage involved conducting informal interviews with a small subset of the sample in order to determine any further aspects that had not been indicated by previous studies. Interviews can be applied as a preparation phase in a quantitative study. Such methods help to enhance quality and guide development of a distributed survey (Rowan, & Wulff, 2007). In fact, this stage helped to clarify further issues that may only be mentioned by the Saudi participants who have different cultural and social factors since previous studies were conducted on other populations such as British, Australian and German ones. The interviews were held on a voluntary basis and all conducted interviews were anonymous. At any time, the interviewee had the right to stop the interview, reject to answer any questions and withdraw from the study.

The small target population was representative as much as possible of the larger population by interviewing 12 participants from various age groups, education levels, and computer skills experience. Also, the researcher involved some participants who worked in health-related jobs and others who had chronic diseases. The interview questions were open ended and consisted of 16 questions focused on a range of topics including; the familiarity with national EHR, advantages of a national EHR, accessing their records, family members who should view their records, fears and concerns, health professionals who can view their records, preferred language to present their information, medical record parts that they would like to have access to in their records, and functionalities from their opinions to be included in a national EHR. The interviews were conducted in Arabic. Appendix B shows the interview protocol.

The interviews were audio recorded by the researcher conducting the analyses. It was conducted by listening to each interview and transcribing answers to different questions. After that, the researcher determined emerging themes and categorized answers under each one of them. The themes included:

1. Benefits of national EHR from a public perspective.
2. Benefits of accessing a national EHR from a public perspective.
3. Required functionalities of a national EHR from a public perspective.
4. Concerns and fears of introducing a national EHR.

Phase III: Survey Modification and First Pilot Study

After stage two, significant modifications were considered which reflected social factors in Saudi Arabia. The first section was not modified, however the author added another question which asked about any other diseases the participant has. This question helped in study analysis.

The first question in the second section, which asked specifically about familiarity with a national EHR was changed to ask generally about the e-Health strategy in Saudi Arabia. The answer options of the second and third items were changed from partial record to a summarized record. Summarized record includes specific purpose documents such as prescriptions, medications, and test results. Several interviewees preferred the summarized record as an option in the answers. Items 12 to 17 were combined under one main question in order to reduce participant reading time. Item 18, which asked about types of healthcare professionals' access to a national EHR, doctor and nurse were separated into two different items because some interviewees provided different access types. In addition, a new healthcare professional, dentist, was added to the question. Item 19 was divided into two separate items. The first item included 7 functionalities and 2 of them were added based on interviewees' answers. However, two functionalities were removed from the preliminary list, which included online information about doctors and hospitals and online consultations, because they were not mentioned by the interviewees. The second item asked the participants which documents they wanted to access electronically from their national EHR and the participants could choose either yes or no.

Also, some interviewees suggested several methods for having their questions related to their health conditions answered. The methods included their physician, medical website, and primary healthcare center visit. Regarding item 23, the interviewees were asked about their preferred method to be informed about bad news related to their health, such as x-ray results, MRI results, pregnancy tests, and cancer screenings. Most of them divided the bad news to fetal and non-fetal news and this categorization was used in the first pilot survey. Since the medical record is written in English in Saudi Arabia healthcare organizations, which is not the primary language, the researcher added a new item about which language the participant would prefer when they read their record. In fact, the language issue was stated in the interviews several times as a main requirement that should be considered in a national EHR development.

Another requirement that was suggested by the interviewees was providing access to their family members. Consequently, two items were added to ask if participants would like his/ her family members to access their records and if so, who would they want to have access. Since interviewees indicated that there are several medical conditions that may cause embarrassment or concern among the family, a related item was attached to ask about these diseases. A significant requirement mentioned in the interviews is that of accessing children's records. Thus, a new item was also included.

In the fourth section, interviewees similarly expressed several new concerns when they would have access to their medical record that were not mentioned in the preliminary survey. These concerns included increasing anxiety, misunderstanding of medical information and reducing interest in their healthcare as a result of complete knowledge. All of these concerns were added as yes - no questions in the modified version of the survey.

The first pilot study involved distributing the adjusted survey to 24 participants. This survey consisted of semi-structured questions to identify any further necessary additions. This instrument was translated to Arabic, which was the main language of the study population.

The goals of the pilot study were to validate the instrument and test its reliability. Also, it was used to check the used language in the questionnaire and make sure that there was no unclear vocabulary. As stated by Welman and Kruger (1999), the advantages of piloting an instrument prior to large-scale use include recognizing unclear questions in a survey and clarifying any inconvenience experienced because of the content or wording of questions through participants' nonverbal behavior.

The pilot study involved distributing the survey in hard copy to 8 participants and as an online survey to 16 participants. After completing the online survey, the researcher also asked the respondents for their feedback. In addition, respondents were asked about any difficulty they experienced, their opinions about the layout and any further areas that should be included in the survey (Marshall, 2005). The first pilot study survey is shown in appendix C.

Phase V: Survey Modification and Second Pilot Study

After conducting the first pilot study, through distributing the surveys to 24 participants, few modifications were considered in the third version of the survey. The modifications were mainly in the required functionalities section. The suggested requirements were answers for the open-ended question which asked about any further functionality that should be included in a national EHR. The first requirement was added in item 18, which asked the participants to rate the importance of the several functionalities. The new functionality is enabling the system to specify the location of the Saudi citizen. In fact, this requirement has not been indicated before in the literature, however it will help to facilitate the healthcare provision and it can be implemented easily with development of IT. Another requirement stated by one of the participants is providing citizens access to their genetic diseases, which they may have in the future. This requirement was added because a genetic diseases project will be implemented in Saudi Arabia. Minor pronoun adjustments were conducted in last section which was changing

"I" to "you" as suggested by one participant in the first pilot study and were approved by other participants.

Van Teijlingen & Hundley, (2002) described the required procedures to conduct a pilot study. They suggested distributing a preliminary survey for a second time after modification of the first pilot study. Consequently, this version of the survey was distributed again to the same first pilot study respondents, which included 24 participants, in order to ask them about their opinions and feedback. The English version of the distributed survey is shown in Appendix D.

Phase IV: Final Study Survey

Most of the modifications in the final version were to convert the unstructured survey to a structured survey. The first item that was added is the type of information the participant would like to enter in their national EHR and the options are symptoms, allergies, over the counter medications, diet, sport, new diseases, and any other information. All of these options were based on the first and second pilot studies. The second item that was included asked the participants to identify all applicable family members who they would like to access their record, including parent, spouse, siblings, relatives who work in the healthcare field, sons, and daughters. Furthermore, a new item asked the participants to check all diseases that they may like to hide from their families, which included sexual diseases, psychiatric diseases, cancer and any other diseases. All of the options in the items were considered according to the participants' responses in pilot studies. Both open ended questions were kept in order to discover any further functionalities and concerns that may be realized from the larger study population. This instrument was translated in to Arabic since the main language of the target population is Arabic. Appendix E presents the English version of the final distributed survey.

Data Collection

The study focused on determining Saudi citizens' attitudes regarding the introduction of a national EHR in Saudi Arabia. A cross-sectional survey design was used. The primary technique was a self-report questionnaire, incorporating various question formats, including: multiple choice, dichotomous answers like "Yes" and "No", a 5-point Likert scale, and open-ended questions.

Recruiting a large number of respondents was desirable, thus, the questionnaire was distributed by hand as well as through the internet. Boynton, (2004, p. 1372) indicated that, "offering a choice between completing the questionnaire on paper or the laptop computer greatly increased response rates." The cover page of both distribution methods indicated that participants should only participate once.

Web- based Survey Distribution

The web-based survey was distributed for all eligible participants and was used to recruit participants who live in cities that are located far away from the researcher. The web-based survey was designed using the Survey Monkey builder tool because it enabled the researcher to calculate the completion rate. The informed consent form was posted on the web as the opening page of the survey. After explaining a national EHR system, the first question on the cover page asked the participants to answer "would you like to complete the survey?". Participants should click on one of two options, saying "yes, I agree to complete this survey, or no, I do not agree to complete this survey”. One of the advantages of web-based surveys is that participants’ responses are automatically stored in a database and can be easily transformed into numeric data in Excel or SPSS, which facilitates its statistical and information analysis. It also saves the time and efforts of the researcher (Wyatt, 2000). Furthermore, web-based surveys can be filled out based on participants’ convenience (Sax, Gilmartin, & Bryant, 2003).

Web- based surveys were posted on several social media applications including Twitter, Instagram and Facebook. Also, it was distributed among formal groups in WhatsApp such as a group including health informatics specialists in Saudi Arabia and Saudi students in the USA.

Paper - based Survey Distribution

A paper-based survey was distributed in several locations including;

- Shopping centers: approval to distribute the survey was obtained from two shopping centers in Dammam and Alahsa. The survey was distributed two separate times. These locations helped to gather surveys from different age groups. The researcher asked the people who were sitting in the food court, “Are you Saudi and are you 18 years old or above?”. If they answered yes, the researcher told them about a potential national EHR. Then, they were asked to fill out a questionnaire, which could be filled out in 15 minutes. During one of the visits, an osteoporosis campaign was conducted by the MOH, which attracted a lot of visitors since this disease has become common in Saudi Arabia. This campaign attracted young people as well as old visitors.

The researcher obtained approval and distributed the surveys to the participants.

- University: before distributing the survey, the researcher obtained IRB approval from the university ethics committee. The researcher communicated with one professor to distribute the surveys after his lectures to the students in three different classes. Also, the researcher hired a research assistant to distribute the surveys because the university was in a different region. In addition, the research assistant asked the workers, including professors and other employees to complete the survey. The target population from this location was students who were aged between 18 to 23 years old and professors who were aged 30 years and older.
- Healthcare organization: the required approval to distribute the survey was acquired from the hospital located in Riyadh. The survey was distributed to patients who were sitting in the waiting areas by a research assistant. The target population from this site included all age groups.
- Personal contacts: since this study involved recruiting all Saudis ages 18 years old and above, the researcher also dispersed the survey to friends and relatives during social events.

Participants completed the questionnaire on their own without receiving any help or other instructions from the researcher. Different age groups were recruited in different locations.

Data Analysis

The second stage of developing the survey included conducting informal interviews with a subset of the participants. In order to analyze these interviews, they were tape-recorded after getting permission from participants. Then, the researcher coded the transcripts and categorized them into possible themes. All new aspects that emerged from the interviews were incorporated in the preliminary survey.

The survey which was administered during the pilot study contained open-ended questions that asked about any further functionalities, concerns and any comments from the public perspective. The answers to these questions were categorized and coded according to possible themes to identify patterns and trends.

Before proceeding with the statistical analysis of the quantitative survey responses, the screening of the data was conducted using univariate and multivariate levels (Kline, 2011; Fidell & Tabachnick, 2006). Data screening helped identify potential multicollinearity in the data, because multivariate tests are sensitive to extremely high correlations among predictor variables. Outlying cases were excluded from the analysis, for there is a high level of probability for belonging to another category which may result in a poor model fit (Fidell & Tabachnick, 2006).

One of the recommended approaches to deal with missing data is deletion of cases that have missing data. After conducting screening analyses, this method was used since missing data appeared random and a small number of cases had missing values (Tabachnick, Fidell, & Osterlind, 2001).

Data was analyzed using SPSS version 22. Descriptive analyses were conducted to determine the percentage of respondents who were in support of the development of a national EHR and wanted their record to be part of a national EHR either as a complete or partial record. Descriptive analyses were also used to examine the proportion of respondents who were willing to include their records in a possible a national EHR for research and healthcare planning, either anonymously or with an identified record. To recognize needed national EHR functionalities from a public perspective and their concerns, descriptive statistics were also conducted.

To analyze possible associations between their opinions and demographic, health, and education characteristics, a logistic regression was conducted. Logistic regression is used when the dependent variable is categorical (DeMaris, 1995). This method helps to describe the relationship between a dependent variable and one or more independent variables (Hosmer & Lemeshow, 2004). To determine which independent variables to include in the logistic regression, bivariate analysis was used. Chi- square tests were used with the following independent variables: gender, marital status, region, having children, working in health related job, having a chronic disease, having any other diseases, taking care of an ill person, age, educational level, computer skills and use of healthcare services. Regression analyses included only independent variables significantly associated with the dependent variable in bivariate analyses ($p < 0.05$). Logistic regression was also conducted to assess the relationship between respondents who wanted to access their record and demographic, health, and education characteristics. To understand the relationship between security concerns and degree of support for a national EHR, chi-squared tests of statistical significance were used.

Reliability of the Instrument

With regards to quantitative research, reliability and validity of the instrument are essential for eliminating errors that might arise from measurement problems in the research study (Joy, 2007). Reliability is defined as, “the degree of consistency or dependability with which the instrument measures the attribute it is designed to measure” (Marshall, 2005).

A suggested statistical method to assess reliability is Cronbach's alpha. It reflects the internal consistency, which is defined as” the extent to which all the items in a test measure the same concept” (Tavakol, & Dennick, 2011, p.53). It is applied to measure the reliability of factors extracted from items with two possible answers and/or multi-point formatted questionnaires or scales (Santos, 1999). Reliability was assessed for the pilot study through gathering data from 20-30 respondents not included in the sample (Radhakrishna, 2007).

Ethical Considerations

Permission to conduct the study was obtained from the university of Wisconsin-Milwaukee Institutional Review Board (IRB) IRB #17.133. The cover page of the instrument explained confidentiality and voluntary participation. It also involved a description of the main research goal and objectives. No names or addresses were included in data collection, which ensured anonymity of respondents. When a respondent returned the completed survey that was considered an indication of the respondent’s consent to participate in the study. Also, IRB approval was acquired from King Saudi University in order to distribute the survey to the students.

Chapter IV: Results of the Study

Reliability of the Survey

The reliability of the survey tool was tested using Cronbach's alpha. The survey is divided into several scales. As a result, the test was calculated for each scale individually. According to Tavakol & Dennick, (2011)," if a test has more than one concept or construct, it may not make sense to report an alpha for the test as a whole as the larger number of questions will inevitably inflate the value of alpha. In principle therefore, alphas should be calculated for each of the concepts rather than for the entire test".

Table 4.1 illustrates the scales of the pilot study surveys and the corresponding Cronbach's alpha levels. As presented in Table 4.1, all scales, except for the Concerns scale, had reliability values higher than 0.7, which is considered acceptable (Tavakol & Dennick, 2011). In fact, the low value of the Concerns scale may be the result of a low number of items (Tavakol & Dennick, 2011). More importantly, these items help to identify the main concerns regarding a national EHR that may be faced by Saudi citizens.

Table 4.1 Pilot study survey scales and corresponding Cronbach's alpha levels.

Scale	**Cronbach's alpha**
Purposes of a National EHR	0.721
National EHR Access Levels of Healthcare Professionals	0.809
National EHR Functionalities	0.732
Health Record Parts	0.773
Concerns	0.185

Reliability of the study was also calculated after distributing the final survey to the study population. Table 4.2 shows that, the alpha values improved for all scales except the Purposes of a National EHR scale. Three of the scales had their alpha values reach 0.8 or more showing that the internal consistency of the scales was substantial.

Even though the Purposes of a National EHR and Concerns scales are approximately 0.6, this value is considered as acceptable by several authors (Bernstein, 1994) (Peterson, 1994) (Sekaran, 1992). Furthermore, Churchill (1979) has indicated that a low value of Cronbach's alpha may result if there are only a few items measured. The first scale has only three items and the last one consists only of four items.

Table 4.2 Final study survey scales and corresponding Cronbach's alpha levels.

Scale	**Cronbach's alpha**
Purposes of a National EHR	0.556
National EHR Access Levels of Healthcare Professionals	0.838
National EHR Functionalities	0.876
Health Record Parts	0.818
Concerns	0.581

Sample Characteristics

The overall response rate of the paper- based survey was 86.6%. The total number of obtained paper- based surveys was 243, however 18 of them were deleted because they were completely unanswered. Out of the 1067 online surveys, only 839 surveys were complete and with a 79% completion rate. The final sample consisted of 1064 surveys after deletion of missing and incomplete cases.

Table 4.3 shows the distribution of the study participants based on their socio demographic, health and job related details. Approximately half of the respondents were female (50.4%) and two thirds of the study participants were between ages 18 and 34 years old. In terms of educational level, most of them had obtained a bachelor's degree. More than half of the participants were married and had kids with 55.8% and 51.6%, respectively. Half of the respondents (50.8%) were from the eastern region of Saudi Arabia. More than half of them rated their computer skills as "average user" with 58.8% and more than a third of the participants were expert users (33.9%). Also, the majority of them (77.9%) were not working in health related jobs. Those working in health related jobs were mostly medical students (25.0%), doctors (12.0%), health informatics specialists (10%), and nurses (5%).

In terms of health-related characteristics, less than a quarter of the respondents had chronic diseases and most of them responded that they had no other diseases. The most common chronic diseases reported were diabetes (19.5%), hypertension (13.0%) and about 10% of the participants had both diabetes and hypertension. Regarding other diseases, the participants also had different conditions such as anemia, eczema, and depression. Furthermore, more than half of the participants (56.5%) had used health care services 1-3 times in the past six months. Only 23.4% of the respondents were caring for someone who is ill, frail, elderly or disabled.

Table 4.3 Socio-demographic and health-related characteristics of the sample.

Characteristic/Variable	(%)	n or frequency
Gender (N= 1061)		
Male	49.6	526
Female	50.4	535
Age category (N=1062)		
18 -24	33.3	354
25 - 34	30.7	326
35 - 44	18.3	194
45 - 54	11.4	121
55 - 64	4.8	51
65<=	1.5	16
Educational Level (N= 1055)		
Elementary	0 .3	3
Intermediate	1.1	12
Secondary	20.4	215
Bachelor's degree	59.4	627
Postgraduate degree	18.8	198
Social Status (N=1062)		
Single	42.2	448
Married	55.8	593
Divorced	1.5	16
Widowed	0 .5	5
Do you have children? (N= 1050)		
Yes	51.6	542
No	48.4	508
Where are you from? (N= 1059)		
Central region	22.7	240
Eastern region	50.8	538
Alahsa region	8.0	85
Western region	9.3	99
Northern region	4.9	52
Southern region	4.2	45
How do you rate your computer skills? (N= 1062)		
Non user	1.8	19
Beginning user	5.6	59
Average user	58.8	624
Expert user	33.9	360

Do you work in a health related job ?(N= 1058)		
Yes	22.1	234
No	77.9	824
Do you have any chronic diseases?(N = 1059)		
Yes	17.4	184
No	82.6	875
Do you have any other diseases? (N= 1056)		
Yes	10.6	112
No	89.4	944
How many times have you used any health care service in the past 6 months? (N= 1063)		
0	17.5	186
1 - 3 times	56.5	601
4 - 6 times	14.0	149
7 - 9 times	3.0	32
10 or more times	3.4	36
I don’t know	5.6	59
Are you a caregiver for someone who is ill, frail, elderly or disabled?(N= 1062)		
Yes	23.4	248
No	76.6	814

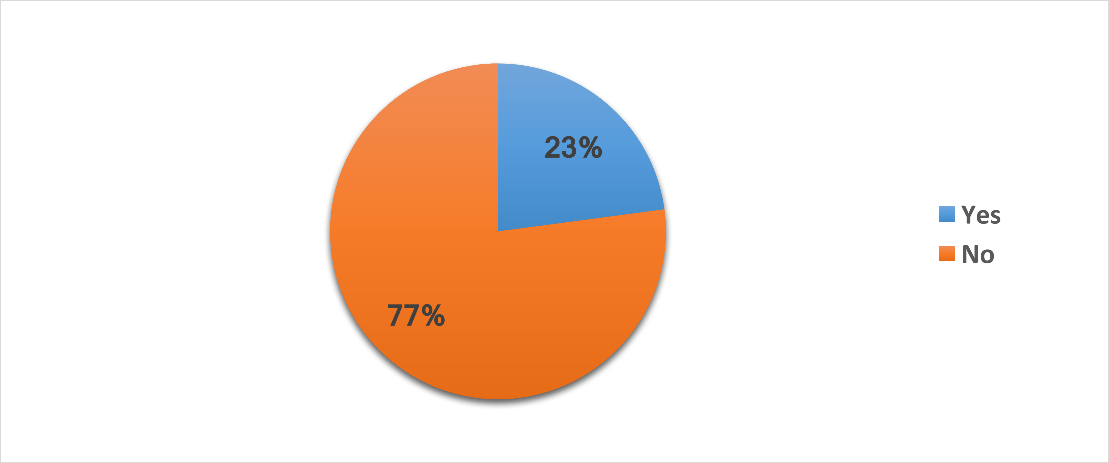


Figure 4.1: Saudi citizens' familiarity with e-Health strategy.

Saudi Citizens' Familiarity with E Health Strategy and Support of a National EHR Development

Out of the 1064 participants, 820 of them had not heard about the national e-Health strategy, conducted by MOH, as shown in Figure 4.1. In terms of a national EHR development support level, the majority of the participants were willing to support the development of a national EHR (86%). However, 121 of the respondents reported being undecided in their opinions and only 24 participants were not supportive, as shown in Figure 4.2. Similarly, 88.2 % of the respondents reported their desire to access their complete health record when it became part of a national EHR system. Only 10.2% of them reported that they would like to access their summarized record. 1.5% of the respondents were opposed to accessing their record, as presented in Figure 4.3.

When the participants were asked more specifically about inclusion of their record in a national EHR for their own healthcare, the majority of them responded that they would like to include their complete record. A very small portion of them preferred inclusion of their summarized record (14.1%) and only 2.7% responded that they would not like to include their records.

Likewise, most of the respondents reported their willingness to include their records in a national EHR for health services planning and policy (95.6%). About 62.7% of the respondents indicated that they would like to include their record without removing identifying information. Nearly one third of the participants supported the inclusion only when their names and addresses were removed (33.2%). However, only 4.1% of the respondents indicated that they would not like to include their health record for healthcare planning and policy.

In terms of including medical records in a national EHR for health research, the support level showed a slight decrease with 90.6%. However, 49.2 % of the respondents disliked including identifying information. On the other hand, 40.9% of the participants reported their support of including their names and addresses within their records. A very small proportion of the participants (9.4%) disliked including their health record for health research in a national EHR, during its development.

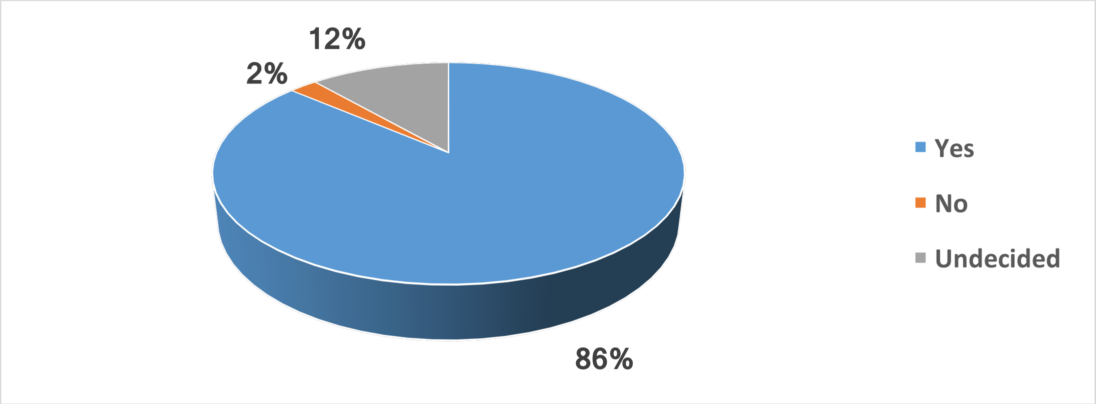


Figure 4.2: Saudi citizens’ support level of a national EHR development.

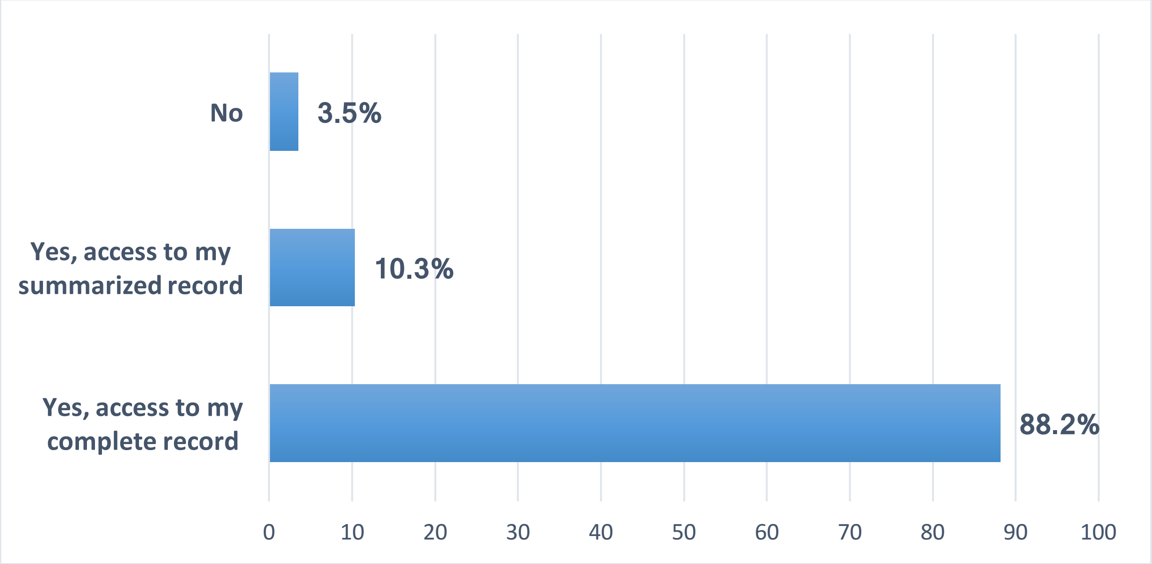


Figure 4.3: Respondents' opinions about accessing their records when it became part of a national EHR.

The Functional Aspects of a National EHR That Interest Saudi Nationals

When participants were asked to specify the parts of their health record that they would like to access if included in a national EHR, the majority of them preferred to access all documents, as indicated in Table 4.4. Over 95% of the participants reported their desire to access both lab results and medication. Similarly, 93% of the respondents would like to access doctor instructions, appointments and allergies. 92% of them stated that they want to access vaccinations, image reports, family history, and progress notes. Sick leaves showed a slightly decreased desire level of access with 85.1% as compared to the other parts.

Table 4.4 Respondents’ opinions regarding which parts of a national EHR they want to access.

Document	Yes % (N)	No% (N)
Vaccination (N= 1052)	92.5 (973)	7.5 (79)
Lab results (N= 1050)	95.2 (1000)	4.8 (50)
Medication list (N=1048)	95.2(998)	4.8 (50)
Image reports (N=1046)	92.7(970)	7.3 (76)
Family history (N=1046)	92.0(962)	8.0(84)
Allergies (N=1044)	93.4(975)	6.6 (69)
Progress notes (N=1047)	92.7(971)	7.3 (76)
Sick leaves (N=1045)	85.1 (889)	14.9 (156)
Appointments (N=1049)	93.7(983)	6.3(66)
Doctor’s instructions (N=1047)	93.9 (983)	6.1(64)

Table 4.5 Preferred access level of healthcare professionals to national health record from public point of view.

Healthcare professionals	Complete record % (N)	Partial record % (N)	Neither record % (N)
Doctor (N= 1051)	82.4 (866)	13.4 (141)	4.2 (44)
Nurse (N= 1046)	43.3 (453)	45.8 (479)	10.9 (114)
Pharmacist (N = 1046)	37.0 (387)	49.7 (520)	13.3 (139)
Dentist (N= 1047)	54.4 (570)	38.9 (407)	6.7(70)
Receptionist (N= 1048)	18.2 (191)	34.6 (363)	47.1 (494)
Emergency department staff (N= 1049)	65.6 (688)	27.3(286)	7.1(75)
Other health professionals (N= 1047)	36.6(383)	49.8 (521)	13.7 (143)

One of the main requirements in a national EHR is to determine healthcare professionals’ level of access to patient records. Most of the participants (82.4 %) wanted their doctors to access their complete health record. However, 45.8% of the respondents preferred to give only partial access to nurses who would provide medical care. Also, 49.7 % of them liked the pharmacists, who prescribe medication, to have partial access to their health record. More than half of the respondents (54.4%) would like their dentists to access the complete health record. Likewise, the majority of them (65.6 %) preferred giving the emergency department staff complete access to their health record. On the other hand, 47.1% of them never wanted a receptionist to access their health record. Almost half of them chose to allow only partial access to other health care professionals, as presented in Table 4.5.

Table 4.6 Importance rating of a national EHR functionalities from a public perspective.

Function	Absolutely not important % (N)	Not important % (N)	Important % (N)	Very important % (N)	Absolutely very important %(N)
Smart phone application	3.5 (37)	1.4 (15)	10.7(114)	29.9(318)	53.9 (573)
Communication methods with doctors such as emails	3.7 (39)	3.8(40)	14.3(151)	33.0 (349)	45.2 (478)
Online appointment booking	3.0 (32)	1.4 (15)	5.0 (53)	23.2 (245)	67.4 (712)
Enabling the system to identify patient's location (N= 1055**)**	2.9 (31)	1.0(11)	5.2(55)	21.1(223)	69.7(735)
Appointments and checkup reminders (N= 1050**)**	2.5(26)	1.0(10)	4.8(50)	28.0(294)	63.8(670)
Medical support to answer your medical questions(N = 1056)	3.2 (34)	1.4 (15)	11.6(123)	33.0 (349)	50.7(535)
Providing a glossary that describes medical terms through hyperlinks (N= 1056)	4.5 (48)	4.5(48)	18.3 (193)	32.5 (343)	40.2 (424)
Presenting medical information by easy language which can be understood by the patients (N= 1057)	2.9 (31)	0.9 (9)	4.7(50)	25.4(269)	66.0 (698)

The importance of several functionalities were rated by the participants. It showed that all of the functionalities were very important from the public view, as presented in Table 4.6. The highest rated functionality from citizens' opinions (69.7%) was enabling a national EHR system to identify patients' location in order to facilitate provision of healthcare. The majority of the respondents (67.4%) rated online appointment booking functionality as absolutely very important. Moreover, 66.0 % of the participants rated presenting medical information in easy language as an absolutely very important function. Providing reminders for appointments and checkups was rated as an absolutely very important function by 63.8% of the participants. The rating slightly decreased (53.9%) for providing a smart phone application of a national EHR system. Also, half of the respondents rated offering medical support to answer medical questions as absolutely very important. Both providing communication methods and a glossary, which describe medical terms through hyperlinks, were rated lower than the other functionalities with 45.2% and 40.2%, respectively.

One of the public requirements in a national EHR system is how to have their medical questions answered. As shown in Figure 4.4, 753 out of 1050 preferred their doctor to answer any medical questions related to their health. Less than a quarter of the respondents preferred to be answered by reading from a medical website that had verified medical information (243 out of 1050). Very few participants preferred getting answers from primary healthcare centers (28 out of 1050). Similarly, only 26 participants suggested using other methods such as doctor from relatives, education clinic, medical team, phone number 973, and service centers.

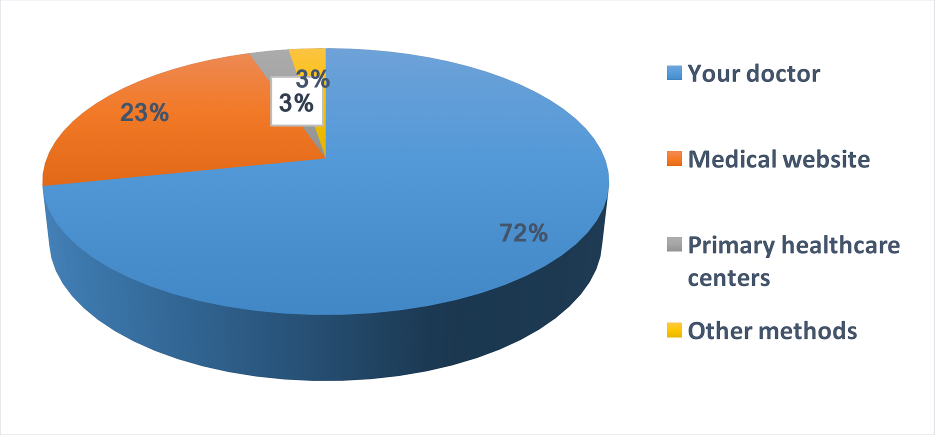


Figure 4.4 Respondents’ preferred methods for having their medical questions answered.

With regard to adding new information to a national EHR, a majority of participants liked adding information (664 out of 1061). Approximately 19% of the respondents disliked adding new information to their record, with a similar proportion being undecided as presented in Figure 4.5. Among the participants who agreed to add information, a majority of them liked adding information about symptoms, new diseases, over the counter medication, diet and allergies. However, 55% disliked adding information about sport, as presented in Figure 4.6. Furthermore, about 50 participants suggested adding other information such as abroad healthcare and doctors, home tests, data collected from health related applications, and medical insurance information.

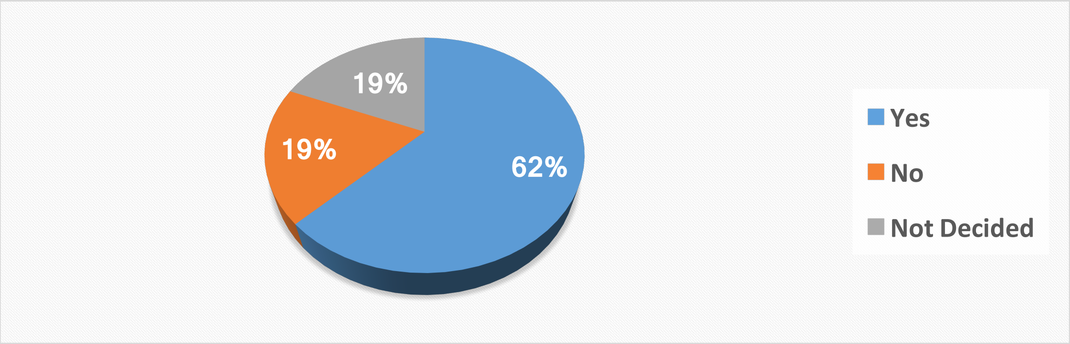
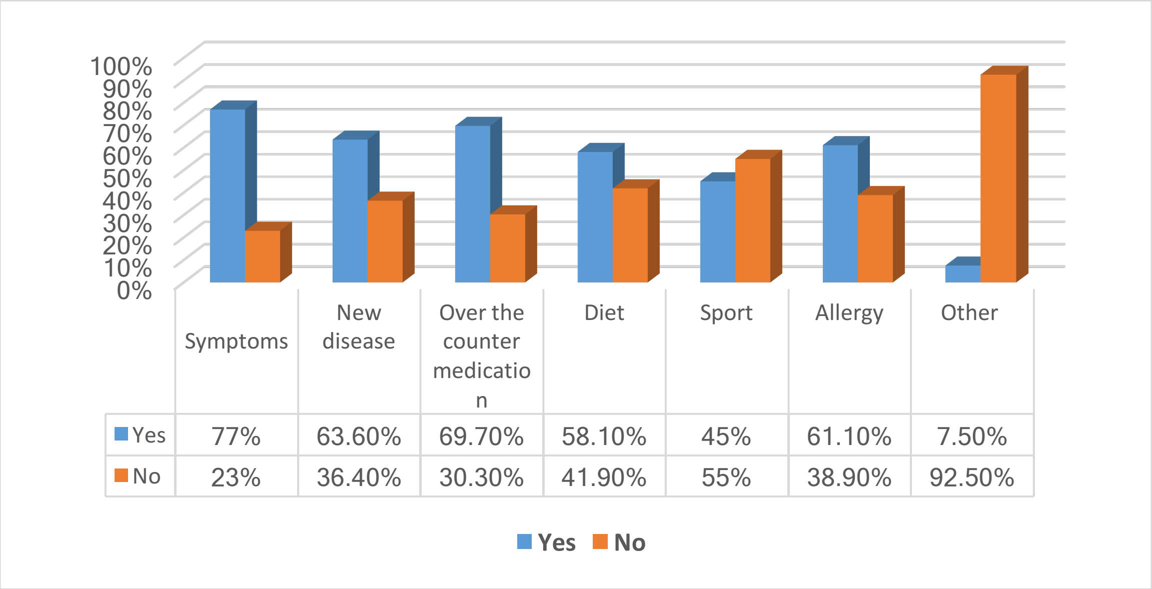


Figure 4.5 Respondents’ opinions regarding adding information to their health record.



	Symptoms	New disease	Over the counter medicatio n	Diet	Sport	Allergy	Other
Yes	77%	63.60%	69.70%	58.10%	45%	61.10%	7.50%
No	23%	36.40%	30.30%	41.90%	55%	38.90%	92.50%

Figure 4.6 Respondents’ opinions regarding type of added information to their health record.

When participants were asked about providing or restraining consent for professionals to access their record, most of them preferred that (71.2%, 755 out of 1060). On the other hand, only 200 respondents disliked to provide or restrain consent for professionals to access their record (18.9%). A very small proportion of them were not able to decide (9.9%), as presented in Table 4.7.

Another requirement in a national EHR is knowing who has accessed a record. The majority of the participants reported their preference for knowing that (89.2%). Only 7.2% of the participants reported that they would not bother to know who had accessed their record. Less than 5% of the respondents had not decided yet, as shown in Table 4.7.

Regarding accessing genetic diseases, 85.4% of participants reported that they would want to access their genetic disease information when it is included in a national EHR. Around

10% of them did not like access to their genetic disease information. Only 47 participants were not able to decide, as indicated in Table 4.7.

Table 4.7 National EHR requirements from a public perspective.

Requirement	**Yes % (N)**	**No %(N)**	**Not decided % (N)**
Providing or restraining consent for professionals to access their record (N= 1060)	71.2% (755)	18.9% (200)	9.9% (105)
Knowing who has accessed their record (N = 1060)	89.2% (945)	7.2% (76)	3.7 % (39)
Access your genetic diseases which you may have in the future (N = 1054)	85.4% (900)	10.2% (107)	4.5% (47)

As shown in Figure 4.6, half of the respondents indicated their desire to read their health record in both Arabic and English. Around 45% of them preferred to read it in Arabic only, while only 43 participants wanted it to be in English only. Four participants suggested other languages, including Spanish and Turkish.

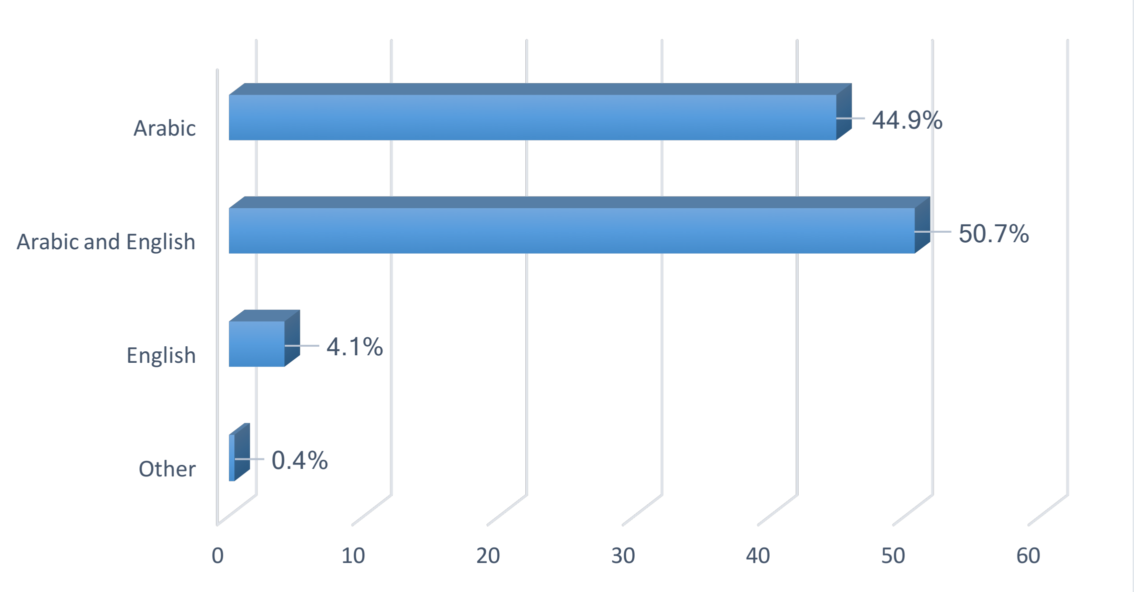


Figure 4.7 Respondents' opinions regarding preferred language to read national health record.

Providing access to family members is another requirement that should be considered during development of a national EHR. 53% of the participants wanted their family to read their health record (564 out of 1064). When asked more specifically about who they would like to give access to, 319 out of 564 wanted their parent to access their records. Also, more than half of this group preferred to give access to their spouse. However, the vast majority of them disliked their siblings reading their record and about same proportion did not want to give access to their relatives who work in healthcare fields. Furthermore, 61.5% of them did not want their sons and daughters to access their health records, as shown in Figure 4.7.

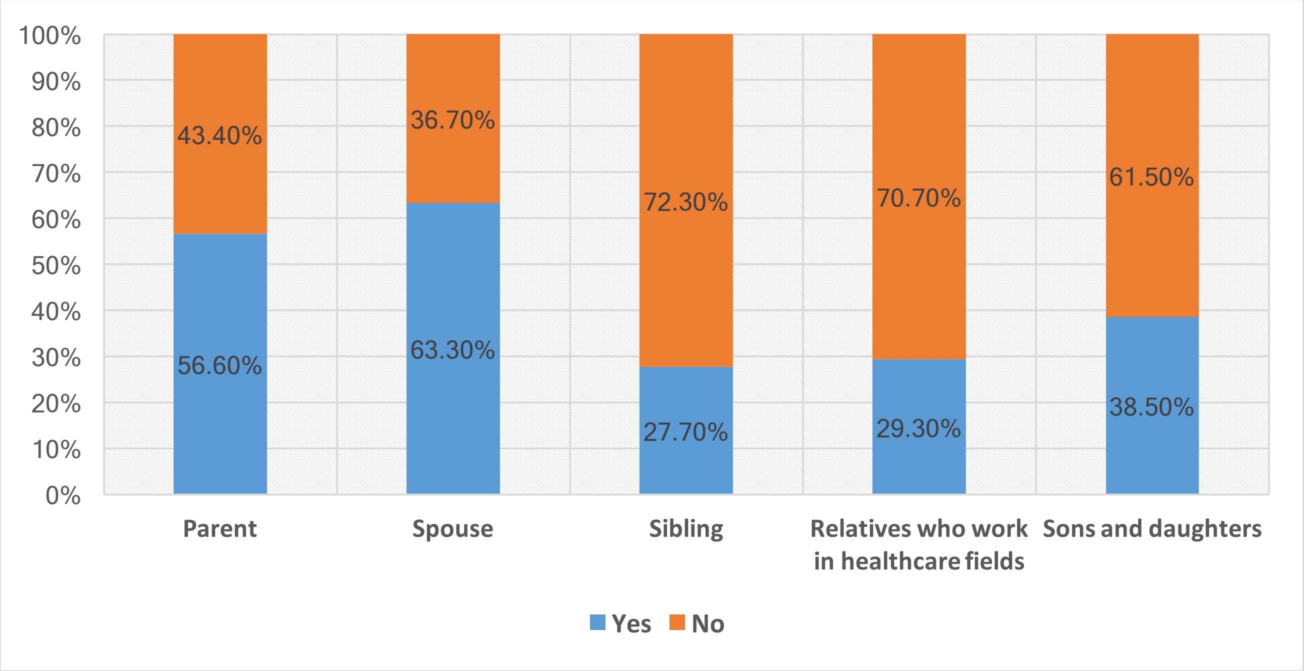


Figure 4.8 Respondents' opinions regarding giving health record access to their family members.

Among participants who would like their families to access their record, 169 out of 559 indicated that there was information about certain medical diseases that should not accessed by their families. When they were asked more specifically about these medical conditions, 110 out of 169 preferred that their families not access sexual diseases information. With regard to psychiatric diseases information, around half of the participants liked their families to access it. Also, 57.4% wanted their families to access cancer diseases information, as presented in Figure 4.7. Only 8 participants selected other diseases which included hemorrhoids, chronic constipation, AIDS, syphilis, chronic diseases, any fetal disease, rhinitis, and any disease that does not affect their health.

With regard to accessing children's records, 88.3% of the participants liked to access their children's records. However, only 11.7% did not want to access their children's health records.

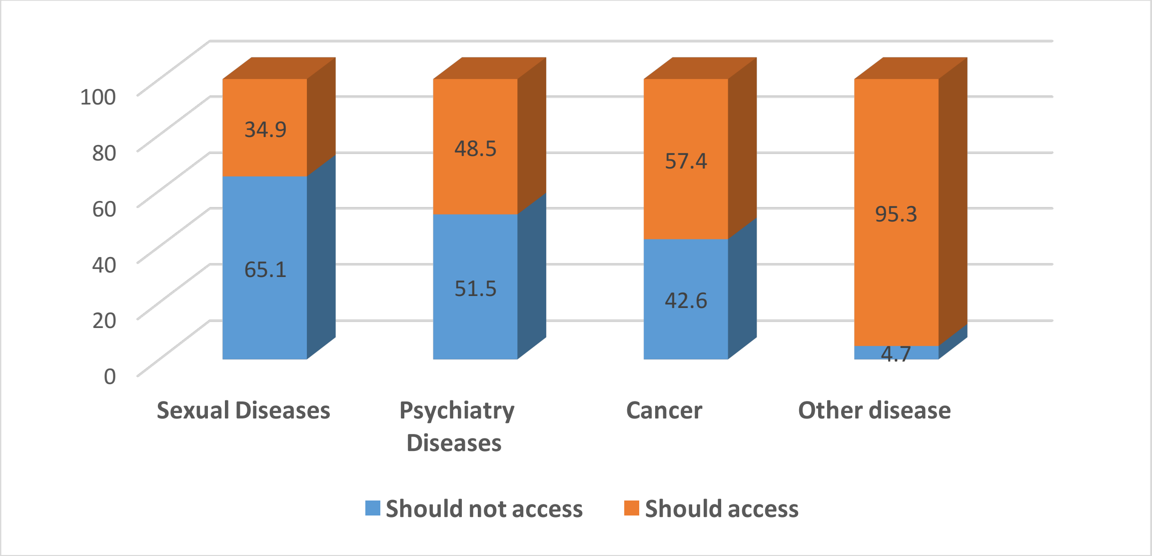


Figure 4.9 Respondents' opinions regarding providing families access to their records.

Bad news related to health were categorized into fatal diseases and non-fatal diseases. Regarding fatal diseases, a vast majority of participants would like to be informed by their physicians and only 89 participants preferred to be informed by their national EHR. On the other hand, the percentage of those preferring to be informed by a doctor slightly decreased when the bad news was related to a non- fatal disease (75.3%). 260 participants liked to be informed about non- fatal diseases via a national EHR, as shown in Figure 4.7.

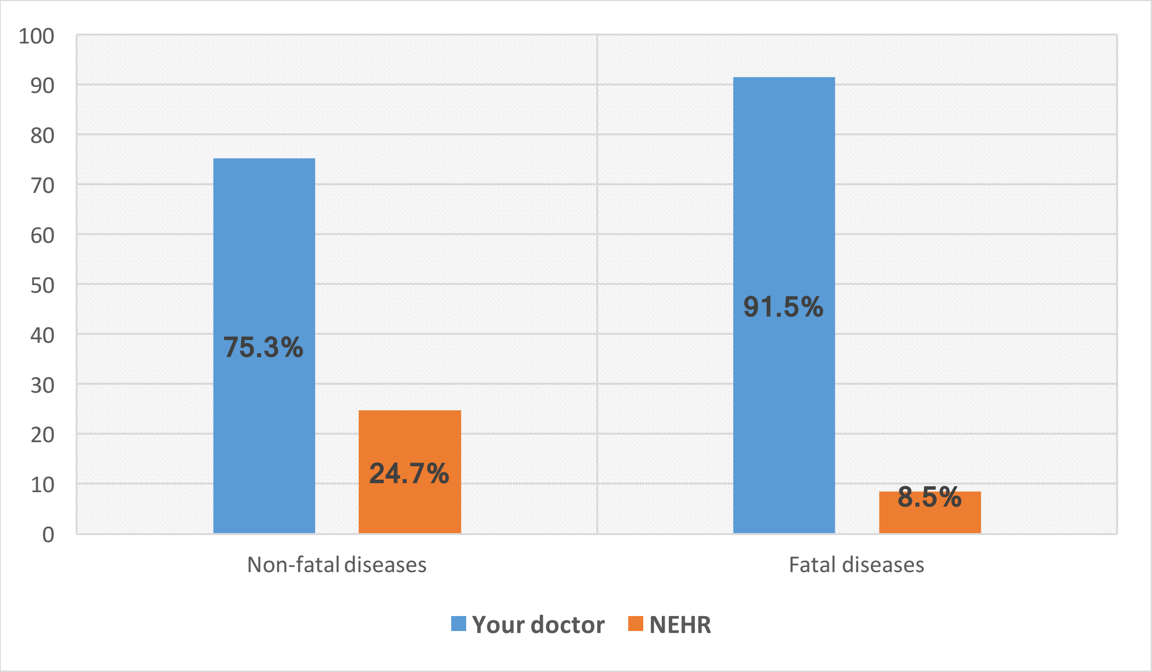


Figure 4.10 Respondents' opinions regarding preferred method to be informed about bad news.

Requirements Open Ended Question

The open ended requirement question, asked participants to list any further requirements from their point of view. These responses were categorized into 24 requirements, 3 of which had already been indicated in the survey. Six respondents suggested to speed up the development of the system. Providing easy access specifically for old people was confirmed again by 5 respondents. Also, answering patients' questions were indicated again by three respondents. Although the researcher asked the respondents to indicate the other preferred methods in item number 19, they suggested new methods for having their questions answered in the open ended item which included phone calls, specialized education clinics, and scanning the questions to their physicians.

A new requirement was recommended by three participants who suggested providing information about responsible medical professionals. Maintaining privacy and confidentiality was also mentioned by 11 respondents. Furthermore, six of the participants recommended the use of access restriction methods such as finger prints and one-time passwords. Some of the respondents suggested adding medical reports and treatment provided outside Saudi Arabia. This would enable doctors to access patient records when treatment was provided abroad. Another related requirement was printing the record or part of it especially if the patient would be traveling to other countries in order to obtain medical care.

Connecting a patient record with his/her national record was requested by 8% of the responses. Several respondents asked for connecting the national record system with all healthcare organizations including; governmental and private hospitals and primary healthcare centers. Three participants suggested providing public awareness information about common diseases and prevention methods. Providing access to insurance companies was mentioned by two respondents, however they had contradictory opinions.

Two respondents, who worked in health related jobs, mentioned access to information about psychological diseases. One of the answers was "Psychological records shouldn't be accessed by the patient nor the Healthcare providers without extra measures." Also, some of the respondents specified several technical issues that should be considered such as system availability, infrastructure readiness, decentralized system and system updating. Each of the remaining requirements was suggested by one or two respondents. Table 4.8 shows the requirements categorizations and the number of answers provided.

Saudi Nationals' Concerns with Regard to the Introduction of a National EHR

The main concern related to developing a national EHR is security. As presented in Figure 4.8, 750 participants stated that they would be worried about the security of their record and only 290 of them were not worried about security. Regarding increasing anxiety, more than half of the participants did not worry about that. On the other hand, most of the participants were concerned about misunderstanding of medical information when reading it from their health record. Reduced taking care of health as a result of having complete knowledge about diseases was not considered as a concern by more than half of the respondents, as shown in Table 4.9.

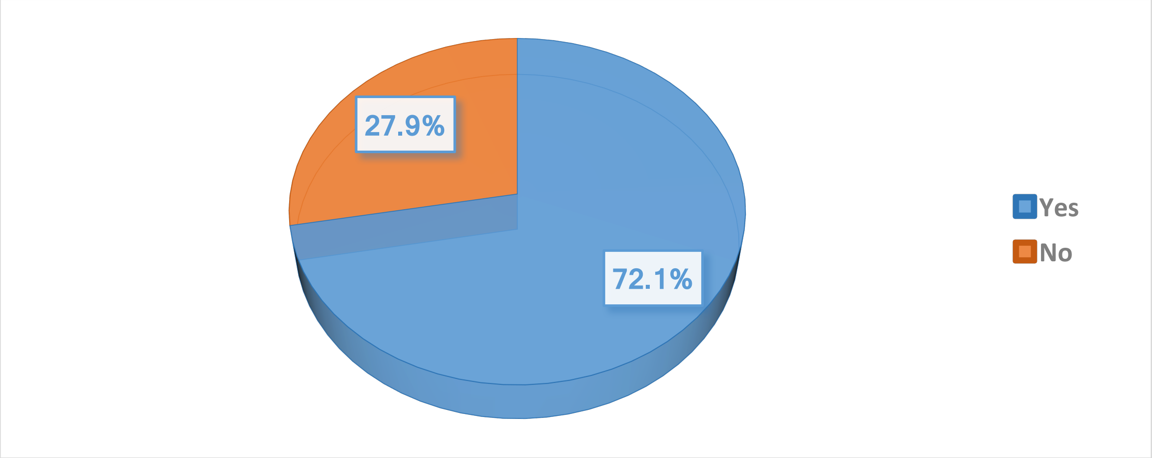


Figure 4.11 Security concerns when national EHR developed from public point of view.

Table 4.8 The requirements categorizations and number of answers provided.

Code	Category	No. of answers in online - based survey	No. of answers in paper- based survey
1	Access of insurance companies and government agencies	2	
2	Psychological diseases access	2	
3	Medical treatment outside KSA	3	
4	Speed up the application	5	1
5	Answers to patient questions	3	
6	Printing part of patient national health record	2	
7	Use SMS to inform patient about any change in the appointments	1	
8	Privacy and confidentiality	11	
9	Connect national health record with national record	6	
10	Incorporate all healthcare organizations	7	1
11	Including awareness information	3	
12	Information about responsible medical professionals	2	1
13	Education about the system	1	
14	Referral recommendations	2	
15	Medication suggestions and side effects	1	
16	Regular checkup appointments	1	
17	Technical issues (Continuous update of the system, infrastructure, decentralized system)	3	1
18	Completing of information		1
19	Easy access to the system	4	1

20	Electronic communication		1
21	Electronic card		1
22	Continuous consultation		1
23	Do not giving the doctor complete authority		1
24	Access restriction	6	
Total		**65**	**10**

Table 4.9 Other public concerns about accessing their health record.

Concern	Yes % (N)	No %(N)
Increasing anxiety (N= 1052)	44.9 (472)	55.1(580)
Misunderstanding of medical information (N= 1056)	63.8(674)	36.2(382)
Reduce taking care of health as a result of having complete knowledge of diseases (N= 1054)	42.6 (449)	57.4(605)

Concern Open-Ended Question

Item 48(see appendix E), which was the last question in the survey, asked the participants to clarify any further concerns that may arise if a national EHR were developed. The responses for this question was given mostly by participants who completed the online survey. There were a total of 93 responses and only 22 of them were from the paper based survey. These responses were categorized into 13 concerns and 4 of them had already been mentioned in the survey, which included security, misunderstanding, increasing anxiety, and less taking care about healthcare. Privacy and unauthorized access were indicated by more than 25% of the answers. Furthermore, 19 of the comments again raised concerns about security. The exploitation of medical information was a concern mentioned by 15 respondents, which may occur from insurance and pharmaceutical companies and research agencies.

In addition, 10 respondents were concerned about the wrong data being entered by healthcare professionals and other employees that may lead to wrong diagnoses and treatment. Several technical concerns such as complex systems, response time, lack of infrastructure, and system failure were indicated by 10 respondents.

An unexpected concern mentioned by one respondent, was the inability to visit several healthcare organizations to treat the same health condition. Less taking care of their health and increasing anxiety concerns were indicated again by four respondents and three respondents, respectively. Each of the remaining five concerns were expressed by one respondent. Table 4.10 shows the concerns categorizations and the frequency of responses for both online and paper based surveys.

Table 4.10 Concerns categorizations and the number of answers.

Code	**Category**	**No. of answers In online - based survey**	**No. of answers in paper online - based survey**
1	The exploitation of medical information and wrong using	14	1
2	Unauthorized access and privacy	20	5
3	Using medical information without consent	1	
4	Security	12	7
5	Wrong entering of data	6	4
6	Technical concerns (Complex system, Response time, Lack infrastructure, System failure)	8	2
7	Less taking care of health	3	1
8	Increasing anxiety	2	1
9	Depending on the system	1	
10	Reduced doctor interest	2	
11	Misunderstanding	1	
12	Inability to visit several hospitals	1	
13	Psychological persons		1
Total		**71**	**22**

Bivariate Analysis

Before conducting a bivariate analysis, categories of six variables were combined in order to decrease the number of cells with less than five. Theses variables include; age, educational level, marital status, region, computer experience, and use of healthcare services. Education level had the following categories; school education (elementary, intermediate, and secondary), bachelor's degree, and post graduate degree. Single, divorced, and widowed were combined to unmarried and other status. In the "region living in" variable, Alhasa and the eastern region were combined. Table 4.11 shows the frequencies and percentages of variables with combined categories.

Table 4.12 shows the findings of a bivariate analysis after conducting Pearson's chi square test between a national EHR development support level with the demographic, health, and education characteristics. Pearson's chi square analysis found that age was significantly related to the support level of a national EHR development, where the participants who were aged 35 – 54 years old were more supportive ($p = 0.000$). Marital status was also significantly related to the support level. The married respondents were more supportive of the development than those in the unmarried and other status ($p = 0.000$). Also, educational level was significantly associated with support level ($p = 0.000$). The test revealed that participants who had post graduate degrees were more likely to support the development. Having children was significantly related to support of a national EHR development ($p = 0.000$). Participants who were parents were more supportive of the development of a national EHR. Similarly, computer skills were significantly associated with support level of a national EHR ($p = 0.001$). As expected, the expert computer users were more likely to be supportive. Working in health related jobs was also significantly related to support of a national EHR ($p = 0.000$). Participants who work in health related jobs were more likely to support the development.

On the other hand, the following variables were not significantly related to the support of the development of a national EHR: gender, living area, having chronic diseases, having other diseases, using of healthcare services and caring for someone who is ill, frail, elderly or disabled, as presented in Table 4.11.

Table 4.11 Frequencies and percentages of the combined categories of the variables

Characteristic	**(%)**	**n or frequency**
Age category (N=1062)		
18 -34	64	680
35 – 54	29.7	315
55 – 65<=	6.3	67
Educational Level (N= 1055)		
School education	21.8	230
Bachelor degree	59.4	627
Postgraduate degree	18.8	198
Social Status (N=1062)		
Married	55.8	593
Unmarried and other	44.2	469
Where are you from? (N= 1059)		
Central region	22.7	240
Eastern region and Alhsa	58.8	623
Western region	9.3	99
Northern region	4.9	52
Southern region	4.2	45
How do you rate your computer skills? (N= 1062)		
Not user	1.8	19
Beginning or average user	64.3	683
Expert user	33.9	360
How many times have you used any health care service in the past 6 months? (N= 1063)		
0	17.5	186
1 - 6 times	70.6	750
7 and more	6.4	68
I don’t know	5.6	59

Table 4.12 Bivariate analysis of support for a national EHR and demographic, health, and education characteristics among Saudi citizens

	Are you in favor of the development of a national electronic health records system?			
	Yes %(N)	**No %(N)**	**Undecided %(N)**	**Total %(N)**
Gender				
Male	85.9(452)	3.2(17)	10.8(57)	100(526)
Female	86.9(465)	1.3(7)	11.8(63)	100(535)
Pearson Chi-Square = 4.575 *p = .102*				
Age				
18 -34	82.8 (563)	2.8 (19)	14.4 (98)	100 (680)
35 - 54	93.3 (294)	1.3 (4)	8.6 (28)	100 (326)
55 – 65<=	92.5(62)	1.5(1)	6 (4)	100(67)
Pearson Chi-Square = 22.8 *p = 0.000*				
Marital status				
Unmarried and other	78 (366)	3.8(18)	18.1(85)	100 (469)
Married	93.1 (552)	1 (6)	5.9 (35)	100 (593)
Pearson Chi-Square = 50.733 *p = 0.000*				
Where are you from?				
Central region	87.9(211)	1.7(4)	10.4(25)	100 (240)
Eastern region and Alhsa	84.4 (527)	2.6(16)	12.8 (80)	100 (623)
Western region	91.9 (91)	1 (1)	7.1 (7)	100 (99)
Northern region	88.5 (46)	1.9 (1)	9.6 (5)	100 (52)
Southern region	88.9(40)	4.4 (2)	6.7 (3)	100 (45)
Pearson Chi-Square = 7.012 *p = 0.535*				
How do you rate your computer skills?				
Not user	89.5(17)	5.3(1)	5.3 (1)	100 (19)
Beginning or average user	83.3(569)	3.1 (21)	13.6(93)	100(683)
Expert user	92.2 (332)	0.6 (2)	7.2(26)	100 (360)
Pearson Chi-Square = 18.733 *p = 0.001*				
Educational Level				
School education	76.1(175)	6.5(15)	17.4(40)	100 (230)
Bachelor degree	88.5 (555)	1.3(8)	10.2(64)	100 (627)
Postgraduate degree	93.9 (186)	0.5 (1)	5.6(11)	100 (198)

Pearson Chi-Square = 42.4 *p = 0.000*				
Do you have children?				
Yes	93 (504)	1.1 (6)	5.9 (32)	100(542)
No	79.9(406)	3.5 (18)	16.5(84)	100(508)
Pearson Chi-Square = 38.804 *p = 0.000*				
Do you work in a health related job?				
Yes	95.7(224)	0.9(2)	3.4(8)	100(234)
No	83.7(690)	2.7(22)	13.6(112)	100(824)
Pearson Chi-Square = 22.309 *p = 0.000*				
Do you have any chronic Diseases?				
Yes	89.7(165)	2.2(4)	8.2(15)	100(184)
No	85.8 (751)	2.3(20)	11.9()104	100 (875)
Pearson Chi-Square = 2.154 *p = 0.341*				
Do you have any other diseases?				
Yes	90.2(101)	3.6(4)	6.2(7)	100(112)
No	86.2(814)	2.1(20)	11.7(110)	100(944)
Pearson Chi-Square = 3.748 *p = 0.154*				
How many times have you used any health care service in the past 6 months?				
0	83.3 (155)	1.6 (3)	15.1 (28)	100 (186)
1-6 times	87.7 (658)	2.3 (17)	10 (75)	100 (750)
7 and more	89.7 (61)	1.5 (1)	8.8 (6)	100 (68)
I do not know	76.3 (45)	5.1 (3)	18.6 (11)	100 (59)
Pearson Chi-Square = 10.393 *p = 0.109*				
Are you a caregiver for someone who is ill, frail, elderly or disabled?				
Yes	84.3(209)	2.4(6)	13.3(33)	100(248)
No	87.1(709)	2.2(18)	10.7(87)	100(814)
Pearson Chi-Square = 1.366 *p = 0.*505				

Table 4.13 presents the findings of bivariate analysis after conducting Pearson's chi square test between access to health records and demographic, health, education characteristics and a national EHR development support level. The test indicated that gender, age, marital status, region, computer skills, education level, having kids, working in health related job, having other diseases, using of healthcare services and caring for someone who is ill, frail, elderly or disabled were not significantly related to access to either the complete or summarized health record. However, having chronic diseases and support level of a national EHR development were significantly related to access to health record. The respondents who had chronic diseases were more likely to prefer access to the complete EHR (*p = 0.031)*. Furthermore, the participants who supported the development of a national EHR preferred accessing their complete record more (*p = 0.000)*.

Table 4.13 Bivariate analysis accessing national EHR and demographic, health, and education characteristics among Saudi citizens

	If there were a national electronic health records system, would you want to access your record?			
	Yes , access to my complete record %(N)	Yes , access to my summarized record %(N) %(N)	No %(N)	Total %(N)
Gender				
Male	89.5(461)	8.5(44)	1.9(10)	100(515)
Female	87 (462)	11.9(63)	1.1(6)	100(531)
Pearson Chi-Square = 4.131 *p = 0.127*				
Age				
18 -34	87.9 (590)	10.7 (72)	1.3 (9)	100 (671)
35 - 54	88.3 (273)	9.7 (30)	1.9 (6)	100 (309)
55 - 65<=	91(61)	7.5 (5)	1.5 (1)	100(67)
Pearson Chi-Square = 1.316 *p = 0.859*				
Marital status				

Unmarried and other	88.7 (409)	10 (46)	1.3 (6)	100 (461)
Married	87.9 (515)	10.4 (61)	1.7 (10)	100 (586)
Pearson Chi-Square =0 .344 *p = 0.842*				
Where are you from?				
Central region	89 (210)	9.3 (22)	1.7 (4)	100 (236)
Eastern/Alahsa region	86.8 (533)	11.7 (72)	1.5 (9)	100 (614)
Western region	93.9 (92)	5.1 (5)	1 (1)	100 (98)
Northern region	88.2 (45)	9.8 (5)	2 (1)	100 (51)
Southern region	91.1 (41)	6.7 (3)	2.2 (1)	100 (45)
Pearson Chi-Square = 5.591 p *=0 .693*				
How do you rate your computer skills?				
Not user	94.4 (17)	5.6 (1)	0 (0)	100 (18)
Beginning or Average user	87.6 (598)	10.6 (71)	1.8 (12)	100 (672)
Expert user	89.1 (318)	9.8 (35)	1.1(4)	100 (357)
Pearson Chi-Square = 1.611 p *=0 .807*				
Educational Level				
School education	87.8(195)	9.9(22)	2.3(5)	100(222)
Bachelor degree	87.4 (543)	11.1(69)	1.4 (9)	100 (621)
Postgraduate degree	92.4(182)	6.6 (13)	1 (2)	100 (197)
Pearson Chi-Square = 4.591 *p = 0.332*				
Do you have children?				
Yes	88 (471)	10.1 (54)	1.9 (10)	100(535)
No	88.4 (442)	10.4 (52)	6(1.2)	100(500)
Pearson Chi-Square = 0 .776 *p = 0 .678*				
Do you work in a health related job?				
Yes	88(206)	12(28)	0(0)	100(234)
No	88.3(715)	9.8(79)	2(16)	100(810)
Pearson Chi-Square = 5.491 *p = 0.064*				
Do you have any chronic diseases?				
Yes	92.8 (168)	5 (9)	2.2(4)	100(181)
No	87.4 (754)	11.2(97)	1.4(12)	100 (863)
Pearson Chi-Square = 6.947 *p = 0.031*				

Do you have any other diseases?				
Yes	88.1(96)	11 (12)	0.9(1)	100(109)
No	88.5(825)	9.9(92)	1.6(15)	100(932)
Pearson Chi-Square = 0.433 *p = 0.805*				
How many times have you used any health care service in the past 6 months?				
0	84.9(157)	14.1 (26)	1.1 (2)	100 (185)
1-6 times	89.4 (660)	9.1 (67)	1.5 (11)	100 (738)
7 times and more	88.1 (59)	11.9 (8)	0 (0)	100 (67)
I do not know	84.5 (49)	10.3 (6)	5.2(3)	100 (58)
Pearson Chi-Square = 10.570 *p = 0.103*				
Do you take care of someone who is ill, frail, elderly or disabled?				
Yes	85.2(208)	13.1(32)	1.6(4)	100(244)
No	89.2(716)	9.3(75)	1.5(12)	100(803)
Pearson Chi-Square = 2.961 *p = 0.228*				
Are you in favor of the development of a national electronic health records system?				
Yes	89.4 (809)	9.5(86)	1.1 (10)	100 (905)
No	83.3 (20)	4.2(1)	12.5 (3)	100 (24)
Undecided	80(96)	17.5 (21)	2.5 (3)	100 (120)
Pearson Chi-Square = 29.351 *p = 0.000*				

Relationship between Security Concerns and Support Level for a National EHRs

As illustrated previously, 86% of the respondents were in support of the development of a national EHR, 12% of them were not able to decide and only 2% of them did not support the development of this national project. To increase our understanding of whether the participants who support the development were concerned about the security of the system, a

Pearson’s chi square test was conducted. As presented in Table 4.14, there was a significant relationship between security concerns and supporting the development of a national EHR. Participants who were in support of the development of a national EHR were concerned about the security. Among those who were worried about the security if their record would be part of a national EHR, 87.2% of them supported the development, 11.6% were not able to decide and only 1.2 % were not supportive. On the other hand, 86.2 % of the participants who did not worry about the security were in support of its development. Around 10% of them did not have a decision regarding the development and only 4.5% of them did not support the development.

Table 4.14: Relationship between security concerns and support of the development of national EHR.

	Are you in favor of the development of a national electronic health records system?			
	Yes %(N)	No %(N)	Undecided %(N)	Total %(N)
When my record is part of a national electronic health record, I will worry about: security				
Yes	87.2(654)	1.2 (9)	11.6 (87)	100(750)
No	86.2(250)	4.5 (13)	9.3 (27)	100(535)
Pearson Chi-Square = 11.678 *p = 0.003*				

Relationship between the Support for A National EHR and Demographic, Health, And Education Characteristics among Saudi Citizens

After conducting bivariate analysis, age, educational level, marital status, computer experience, having children and working in a health related job were significantly related to support for a national EHR development. These variables were included in multivariate multinomial regression analysis. Table 4.15 shows the multivariate multinomial regression models after adjusting for other variables. The variables like age, education, marital status, having kids, computer experience and working in health related job were identified to show differences in favor of the development of a national EHR. In comparison with the reference category of not working in a health related job, participants who work in health related jobs were more likely to favor (OR=4.29, p=0.000) support the development of a national EHR. As compared to the school level of education, the participants with bachelor's degrees were less likely (OR=0.34, p=0.030) to be in favor of the development of a national EHR.

Relationship between Accessing National EHR and Demographic, Health, And Education Characteristics among Saudi Citizens

After conducting bivariate analyses, having chronic diseases and support for the development of a national EHR were significantly related to access to health record. These variables were included in a multivariate multinomial regression analysis. Table 4.16 shows the multivariate multinomial regression models after adjusting for other variables. The test indicated that there was no significant relationship between access to a national EHR and demographic, education and health related characteristics.

Table 4.15 Multivariate multinomial regression models of national EHR support level and demographic, health, and education characteristics among Saudi citizens.

	Saudi citizens support of the development of a national EHR (Reference category: Undecided)					
	Yes			**No**		
	OR	**95% CI(OR)**	**p value**	**OR**	**95% CI(OR)**	**p value**
Age (reference: 18-34 years)						
55-65	1.65	(0.53,5.14)	0.390	1.16	(0.09,14.59)	0.911
35-64	1.53	(0.75,3.11)	0.241	1.35	(0.23,7.78)	0.738
Education (reference: School education)						
Postgraduate	1.81	(0.85,3.87)	0.125	0.28	(0.03,2.54)	0.259

Bachelor degree	1.48	(0.93,2.37)	0.099	0.34	(0.13,0.90)	0.030
Marital status (reference: Single/Others)						
Married	2.21	(0.96,5.09)	0.062	0.54	(0.07,4.00)	0.551
Do you have kids? (reference: No)						
Yes	1.25	(0.51,3.06)	0.629	1.46	(0.17,12.67)	0.732
Computer experience (reference: Not a user)						
Expert user	0.51	(0.06,4.30)	0.540	0.14	(0.01,3.57)	0.237
Beginning or average user	0.33	(0.04,2.67)	0.300	0.36	(0.02,6.39)	0.490
Working in a health related job (reference: No)						
Yes	4.29	(2.03,9.07)	0.000	1.57	(0.30,8.09)	0.591

Table 4.16 Multivariate multinomial regression models of national EHR access and demographic, health, and education characteristics among Saudi citizens.

	Saudi citizens who want to access to national EHR (Reference category: Undecided)					
	Access to my complete record			**Access to my summarized record**		
	OR	**95% CI(OR)**	**p value**	**OR**	**95% CI(OR)**	**p value**
Have any chronic disease? (reference: No)						
Yes	0.63	(0.20,2.01)	0.434	0.27	(0.07,1.02)	0.053
Do you favor the NEHR (reference: Undecided)						
Yes	2.59	(0.70,9.60)	0.155	1.44	(0.36,5.77)	0.606
No	0.21	(0.04,1.12)	0.068	0.05	(0.00,0.71)	0.027

Chapter V: Discussion and Conclusion

Main Findings

The general objective of this quantitative study was to understand perceptions and attitudes regarding the introduction of a national EHR among the Saudi citizenry. Specifically, it evaluated the level of support for the development of a national EHR, preferences for access to a national EHR, the association between level of support and demographic and health related attributes, the relationship between being in favor of a national EHR, access and support level, demographic and health related characteristics. It also determined Saudi nationals' interest in functional aspects of a national EHR and their concerns regarding the introduction of a national EHR.

The study indicated that 77% of the respondents had never heard about the national e-Health strategy. It also illustrated that most of the Saudi citizens support the development of a national EHR system, which might be used for several services, such as healthcare, health services planning and health research. On the other hand, 12% of the respondents stated being undecided in their view and only 2% of them would be opposed to such a system.

The current study also examined preferences for the purposes for which their health record would be used in a national EHR, including provision of healthcare, development and planning of health services, and health research. Most participants (83.2%) preferred involving their full health record in a national EHR for the provision of healthcare services. When including the health record for health service policy development and planning, level of support increased to 95.6% being in favor. In addition, most of them were in favor of including identifiable information in their record, however more than one third of them indicated a preference for having their identifiable information removed. Less than 5% indicated that they would not want to include their health record for use in health service policy and planning.

With regard to health research, 40.9% of the participants were agreeable to their health record being available with their identifiable information included. With their names and addresses removed, those who were agreeable to their record being used for health research increased to 49.2 %. A small percentage of the sample, less than 10% were opposed to the inclusion of their health record for research purposes.

In terms of accessing health records in a national EHR, most were in favor of accessing their complete record, which would contain all medical documents related to their healthcare maintained across different healthcare organizations. Accessing a summarized record was preferred by only by 10.2% of participants. The summarized record would include limited medical documents, such as prescriptions, allergies, diseases etc, which would be used for definite purposes. In contrast, less than 2% of the participants did not want access to either a complete or summarized health record that would be part of a national EHR.

Regarding which part of the health record they would like to access, most of them would want to access all parts of health record, which would include vaccinations, lab results, medication list, family history, allergies, progress notes, sick leaves, appointments and doctor’s instructions, as ensured by health record access question. All types of documents preferred to be accessed by more than 90% of the participants. To some extent sick level has decreased level to be accessed with 85%.

Not only did participants indicate their preferences for accessing their own health records in a national EHR, but they also mentioned the ability to give varying levels of access to different healthcare professionals as a required functionality. Most of them were in favor of giving doctors, emergency staff and dentists complete access to their health record. Almost half, 45.8 % of respondents suggested giving nurses only partial access to their health record, which would include only limited information required to provide healthcare. Similarly, almost half of them would also want to give pharmacists partial access to their health record. Around 50% of the participants indicated that they would not want receptionists to have any access to their record. In terms of other healthcare professionals, approximately half of them preferred to give them access only to the parts of the record required to provide needed healthcare.

Another function preferred by most of the participants was requiring consent for professionals to access their record. Similarly, the vast majority of the participants stated their desire to be informed about who accessed their health record. Accessing information about genetic diseases which they may have in the future was also a function supported by most of them. More than half of the participants preferred that information be provided to citizens in both Arabic and English. Also, the largest proportion of the participants indicated that they would like to be informed about both fetal and non- fetal bad news by their physicians.

Furthermore, providing family members' access to a national EHR was one of the requirements that 564 out of 1064 participants were agreeable to. Among those, more than 50% of them would like to allow their parent and spouse to access their health record. Almost 40% of them would want their sons and daughters to read their health records. Likewise, the vast majority of the participants would like to access their children's records. In contrast, less than one third of them would like their siblings and relatives who work in the healthcare field to access their health records.

When the participants who wanted their families to access their health record were asked if there was information about any medical diseases that should not be accessed by their families, 169 out of 559 indicated that there was. More specifically, more than 40% of them did not want their families to have access to information related to sexual, psychiatric and cancer diseases.

In addition to functions related to access, this study examined the public's opinion regarding importance of several other functionalities that can be incorporated within a national EHR. Accordingly, all of the functionalities that were included were identified as important functions from the participants' opinions. These functionalities included; smart phone applications, communication means with physicians, online appointment booking, identifying patients' locations, reminders for appointments and checkups, answering medical questions by medical support team, including a glossary with medical terminology, and presenting medical information in a simple way.

The study also showed that the preferred method for having patient questions answered when they accessed their record was through their responsible physicians. Also, the majority of respondents indicated that they would like the ability to add information in their health record. More specifically, more than half of them wanted to be able to add information about symptoms, new diseases, over the counter medications, diet and allergies. In contrast, the same proportion of them did not want to add information about their sport in their health record.

The study results also highlighted that more than 70% of respondents would be concerned about the security of their health record if it were to become part of a national EHR. Once Saudi citizens were given the opportunity to access their record, more than half of the participants indicated that they would be concerned about misunderstanding medical information. On the other hand, more than half of the respondents indicated that they would not be concerned about increasing anxiety and decreasing taking care of their health due to reading their national EHR.

This study also showed significant differences in levels of support and security concerns. Among those that were worried about security, 87.2% were still in support of the development of a national EHR.

The results also revealed significant differences in levels of support depending on sociodemographic characteristics. Working in health related jobs and level of education were important factors related to level of support for the development of a national EHR. Participants who reported working in health related jobs were more likely to favor (OR=4.29, p=0.000) the development of a national EHR. With regard to level of education, participants with a bachelor’s degree were less likely (OR=0.34, p=0.030) to be in favor of the development of a national EHR. On the other hand, there was no association found between support for a national EHR system and age, marital status, having kids, and computer experience.

Additionally, the study indicates that there is no significant relationship between preferences for access to a national EHR and demographic, education and health related characteristics.

Previous Studies

The present study showed that more than 80% of the Saudi citizen participants were in support of the development of a national EHR. In fact, several participants in open-ended questions ensured that they not only agree with development, but they preferred speeding up the development process of this system which will have a positive impact on their health and time. Similarly, in another recent study, the majority of English respondents indicated their support for a national EHR development. However, the number of respondents who were undecided in the United Kingdom (UK) study (27.9 %) was higher than in the present study (12%) of Saudi citizens. Those who were opposed to a national EHR was also higher in the UK study as compared to the present study with 9.6% and 2% being opposed, respectively (Papoutsi, 2015). Also similar to the current study, the support level for health information exchange, which has been considered as a trans-institutional EHR, was also high among both German and Austrian citizens with 80% to 90% support (Hoerbst, 2010).

The current study showed that most of the Saudi participants would like to include their full health record in a national EHR for healthcare provision. A similar result was also supported by the UK study where 66.75% agreed with inclusion of their complete record in a national EHR. Inclusion of limited health information in a national EHR was selected by only 14% of the study population. This proportion was higher in the UK study where 25% of participants indicated that they would like to include their partial record for health care purposes. Similarly, the proportion who would not like to include their record for the provision of healthcare was higher in the UK study when compared to the current study (Papoutsi, 2015).

Furthermore, this study illustrated that the majority of participants agreed to use their health record in policy and planning with the inclusion of their identifiable information. Our results are higher than the results of the previous study in the UK which showed that only 19.8% of participants supported the use of identifiable data. Although 4.1% of the current study participants did not support the use of their health record in planning, this proportion is less than the other study which concluded that 20.4% were opposed to any use of their EHRs for planning and policy (Papoutsi, 2015).

In terms of health research, around half of the participants did not want their identifiable information included in their record used for health research. Another study had a similar result with 67.10% of their respondents indicating that they would like to have their name and address removed before using their health record in health research. On the other hand, 40% of respondents in the current study approved the use of their health record with the inclusion of identifiable data. This level of agreement was not found in another study conducted in the UK, which concluded that only 14% of the participants approved the inclusion of their identifiable data (Papoutsi, 2015). Interestingly, the positive attitudes regarding the inclusion of health records in health research is synchronized with increasing the amount of medical and biomedical research in Saudi Arabia (Latif, 2015). The UK study also found that around 19% of respondents did not want their record to be used in health research. Conversely, our study found that only half of this proportion did not support the inclusion of their health record in research. Actually, the UK study illustrated that 71 % of the participants thought the

National Health Service in the UK was unable to guarantee EHR safety at the time this work was carried out (Papoutsi, 2015).

Attitudes regarding access to a national EHR were also positive, where the vast majority of the participants wanted to access their complete health record. This positive attitude was also found in other studies (Hassol, 2004) (Honeyman, Cox, and Fisher, 2005). Indeed, these attitudes were also illustrated in another question, which asked participants to select the parts of the health record they would like to have access to. The vast majority of them reported their desire to access all listed documents, including progress note. Attitudes toward accessing progress notes was also positive in another study conducted by Delbanco and colleagues (2012). Similarly, having access to vaccinations, imaging reports, and medication lists was also required by more than half of Austrian and German participants (Hoerbst, 2010). In the same study, online information on doctors and hospitals gained a high level of agreement between both Austrian and German citizens. In the current study, this functionality was also mentioned by several respondents in the requirements open- ended question. Having access to sick leaves was less desired than other parts of medical record. Indeed, sick leave is not part of a medical record, however it can be included in a national EHR. This inclusion would facilitate informing employers about employees' leaves.

The positive attitudes toward accessing health records when they become part of a national EHR might be the result of Saudi citizens' realization regarding the potential benefits of such access, such as identifying problems related to accuracy and completeness, improving patient- doctor relationships, and enhancing their own understanding about their health conditions (Hassol et al., 2004) (Honeyman, Cox, & Fisher, 2005) (Pyper, Amery, Watson, and Crook, 2004a).

As expected, most of the participants in this study were willing to give complete access to physicians, dentists and emergency staff. This result was similar to a study (Whiddett, Hunter, Engelbrecht & Handy, 2006) which found that respondents were generally happy to consider sharing all of their information with health professionals, especially if they were consulted first. In Saudi Arabia, the healthcare council started an initial trial in emergency departments to share patient information, which includes demographics, allergies, medication, diagnoses and recent encounters. Six hospitals have been involved in this project, though the results have not been studied (Attallah, 2016). However, almost half of respondents were in favor of giving pharmacists, nurses and other healthcare professionals partial access to their health record. On the other hand, the Royal pharmaceutical society in the UK recently recommended giving pharmacists full read and write access to the patient health record, which will enhance patient safety (Royal Pharmaceutical Society, 2015).

More than half of the participants were in support of each of the proposed national EHR functionalities. Appointment reminders and online appointment booking were also mentioned by another study which concluded that these two functionalities were supported by at least half of participants (Hoerbst, 2010).

Designing a smart phone application for a national EHR was mentioned in the exploratory interviews and was also considered by the vast majority of the participants as a very important function. This support is associated with the increasing rate of mobile phone usage in Saudi Arabia, which has reached 186% compared to the73% average of developing countries and 116% average of developed countries (Albabtain, AlMulhim, Yunus, & Househ, 2014). One of the mobile health applications developed by MOH is Health Awareness, which provides subscribers with daily text messages that include information about updates in medicine, and health and disease prevention (Ministry of Health, 2013). In fact, this application could be incorporated with a national EHR, once developed, given that several participants recommended offering public awareness information about common diseases and prevention methods as part of the national EHR.

A new functionality that was added after being mentioned by a participant in the pilot study was enabling national EHR to identify patient's location, which was rated as a very important functionality. This can be easily implemented with the advancement of information technology. One method is the Geolocation Application Program Interface (API), which is an interface used to obtain geographic location information of a user that can be implemented in web browsers (Pejić, Pejić, & Čović, 2010).

Another important feature that should be considered in a national EHR, is presenting documented medical information in a way that can be easily understood by the citizens. In fact, this study confirmed this requirement with the vast majority (91%) of the participants reporting it as very important. Furthermore, patients in one study, who had access to their doctors' clinical notes, indicated their preference for clearer documentation and they used medical dictionaries, online references, friends or family members' assistance who were medical professionals, and their doctors or nurses for clarification (Earnest, Ross, Wittevrongel, Moore, & Lin, 2004).

Another component of the national EHR that was addressed by this study was that the preferred method for having citizens' health questions answered is by their responsible physicians. Also, the preferred method to be informed about any bad news, whether it is fetal or non-fetal news was also their doctors. Another study had a similar result with the major proportion of participants preferring in-person communication for getting test results and instructions about treatment (Hassol et al., 2004).

When considering these findings, it is important to recognize that the cultural and social background in Saudi Arabia is different than other western countries. Since the communication and informing about health related news is preferred to be conducted by doctors, policy makers should be aware of this difference especially with regard to gender. A study conducted in Saudi Arabia found that female patients trusted female physicians more than male physicians (Badreldin, 2011).

Another method for answering medical questions suggested by one of the participants was the 937 telephone service offered by Saudi MOH. By calling this phone number, the citizen can obtain several services which include; providing medical advice by doctors working 24 hours/day, receiving and reporting any citizen complaints, and providing instructions and advice needed in the event of poisoning. This service is also available as a smart phone application. Furthermore, the 937 website includes medical question and answers about common diseases (Ministry of Health, n.d.). Having such services in place can be incorporated with the implementation of a national EHR. This service may be employed to facilitate difficulties related to answering medical questions and the explanation of medical information, especially if doctors, who provide the service, can access citizens' health records after getting their consent.

Another potential function of a national EHR that was addressed by the current study was the ability for adding information into one's own record. The study found that the majority of Saudi participants preferred adding information in their health record if it were included in a national EHR. This result agreed with a literature review study which stated that patients would like to add their annotations to a Shared Electronic Health Record. They also expressed a desire to document medical diaries such as pain, blood pressure, and glucose level diaries. Furthermore, they indicated that they would like to add information about testaments such as organ donation and treatment restrictions due to religious or ethnic reasons (Schabetsberger, 2005). Hoerbst & Ammenwerth (2010) stated that the patient should have the right to add self-reported health information, which is considered one of the general functionalities in EHR. This feature is also provided to Australians in the My Health Record project which allows them to add emergency contact details, allergies and medications (My Health Record, 2016). On the other hand, around 20% of the respondents in the current study would not like the ability to add information to their health records which may be a result of their fears about entering wrong information that may impact their health.

An unexpected finding of the study, was that among those who indicated a preference for being able to add information to their EHR, 55% of them would not want to add information about sport. This may be due to the high prevalence of inactivity among Saudi society and the reduced prevalence of leisure time physical activity in Saudi Arabia (Al-Hazzaa, 2004) (Amin, Al Khoudair, Al Harbi, & Al Ali, 2012).

Granting or denying consent to access a national EHR and knowing who has accessed the health record were requirements that were agreed upon by a large proportion of participants. These two functionalities are also available in the Australian national EHR (My Health Record, 2016). Hoerbst, & Ammenwerth, (2010) categorized them as one of the confidentiality requirements in EHR that were reported in several studies. Giving patients these rights may help to increase their trust regarding maintaining the confidentiality of their health record.

Accessing genetic disease records was also a required functionality stated by most of the participants. Actually, the Saudi Government has recently announced its plan to develop a Saudi Human Genome Project by sequencing 100,000 Saudis (Alkuraya, 2014). Shoenbill, Fost, Tachinardi, & Mendonca, (2014) have stated several challenges that should be considered in order to incorporate genetic tests in a national EHR. These include developing standardized ontologies to facilitate genetic interpretation, creating CDS tools to help healthcare professionals in interpretation, developing compression methods to enable efficient storage, and designing workflows to ensure security of data.

Unsurprisingly, one of the main requirements that should be considered before a national EHR is developed is the language of the record, given that health records in Saudi Arabia are documented in English. The current study found that half of the participants preferred to read their record in Arabic and English. Although Arabic is the main Saudi language, having a record in English may help them to search about medical information more widely. Recently, English has been used to write the most influential medical journals, and has become the language used at international conferences (Wulff, 2004). In recent times, the number of Saudis who speak English has increased since English is taught as one of the compulsory courses in the education system of Saudi Arabia, which is included in fourth grade (ur Rahman & Alhaisoni, 2013).

In terms of family members having access to their records, more than half of the respondents preferred providing access to their family members. The main reason behind this result is the strong connection between family members in Saudi Arabia as compared to other countries. Thus, giving access to parents and spouses was suggested by more than half of the participants. Among participants who would like their families to access their record, 65% of them would not allow their families to access their sexual diseases, which is as expected. However, any patient may inform their partners about sexual diseases in order to reduce spreading of disease. This result is similar to the findings of another study which concluded that people are increasingly unwilling to share their sensitive information with anyone other than their physicians (Whiddett, Hunter, Engelbrecht & Handy, 2006). As expected, more than half of the participants wanted their families to have access to cancer diseases information, since family support is very important for cancer patients. In terms of accessing their children's records, the vast majority of the participants were in favor of accessing their kids' records, as expected. This reflected parents caring about their about children's health.

With regard to participants' concerns with a national EHR, our study concluded that most of the sampled citizens were concerned about the security of their health records if it became part of a national EHR. Similarly, a study conducted in the UK reported that the majority of participants reported that they would be concerned about the security of their health record if it were included in a national electronic records system (Papoutsi, 2015). Moreover, 21 participants expressed their security concerns for a second time in open-ended questions. Furthermore, several participants clarified their concern about unauthorized access and breach of privacy in their responses to the open-ended question about concerns. This was also mentioned in the UK study after conducting a focus group discussion. Security and privacy were also concerns of other participants of other studies such as the Australian and German study (Hoerbst, 2010)(Simon, 2009).

As compared to previous studies, the current study more deeply analyzed the relationship between support for the development of a national EHR and security concerns. The results suggest that there is a significant relationship between them. The participants who were in support national EHR development were concerned about the security. Among those who worried about the security if their record would be part of a national EHR, a majority of them supported the development of such a system. Likewise, the UK study results indicated that more than half of those who reported being worried about the security of their record in a national EHR system would still support its development (Papoutsi, 2015). Several methods can help to guarantee its confidentiality, privacy, and security such as access control methods and encryption techniques (HealthIT.gov., 2013). In fact, some participants in the present study recommend the use of these methods. For example, one participant stated that “We should insure that Access restrictions and auditing to monitor access on a regular bias.” Informing the public about the use of these methods may lead to an increased level of trust when employing a national EHR.

Another factor that was examined was anxiety when accessing a national EHR. More than half of participants did not express worry over that. This result is supported by a literature review study which concluded that patients accessing health records seemed to improve patient perceptions of control and either decreased or had a neutral effect on patient anxiety (Giardina, Menon, Parrish, Sittig, & Singh, 2014). However, three participants stated their anxiety concern again in open-ended question. Another concern expressed by most of the participants was a misunderstanding of the medical information they would read in their health record. Correspondingly, this concern was reported by physicians who had negative attitudes towards patient access to records (Fisher and Britten, 1993).

Although exploitation of medical information was not a proposed concern in the survey, 15 participants mentioned this concern in the open-ended question. They were particularly concerned about this from insurance and pharmaceutical companies. This finding is similar to another study which reported that patients were concerned about using health data outside healthcare provision by non-medical staff, other patients, employers, insurance companies, pharmaceutical companies, the government, police, social services, and computer hackers (Pyper, Amery, Watson, & Crook, 2004a).

An additional consideration in the development of a national EHR highlighted by the results of our study is the importance of identifying differences between socio-demographic educational groups in Saudi Arabia. The regression model indicated that both workers in health related jobs and education level were significantly related to support level of a national EHR. Participants who worked in health related job were more likely to favor the development of a national EHR, as expected. One of participants who worked in a health related job stated his desire to speed up the development because this project would help physicians to understand the complete history of their patients. However, participants with bachelor's degrees were less likely to be in favor of the development of a national EHR, which was an unexpected result. This finding is inconsistent with the UK study which found that age and ethnic background affect the attitudes regarding support of the development of a national EHR (Luchenski et al., 2013).

This study assessed relationship of desire to access a national EHR and demographic, health, and education characteristics among Saudi citizens. It concluded that there was no significant relationship between access to a national EHR and demographic, education and health related characteristics among Saudi citizens. Similarly, a study conducted in the USA concluded that health status, use of health care, education, and income were not independently related to patients' interest in reading their health records (Fowles, 2004).

Implications

The study showed that although it launched in 2011, a large proportion of people have never heard of the e-Health strategy conducted by MOH. This implies a need for increasing its awareness among Saudi citizens. In fact, Initiatives are in progress and strategies for the development and implementation of a national integrated EHR system is one of the main priorities of the Saudi MOH. However, the adoption rate of EHR in Saudi Arabia is low and moving slowly, especially in MOH organizations (Hasanain, Vallmuur, & Clark, 2014).

Moreover, the results illustrated that there is a proportion of Saudi citizens who are undecided about their support level. This necessitates increased awareness and education about EHR and its advantages which may positively affect their attitudes about the development of a national EHR.

Even though most of the population in Saudi Arabia has never been given the opportunity to access their health record, most of them were interested in having access to and reading it. At the same time, they worried about misunderstanding medical information presented in their record. This suggests that they recognized the advantages and possible consequences of such access. However, providing methods that help them to understand medical information may lead to huge benefits such as enhancing their understanding about their medical conditions. Actually, the 937 service is one such method which has already been established.

Support for development of a national EHR and its different uses is present, however concerns regarding security and maintaining privacy also exist. It is important to recognize that people choose to refuse to share information with medical professionals due to security concerns (Agaku, Adisa, Ayo-Yusuf, & Connolly, 2014). Accordingly, resistance to a national EHR may increase if these concerns are not addressed. This implies the importance of improving infrastructure that safeguards the confidentiality of EHRs prior to the development of a national EHR. More importantly, educating the Saudi population about security threats and means to reduce breaches will help to establish required trust in the future project.

The study indicated that a very small proportion of the Saudi population preferred primary healthcare centers to answer their medical questions. This may indicate that most Saudis do not trust quality of services provided in primary healthcare centers. In fact, poor quality aspects in primary health care centers were stated for chronic diseases management and health education (Hanan & Roland, 2005). Another possible cause for that is absence of comprehensive services and specialties (Alzaied, & Alshammari, 2016). To increase the quality of the health services provided, MOH launched an initiative to involve consulting specialized clinics in primary healthcare centers that include Internal Medicine, General Surgery, Obstetrics and Gynecology, pediatric, and mental health care. The number of these clinics reached 69 clinics around Saudi Arabia (MOH, 2016a).

Most of the Saudi population would like their identifying data included when using a national EHR for planning and policy. Planning and policy of healthcare services is generally conducted by Saudi MOH. This indicated that the Saudi population trusts MOH when using of their health information without any fears. One of initiatives that help to build this trust is called “citizen voice”. This service allows Saudi citizens to send complaints, suggestions and inquiries through the MOH website (MOH, 2016b).

Recommendations and Further Research

Since most of the Saudi population sampled in this study were in support of the development of a national EHR, which can be used for the provision of healthcare, in healthcare policy and planning, and in healthcare research, the development of such a system is required. This system will benefit patients, healthcare providers and administration. Even though adoption of EHR is slow in Saudi Arabia healthcare organizations, initiatives need to be conducted in order to ensure coordinated efforts. This should start with the building of an EHR infrastructure that involves all of the required functionalities of the national EHR. This will make implementation of a national project much easier, as stated by Attallah, (2016).

Before implementation, all of the required functionalities, which are mentioned in this study, should be considered to meet the citizens’ expectations. One of the critical issues that should be taken into account is the language of a national EHR. The study indicated that using both English and Arabic is required to present medical information. As a result, more effort would be required to translate health records to Arabic since health records are currently maintained primarily in English.

Not only was the support level of a national EHR high, but also the desire to access one's own health record was high. This suggests the need for providing this opportunity to Saudi citizens. In fact, providing access to health records can be implemented on a basic level by enabling patients to access their health record of one healthcare organization. Consequently, any emerging challenges may be identified and overcome on this level before developing a national EHR.

Furthermore, education and awareness about EHR will play an important role in facilitating the implementation of such a project. Education needs to be provided to healthcare professionals, patients and administration. Increasing awareness may help to reduce concerns related to security and misunderstanding of medical information. Since the preferred method of having medical questions answered is via physicians, special education should be provided to them. This education may help to reduce workload, which may result from misunderstanding or further patients' questions.

Given that the present study examined the general public's perspective, and was not specific to healthcare professionals, further studies can be conducted to assess health care professionals' attitudes regarding a national EHR before implementation. Realizing their requirements and concerns may also help in meeting their expectations. As a result, both citizens and healthcare professionals' requirements should be considered and incorporated in the development of a national EHR.

Finally, potential benefits after implementing a national EHR should be evaluated in order to overcome any evolving challenges. This project will not be one implemented in one day. Without continuous maintaining, the level of support may decrease, as with any project.

Since this study did not find any sociodemographic factors that were related to desire to access a national EHR, further research could be conducted to determine any factors that may impact access after it is provided to citizens.

Limitations

Although this study reached it aims, there were several limitations. First, while the sample included 1064 participants, the sample is not representative of the overall Saudi population. The sample was recruited from main cities in Saudi Arabia, where most of them are educated and know how to use a computer. Attitudes among rural citizens were not assessed yet, which may differ from the attitudes of urban populations.

Also, most of the sample was from eastern and Alhsa regions. Although, the researcher attempted to recruit participants from other regions, fewer participants in this study were from the north and south regions. The researcher tried to distribute the survey to older Saudi citizens. However, recruiting older persons aged 55 to 65 was very difficult. Consequently, only a small number of participants were from this age group. These limitations may have impacted the data and results of this study.

Conclusion

The results of this study showed that Saudi citizens are supportive of a national EHR development that might be used in healthcare provision, health research and healthcare policy and planning. Although most citizens do not access their health records, most of them indicated their desire to access their complete health records. However, concerns related to data security and misunderstandings were stated by most of them. Moreover, this study clarified several important requirements, which need to be considered before implementation of a national EHR.

These findings support the need for expediting the incorporation of health information technology especially EHR in healthcare organizations in Saudi Arabia. Making a national EHR as an optimal goal before adoption of local EHR in each healthcare institution will help to facilitate the complex implementation. This can be conducted by considering all of the requirements and concerns in advance and finding required solutions for any anticipated challenges, such as interoperability. Also, taking advantage of other countries' experiences, such as Australia and the UK will shorten the implementation process in terms of lessons learned and avoiding emergent problems.

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Appendix A: The preliminary survey

Dear Participant:

My name is Jwaher Almulhem and I am a graduate student at University of Wisconsin- Milwaukee. For my PhD dissertation, I am examining citizen's perceptions and attitudes of national electronic health record introduction in Saudi Arabia. Please only complete in this survey once and only if you are over the age of 18.

I kindly request that you complete the following short questionnaire regarding your attitudes towards national electronic health record. National electronic health record, if developed, will collect your health information from birth to death electronically. It will gather all your health records which is separated in different healthcare organizations into a single record stored electronically. All your healthcare providers will be able to exchange your health information.

If you agree to participate in this study, please answer the questions on the questionnaire as best you can. It should take no longer than 15 minutes of your time. Your response is of the utmost importance to me. There is no compensation for responding nor is there any known risk. After completing the questionnaire, please return the questionnaire to the distributor.

Please do not enter your name or contact details on the questionnaire. It remains anonymous. This survey is voluntary and you may refuse to participate at any time. If you require additional information or have questions, you are welcome to email me at Almulhem@uwm.edu

Thank you for taking the time to assist me in my educational endeavors.

Sincerely,

Jwaher Almulhem

Almulhem@uwm.edu

Survey Instrument

PLEASE ANSWER THE FOLLOWING QUESTIONS BY CROSSING (X) THE RELEVANT BLOCK OR WRITING DOWN YOUR ANSWER IN THE SPACE PROVIDED.

Section A – Demographic and health information

This section of the questionnaire refers to background. The information of this section will allow us to compare groups of respondents. Once again, we assure you that your response will remain confidential. Your cooperation is appreciated.

1. What is your gender?
    - ☐ Male
    - ☐ Female
2. What is your age?
    - ☐ 18-24,
    - ☐ 25-34,
    - ☐ 35-44,
    - ☐ 45-54,
    - ☐ 55-64,
    - ☐ 65+
3. What is the highest level of education you have completed?
    - ☐ Elementary,
    - ☐ Intermediate,
    - ☐ Secondary,
    - ☐ Bachelor’s degree,
    - ☐ Postgraduate degree
4. What is your current marital status?
    - ☐ Single,
    - ☐ Married,
    - ☐ Divorced,
    - ☐ Widowed
5. Do you have children:
    - ☐ Yes If yes: how many children do you have ☐
    - ☐ No.

6. Where are you from?
   - ☐ Central region
   - ☐ Eastern region
   - ☐ Western region
   - ☐ North region
   - ☐ South region
7. How do you rate your computer skills?
   - ☐ Not computer user,
   - ☐ Beginning user,
   - ☐ Average user,
   - ☐ Expert user

8. Do you work in health related job?
   - ☐ Yes, if yes: what is your job? ☐
   - ☐ No
9. Do you have any chronic disease?
   - ☐ Yes, If yes: what is the disease? ☐
   - ☐ No
10. How many times have you used any healthcare service in the past 6 months?
    - ☐ No healthcare used,
    - ☐ 1-3 times,
    - ☐ 4-6 time,
    - ☐ 7-9 times,
    - ☐ 10 and more times,
    - ☐ I don’t know
11. Are you take care for someone who is ill, frail, elderly or disabled?
    - ☐ Yes,
    - ☐ No

Section B – National Electronic Health Record

This section of the questionnaire helps to determine the acceptance level of national electronic health record among patient and general population. By 'national electronic health record' we mean a single record that collects all health information about individual electronically instead of having several health records distributed among different healthcare facilities. This single record can be accessed by different healthcare providers in various healthcare organizations, as explained on the first page of the survey.

12. Have you heard about the national electronic health record?
    - ☐ Yes
    - ☐ No
13. Are you in favor of the development of a national electronic health records system?
    - ☐ Yes
    - ☐ No
    - ☐ Undecided
14. If there is a national electronic health records system, would you want your record to be part of it for your own health care?
    - ☐ Yes, complete record, which means all of your detailed health information (e.g. complete health history).
    - ☐ Yes, partial record, which means information will be limited to a specific purpose (e.g. prescriptions, allergies, etc.)
    - ☐ No

15. If there is a national electronic health records system, would you want your record to be part of it for health services planning and policy?
    - ☐ Yes, name and address present
    - ☐ Yes, name and addressed removed
    - ☐ No
16. If there is a national electronic health records system, would you want your record to be part of it for health research?
    - ☐ Yes, name and address present
    - ☐ Yes, name and addressed removed
    - ☐ No
17. If there is a national electronic health records system, would you want to access your record?
    - ☐ Yes, complete record, which means all of your detailed health information (e.g. complete health history).
    - ☐ Yes, partial record which means information will be limited to a specific purpose (e.g. prescriptions, allergies, etc.)
    - ☐ No

Section C – Required functionalities of national electronic health record

This section of the questionnaire helps to recognize needed national electronic health record functionalities from public perspective

17. If your name and address were present, should these groups have access to your 'Complete record', 'Partial record' or Neither record?

By 'Complete record' we mean all of your detailed health information (e.g. complete health history)

By 'Partial record' we mean information will be limited to a specific purpose (e.g. prescriptions, allergies, etc.)

	Complete record	Partial record	Neither record
Doctors and nurses (e.g. deciding your treatment)			
Pharmacists (e.g. giving you medicines)			
GP receptionists (e.g. booking appointments)			
Ambulance and emergency department staff (e.g. responding to an emergency)			
Other health professionals (e.g. physiotherapists)			

18. If you have access to your national electronic health records system, please rate the importance of the following functionalities. Please indicate your answer where:
    1 = absolutely not important functionality
    5 = very important functionality

	Absolutely not important				Very important
Functionality	**1**	**2**	**3**	**4**	**5**
Electronic vaccination record					
Online information on doctors and hospitals					
Administration of appointments and reminders					
Electronic medication list (provided by the physician)					
Findings and medical images					
Online appointment booking					
Online consultation of a GP or specialist					
Providing hyperlinks to explain medical terms					
Reading progress note written by your doctor					

19. If there is a national electronic health record, would you like to add new information about your health?
    - ☐ Yes
    - ☐ No
    - ☐ Undecided
20. If there is a national electronic health record, would you like to provide or restrain consent for professionals to access your record?
    - ☐ Yes
    - ☐ No
    - ☐ Undecided
21. If there is a national electronic health record, would you like to know who have access your record?
    - ☐ Yes
    - ☐ No
    - ☐ Undecided
22. If your record was part of a national electronic records system, how would you like to be informed about bad news?
    - ☐ by a health professional
    - ☐ by reading it from your record
    - ☐ undecided

23. From your opinion, do you suggest any further functionalities to be included in the national electronic health record?

Section D – Required functionalities of national electronic health record

This section of the questionnaire helps to identify your concerns and fears when a national electronic health record developed.

24. If your record was part of a national electronic records system, would you worry about the security of your record?
    - ☐ Yes
    - ☐ No
25. If your record was part of a national electronic records system, would you worry about possible exploitation and profit-oriented use of your information?
    - ☐ Yes
    - ☐ No

26. If your record was part of a national electronic records system, would you like to receive bad news by accessing you record?
    - ☐ Yes
    - ☐ No
27. If your record was part of a national electronic records system and you discover an error in your health information, would you worry about sharing on inaccurate information between your healthcare providers?
    - ☐ Yes
    - ☐ No
28. From your viewpoint, do you have any fears when a national electronic health record developed?

Appendix B

Interview Protocol

Study Title: Layperson Perceptions and Attitudes towards National Electronic Health Record Introduction in Saudi Arabia

Protocol: One-on-One Interview.

Interview Guide:

Before the Interview:

The interviewer should specify an appropriate place to conduct the interview. She should ensure that the interviewee know the place in advance and be in the location at least 5 minutes before interview conducting time. The interviewer will attend early in the location. All required equipment such as recorder, pen, and paper will be brought by the interviewer.

Introduction and Consent:

Identify yourself by your name, age, and computer experience. The interviewees should be informed that they will be asked questions regarding their attitudes toward the introduction of national electronic health record in Saudi Arabia .

Informed Consent:

After giving the consent form, the interviewer should read that again "Your participation in this interview session is completely voluntary. You are free to stop your participation at any time. The interview session is estimated to take 15 to 20 minute, do you wish to continue and participate in the interview session today?

Permission to Audiotape:

To facilitate note-taking, the interviewer is extremely recommended to audio tape the conversations. Hence, the participant should sign the form for audiotaping. For interviewees' information, only researchers on the project will be privy to the tapes which will be eventually destroyed after they are transcribed. Otherwise, if the participant does not accept to be audiotaped, the interviewer should be ready to take notes from participants' responses. Make sure to turn ON and OFF the recorder.

Interview Question

1- Do you know what medical record is?
2- What is electronic medical record system?
3- Do you know what a national electronic health record system is?
    - If yes describe it.
    - If no, the author will provide a definition about a national EHR

4- What do you think the advantages of a national EHR system might be?
5- Do you want to access your information when it became part of national EHR? Why?
6- What language do want to view your record? Arabic English Both
7- Who should from your family able to access your record?
8- If you have a child, do you want to access his/her record?
9- Do you think there are situations in which a family member should not be able to see someone's health record? e.g. husband
10- Who should access your record from healthcare professionals?
11- How do you want healthcare professionals access your record? just part of it or all information
12- What type of information do you want to see in a national electronic health record? e.g. vaccination record, Lab result
13- Do you want to add other information to your record when it became part of a national electronic health record? What is the information you want to add? e.g allergies, over counter medication etc.
14- The researcher will provide an example of lab result and ask, how do you think you will benefit from it? What methods will help you to understand it better?
15- How do you want to be informed about any bad news related to your health? Routine blood tests, X- rays, Cancer screening, Pregnancy test, Genetic disease
16- Do you have any fears from national EHR? e.g. security, `

Warp-up:

Is there anything else you think is important for us to know regarding attitudes toward the introduction of national electronic health record in Saudi Arabia that was not covered today?

Conclusion:

Thank the interviewees for their participation.

Appendix C: First pilot study survey

Dear Participant:

My name is Jwaher Almulhem and I am a graduate student at the University of Wisconsin-Milwaukee. For my PhD dissertation, I am examining Saudi Arabian citizens’ perceptions and attitudes of national electronic health record introduction in Saudi Arabia.

I kindly request that you complete the following questionnaire regarding your attitudes towards national electronic health record. Please only complete this survey once and only if you are over the age of 18.

The national electronic health record, if developed, will collect your health information from birth to death electronically. By ‘national electronic health record’ we mean a single record that collects all health information about individual electronically instead of having several health records distributed among different healthcare facilities. It will gather all your health records which are maintained as separate records by different healthcare organizations into a single record stored electronically. As a result, all your healthcare providers will be able to exchange your health information.

If you agree to participate in this study, please answer the questionnaire as best as you can. It should take no longer than 15 minutes of your time. Your response is the utmost importance to me. There is no compensation for responding nor is there any known risk. After completing the questionnaire, please return it to the distributor.

Please do not enter your name or contact details on the questionnaire. It remains anonymous. This survey is voluntary and you may refuse to participate at any time. If you require additional information or have questions, you are welcome to email me at Almulhem@uwm.edu

Thank you for taking the time to assist me in my educational endeavors.

Sincerely,

Jwaher Almulhem

Almulhem@uwm.edu

Survey Instrument

PLEASE ANSWER THE FOLLOWING QUESTIONS BY CROSSING (X) THE RELEVANT BLOCK OR WRITING DOWN YOUR ANSWER IN THE SPACE PROVIDED.

Section A – Demographic and health information

This section of the questionnaire refers to background. The information of this section will allow us to compare groups of respondents. Once again, we assure you that your response will remain confidential. Your cooperation is appreciated.

1. What is your gender?

   ☐ Male ☐ Female

2. What is your age?

   ☐ 18-24 ☐ 25-34 ☐ 35-44
   ☐ 45-54 ☐ 55-64 ☐ 65+

3. What is the highest level of education you have completed?

   ☐ Elementary ☐ Intermediate ☐ Secondary
   ☐ Bachelor's degree ☐ Postgraduate degree

4. What is your current marital status?

   ☐ Single ☐ Married ☐ Divorced ☐ Widowed

5. Do you have children:

   ☐ Yes If yes: how many children do you have?
   ☐ No

6. Where are you from?

   ☐ Central region ☐ Eastern region ☐ Western region
   ☐ Northern region ☐ Southern region

7. How do you rate your computer skills?

   ☐ Not a computer user ☐ Beginning user ☐ Average user ☐ Expert user

8. Do you work in a health related job?

   ☐ Yes if yes: what is your job? ……………………..
   ☐ No

9. Do you have any chronic diseases?

   ☐ Yes if yes: what are the diseases?
   ……………………………………………
   ☐ No

10. Do you have any other diseases?

   ☐ Yes if yes: what are the diseases? ……………………………………..
   ☐ No

11. How many times have you used any healthcare service in the past 6 months?

☐ No healthcare used ☐ 1-3 times ☐ 4-6 time
☐ 7-9 times ☐ 10 and more times ☐ I don't know

12. Are you take care for someone who is ill, frail, elderly or disabled?

☐ Yes ☐ No

Section B – National Electronic Health Record

This section of the questionnaire helps to determine the acceptance level of national electronic health record among patients and general population. By 'national electronic health record' we mean a single record that collects all health information about individual electronically instead of having several health records distributed among different healthcare facilities. This single record can be accessed by different healthcare providers in various healthcare organizations as explained on the cover page of this survey.

13. Have you heard about the national e health strategy that will be conducted by the ministry of health?

☐ Yes ☐ No

14. Are you in favor of the development of a national electronic health records system?

☐ Yes ☐ No ☐ Undecided

15. If there is a national electronic health records system,
    - Would you want your record to be part of it for your own health care?
        - ☐ Yes, my complete record, which has all medical documents maintained about my healthcare.
        - ☐ Yes, my summarized record, which includes limited medical documents such as prescriptions, allergies, diseases etc.
        - ☐ No
    - Would you want to access your record?
        - ☐ Yes, access to my complete record, which has all medical documents maintained about my healthcare.
        - ☐ Yes, access to my summarized record, which includes limited medical documents such as prescriptions, allergies, diseases etc.
        - ☐ No
    - Would you want your record to be part of it for health services planning and policy?
        - ☐ Yes, with my name and address present
        - ☐ Yes, with my name and addressed removed
        - ☐ No

- Would you want your record to be part of it for health research?
  - ☐ Yes, with my name and address present
  - ☐ Yes, with my name and addressed removed
  - ☐ No

Section C – Required functionalities of national electronic health record

This section of the questionnaire helps to recognize needed national electronic health record functionalities from public perspective

16. If your name and address were present, should these groups have access to your 'Complete record', 'Partial record' or Neither record?

The 'Complete record' includes all medical documents maintained about your healthcare.

By 'Partial record' we mean information will be limited to a specific purpose which help healthcare professional to provide needed healthcare (e.g. prescriptions, allergies, instruction etc.)

	Complete record	Partial record	Neither record
Doctors who provide healthcare			
Nurses who provide healthcare			
Pharmacists who give you medication			
Dentists			
Receptionists for booking appointments			
Emergency department staff for responding to an emergency			
Other health professionals (e.g. physiotherapists)			

17. If you were to have access to your national electronic health record, please rate the importance of the following functionalities. Please indicate your answer where:

1 = absolutely not important
5 = absolutely very important

Functionality	1	2	3	4	5
Communication methods with doctors such as emails					
Smart phone application					
Appointments and checkups reminders					
Medical support to answer your medical questions					
Online appointment booking					
Providing a glossary that describes medical terms through hyperlinks					
Presenting medical information by easy language which can be understood by the patients					

18. If you were to have access to your national electronic health records system, which parts of your record would you want to access? Check either yes or no for all the applicable:

Document	Yes	No
Vaccination		
Lab results		
Medication list		
Image reports		
Family history		
Allergies		
Progress note		
Sick leaves		
Appointments		
Doctor’s instructions		

19. If you were to have access to your medical record and you had a question about your condition, how would you want to answer this question?

☐ Your doctor
☐ Medical website includes verified medical information
☐ Primary healthcare centers appointments
☐ Other method …………………………………………..

20. If there were a national electronic health record,

- Would you like to add new information about your health?

  ☐ Yes if yes, what is information you will add? ………………………………
  ☐ No ☐ Undecided

- Would you like to provide or restrain consent for professionals to access your record?

  ☐ Yes ☐ No ☐ Undecided

- Would you like to know who have access your record?

  ☐ Yes ☐ No ☐ Undecided

- How would you like to be informed about bad news related to your health?

If the bad news is related to non-fatal diseases:

☐ by a health professional
☐ by reading it from my electronic record

If the bad news is related to fatal diseases:

☐ by a health professional
☐ by reading it from my electronic record

- In which language would you want to read your record?
  - ☐ Arabic ☐ English ☐ Both
  - ☐ Other language what is it? ....
- Would you want your family members to access your record?
  - ☐ Yes if yes, who should access? ....
  - ☐ No go to question number 29

If your answer is yes, please answer the following question:

- Is there any medical disease information that should not be accessed by family members?
  - ☐ Yes if yes, what? ....
  - ☐ No
- Were you want to access your child's record, who is aged under 18 years old?

☐ Yes ☐ No

21. From your opinion, do you suggest any further functionalities to be included in the national electronic health record?

Section D –Concerns and fears related to introduction of national electronic health record

This section of the questionnaire helps to identify your potential concerns and fears if a national electronic health record is developed.

22. Check either yes or no:

When my record is part of a national electronic health record, I will worry about:

Question	Yes	No
Security of my record		

23. Check either yes or no:

When I access my national electronic health record, I will worry about:

Question	Yes	No
Increasing my anxiety		
Misunderstanding of medical information		
Reduce taking care of my health as a result of having complete knowledge on my disease		

24. From your viewpoint, do you have any other fears when a national electronic health record developed?

Appendix D: Second pilot study survey

Dear Participant:

My name is Jwaher Almulhem and I am a graduate student at the University of Wisconsin-Milwaukee. For my PhD dissertation, I am examining Saudi Arabian citizens' perceptions and attitudes of national electronic health record introduction in Saudi Arabia.

I kindly request that you complete the following questionnaire regarding your attitudes towards national electronic health record. **Please only complete this survey once and only if you are over the age of 18.**

The national electronic health record, if developed, will collect your health information from birth to death electronically. By '<u>national electronic health record' we mean a single record that collects all health information about individual electronically instead of having several health records distributed among different healthcare facilities</u>. It will gather all your health records which are maintained as separate records by different healthcare organizations into a single record stored electronically. As a result, all your healthcare providers will be able to exchange your health information.

If you agree to participate in this study, please answer the questionnaire as best as you can. It should take no longer than 15 minutes of your time. Your response is the utmost importance to me. There is no compensation for responding nor is there any known risk. After completing the questionnaire, please return it to the distributor.

Please do not enter your name or contact details on the questionnaire. It remains anonymous. This survey is voluntary and you may refuse to participate at any time. If you require additional information or have questions, you are welcome to email me at Almulhem@uwm.edu

Thank you for taking the time to assist me in my educational endeavors.

Sincerely,

Jwaher Almulhem

Almulhem@uwm.edu

Survey Instrument

PLEASE ANSWER THE FOLLOWING QUESTIONS BY CROSSING (X) THE RELEVANT BLOCK OR WRITING DOWN YOUR ANSWER IN THE SPACE PROVIDED.

Section A – Demographic and health information

The information of this section will allow us to compare groups of respondents. Once again, we assure you that your response will remain confidential.

1. What is your gender?

   ☐ Male ☐ Female

2. What is your age?

   ☐ 18-24 ☐ 25-34 ☐ 35-44
   ☐ 45-54 ☐ 55-64 ☐ 65+

3. What is your education level?

   ☐ Elementary ☐ Intermediate ☐ Secondary
   ☐ Bachelor's degree ☐ Postgraduate degree

4. What is your current marital status?

   ☐ Single ☐ Married ☐ Divorced ☐ Widowed

5. Do you have children:

   ☐ Yes, how many children do you have?..........................
   ☐ No

6. Where are you from?

   ☐ Central region ☐ Eastern region ☐ Alhsa region ☐ Western region
   ☐ Northern region ☐ Southern region

7. How do you rate your computer skills?

   ☐ Not a computer user ☐ Beginning user ☐ Average user ☐ Expert user

8. Do you work in a health related job?

   ☐ Yes, what is your job? ……………………..
   ☐ No

9. Do you have any chronic diseases?

   ☐ Yes, what are the diseases? ....
   ☐ No

10. Do you have any other diseases?

    ☐ Yes, what are the diseases? ……………………………………..
    ☐ No

11. How many times have you used any healthcare service in the past 6 months?

    ☐ No healthcare used ☐ 1-3 times ☐ 4-6 time
    ☐ 7-9 times ☐10 and more times ☐ I don't know

12. Are you take care for someone who is ill, frail, elderly or disabled?

    ☐ Yes ☐ No

Section B – National Electronic Health Record

This section of the questionnaire helps to determine the acceptance level of national electronic health record among patients and general population. By 'national electronic health record' we mean a single record that collects all health information about individual electronically instead of having several health records distributed among different healthcare facilities. This single record can be accessed by different healthcare providers in various healthcare organizations as explained on the cover page of this survey.

13. Have you heard about the national e health strategy that will be conducted by the ministry of health?
    ☐ Yes ☐ No

14. Are you in favor of the development of a national electronic health records system?
    ☐ Yes ☐ No ☐ Undecided

15. **If there is a national electronic health records system,**
    - Would you want your record to be part of it for your own health care?

    ☐ **Yes, my complete record**, which has all medical documents maintained about my healthcare in different healthcare organizations.
    ☐ **Yes, my summarized record**, which includes limited medical documents such as prescriptions, allergies, diseases etc.
    ☐ No

    - Would you want to access your record?

    ☐ **Yes, access to my complete record,** which has all medical documents maintained about my healthcare in different healthcare organizations.
    ☐ **Yes, access to my summarized record**, which includes limited medical documents such as prescriptions, allergies, diseases etc.
    ☐ No

    - Would you want your record to be part of it for health services planning and policy?

    ☐ Yes, with my name and address present ☐ Yes, with my name and address removed
    ☐ No

    - Would you want your record to be part of it for medical research?

    ☐ Yes, with my name and address present ☐ Yes, with my name and address removed
    ☐ No

Section C – Required functionalities of national electronic health record

This section of the questionnaire helps to recognize needed national electronic health record functionalities from public perspective

16. If you were to have access to your national electronic health records system, which parts of your record would you want to access? Check either yes or no for all the applicable:

Document	**Yes**	**No**
Vaccination		
Lab results		
Medication list		
Image reports		
Family history		
Allergies		
Progress note		
Sick leaves		
Appointments		
Doctor's instructions		

17. If your name and address were present, should these groups have access to your 'Complete record', 'Partial record' or Neither record?

The **<u>'Complete record'</u>** includes all medical documents maintained about your healthcare.

By **<u>'Partial record'</u>** we mean information will be limited to a specific purpose which help healthcare professional to provide needed healthcare (for example, pharmacist will have access to diseases and prescriptions without accessing the rest of the record.)

	Complete record	**Partial record**	**Neither record**
Doctors who provide healthcare			
Nurses who provide healthcare			
Pharmacists who give you medication			
Dentists			
Receptionists for booking appointments			
Emergency department staff for responding to an emergency			
Other health professionals (e.g. physiotherapists)			

18. If you were to have access to your national electronic health record, please rate the importance of the following functionalities. Please indicate your answer where:

1 = absolutely not important
5 = absolutely very important

Functionality	**1**	**2**	**3**	**4**	**5**
Smart phone application					
Communication methods with doctors such as emails					
Online appointment booking					
Enabling the system to identify patients' locations to facilitate healthcare provision					
Appointments and checkups reminders					
Medical support to answer your medical questions					
Providing a glossary that describes medical terms through hyperlinks					
Presenting medical information by easy language which can be understood by the patients					

19. If you were to have access to your medical record and you had a question about your condition, how would you want to answer this question?
    - ☐ Your doctor
    - ☐ Medical website includes verified medical information
    - ☐ Primary healthcare centers appointments
    - ☐ Other method ………………………………………….

20. **If there were a national electronic health record,**
    - Would you like to add new information about your health?
      ☐ Yes, what is information you will add? ……………………………
      ☐ No ☐ Undecided

    - Would you like to provide or restrain consent for professionals to access your record?
      ☐ Yes ☐ No ☐ Undecided
    - Would you like to know who have access your record?
      ☐ Yes ☐ No ☐ Undecided
    - Would you like to access your genetics disease, which you may have in future?
      ☐ Yes ☐ No ☐ Undecided
    - In which language would you want to read your record?
      ☐ Arabic ☐ English ☐ Both
      ☐ Other language …………………………

    - Would you want your family members to access your record?
      ☐ Yes, who should access? ……………………………

☐ No

If your answer is yes, please answer the following question:

Is there any medical diseases that should not be accessed by family members?

☐ Yes, what? ....
☐ No

- Were you want to access your child's record, who is aged under 18 years old?

☐ Yes ☐ No

- How would you like to be informed about bad news related to your health?

If the bad news is related to non-fatal diseases:

☐ by your doctor
☐ by reading it from my electronic record

If the bad news is related to fatal diseases:

☐ by your doctor
☐ by reading it from my electronic record

21. From your opinion, do you suggest any further functionalities to be included in the national electronic health record?

Section D –Concerns and fears related to introduction of national electronic health record

This section of the questionnaire helps to identify your potential concerns and fears if a national electronic health record is developed.

22. When your record is part of a national electronic health record, will you worry about the security of your record?

☐ Yes ☐ No

23. Check either yes or no:
When you access your national electronic health record, you will be worry about:

Question	**Yes**	**No**
Increasing your anxiety because of reading your medical record		
Misunderstanding of medical information		
Reduce taking care of your health as a result of having complete knowledge on my disease (e.g. do not go to appointment)		

24. From your viewpoint, do you have any other fears when a national electronic health record developed?

Appendix E: Final Survey

Dear Participant:

My name is Jwaher Almulhem and I am a graduate student at the University of Wisconsin-Milwaukee. For my PhD dissertation, I am examining Saudi Arabian citizens' perceptions and attitudes of national electronic health record introduction in Saudi Arabia.

I kindly request that you complete the following questionnaire regarding your attitudes towards national electronic health record. **Please only complete this survey once and only if you are over the age of 18.**

The national electronic health record, if developed, will collect your health information from birth to death electronically. By 'national electronic health record' we mean a single record that collects all health information about individual electronically instead of having several health records distributed among different healthcare facilities. It will gather all your health records which are maintained as separate records by different healthcare organizations into a single record stored electronically. As a result, all your healthcare providers will be able to exchange your health information.

If you agree to participate in this study, please answer the questionnaire as best as you can. It should take no longer than 15 minutes of your time. Your response is the utmost importance to me. There is no compensation for responding nor is there any known risk. After completing the questionnaire, please return it to the distributor.

Please do not enter your name or contact details on the questionnaire. It remains anonymous. This survey is voluntary and you may refuse to participate at any time. If you require additional information or have questions, you are welcome to email me at Almulhem@uwm.edu

Thank you for taking the time to assist me in my educational endeavors.

Sincerely,

Jwaher Almulhem

Almulhem@uwm.edu

Survey Instrument

PLEASE ANSWER THE FOLLOWING QUESTIONS BY CROSSING (X) THE RELEVANT BLOCK OR WRITING DOWN YOUR ANSWER IN THE SPACE PROVIDED.

Section A – Demographic and health information

The information of this section will allow us to compare groups of respondents. Once again, we assure you that your response will remain confidential.

25. What is your gender?

☐ Male ☐ Female

26. What is your age?

☐ 18-24 ☐ 25-34 ☐ 35-44
☐ 45-54 ☐ 55-64 ☐ 65+

27. What is your education level?

☐ Elementary ☐ Intermediate ☐ Secondary
☐ Bachelor’s degree ☐ Postgraduate degree

28. What is your current marital status?

☐ Single ☐ Married ☐ Divorced ☐ Widowed

29. Do you have children:

☐ Yes, how many children do you have?..........................
☐ No

30. Where are you from?

☐ Central region ☐ Eastern region ☐ Alhsa region ☐ Western region
☐ Northern region ☐ Southern region

31. How do you rate your computer skills?

☐ Not a computer user ☐ Beginning user ☐ Average user ☐ Expert user

32. Do you work in a health related job?

☐ Yes, what is your job? ……………………..
☐ No

33. Do you have any chronic diseases?

☐ Yes, what are the diseases? ....
☐ No

34. Do you have any other diseases?

☐ Yes, what are the diseases? ……………………………………..
☐ No

35. How many times have you used any healthcare service in the past 6 months?

☐ No healthcare used ☐ 1-3 times ☐ 4-6 time
☐ 7-9 times ☐10 and more times ☐ I don’t know

36. Are you take care for someone who is ill, frail, elderly or disabled?

☐ Yes ☐ No

Section B – National Electronic Health Record

This section of the questionnaire helps to determine the acceptance level of national electronic health record among patients and general population. By '<u>national electronic health record' we mean a single record that collects all health information about individual electronically instead of having several health records distributed among different healthcare facilities</u>. This single record can be accessed by different healthcare providers in various healthcare organizations as explained on the cover page of this survey.

37. Have you heard about the national e health strategy that will be conducted by the ministry of health?

☐ Yes ☐ No

38. Are you in favor of the development of a national electronic health records system?

☐ Yes ☐ No ☐ Undecided

39. **If there is a national electronic health records system,**

- <u>Would you want your record to be part of it for your own health care?</u>

☐ **Yes, my complete record**, which has all medical documents maintained about my healthcare in different healthcare organizations.

☐ **Yes, my summarized record**, which includes limited medical documents such as prescriptions, allergies, diseases etc.

☐ **No**

- <u>Would you want to access your record?</u>

☐ **Yes, access to my complete record,** which has all medical documents maintained about my healthcare in different healthcare organizations.

☐ **Yes, access to my summarized record**, which includes limited medical documents such as prescriptions, allergies, diseases etc.

☐ **No**

- <u>Would you want your record to be part of it for health services planning and policy?</u>

☐ Yes, with my name and address present ☐ Yes, with my name and address removed

☐ No

- <u>Would you want your record to be part of it for medical research?</u>

☐ Yes, with my name and address present ☐ Yes, with my name and address removed

☐ No

Section C – Required Functionalities of National electronic Health Record

This section of the questionnaire helps to recognize needed national electronic health record functionalities from public perspective

40. If you were to have access to your national electronic health records system, which parts of your record would you want to access? Check either yes or no for all the applicable:

Document	Yes	No
Vaccination		
Lab results		
Medication list		
Image reports		
Family history		
Allergies		
Progress note		
Sick leaves		
Appointments		
Doctor's instructions		

41. If your name and address were present, should these groups have access to your 'Complete record', 'Partial record' or Neither record?

The **'Complete record'** includes all medical documents maintained about your healthcare.

By **'Partial record'** we mean information will be limited to a specific purpose which help healthcare professional to provide needed healthcare (for example, pharmacist will have access to diseases and prescriptions without accessing the rest of the record.)

	Complete record	Partial record	Neither record
Doctors who provide healthcare			
Nurses who provide healthcare			
Pharmacists who give you medication			
Dentists			
Receptionists for booking appointments			
Emergency department staff for responding to an emergency			
Other health professionals (e.g. physiotherapists)			

42. If you were to have access to your national electronic health record, please rate the importance of the following functionalities. Please indicate your answer where:

1 = absolutely not important
5 = absolutely very important

Functionality	**1**	**2**	**3**	**4**	**5**
Smart phone application					
Communication methods with doctors such as emails					
Online appointment booking					
Enabling the system to identify patients' locations to facilitate healthcare provision					
Appointments and checkups reminders					
Medical support to answer your medical questions					
Providing a glossary that describes medical terms through hyperlinks					
Presenting medical information by easy language which can be understood by the patients					

43. If you were to have access to your medical record and you had a question about your condition, how would you want to answer this question?

☐ Your doctor
☐ Medical website includes verified medical information
☐ Primary healthcare centers appointments
☐ Other method ………………………………………..

44. **If there were a national electronic health record,**

- Would you like to add new information about your health?

☐ Yes ☐ No ☐ Undecided

If your answer is yes, please check applicable information that you would like to add:

☐ Symptoms ☐ New diseases ☐ Over the counter medications ☐ Diet
☐ Sport ☐ Allergies ☐ Other……………………

- Would you like to provide or restrain consent for professionals to access your record?

☐ Yes ☐ No ☐ Undecided

- Would you like to know who have access your record?

☐ Yes ☐ No ☐ Undecided

- Would you like to access your genetics disease, which you may have in future?

☐ Yes ☐ No ☐ Undecided

- In which language would you want to read your record?

☐ Arabic ☐ English ☐ Both
☐ Other language ....

- Would you want your family members to access your record?

☐ Yes
☐ No

If your answer is yes, please answer the following two questions:

Select all applicable family members who you would like to access your record:

☐ Parent ☐ Spouse ☐ Splining

☐ Relatives who work in healthcare field ☐ Sons and daughters

Is there any medical diseases that should not be accessed by family members?

☐ Yes ☐ No

If yes, please check the diseases:

☐ Sexual diseases ☐ Psychiatric diseases ☐ Cancer ☐ Other.........

- Were you want to access your child's record, who is aged under 18 years old?

☐ Yes ☐ No

- How would you like to be informed about bad news related to your health?

If the bad news is related to non-fatal diseases:

☐ by your doctor
☐ by reading it from my electronic record

If the bad news is related to fatal diseases:

☐ by your doctor
☐ by reading it from my electronic record

45. From your opinion, do you suggest any further functionalities to be included in the national electronic health record?

Section D –Concerns and Fears Related to Introduction of National Electronic Health Record

This section of the questionnaire helps to identify your potential concerns and fears if a national electronic health record is developed.

46. When your record is part of a national electronic health record, will you worry about the security of your record?

☐ Yes ☐ No

47. Check either yes or no:

When you access your national electronic health record, you will be worry about:

Question	**Yes**	**No**
Increasing your anxiety because of reading your medical record		
Misunderstanding of medical information		
Reduce taking care of your health as a result of having complete knowledge on your disease (e.g. do not go to appointment)		

48. From your viewpoint, do you have any other fears when a national electronic health record developed?

Curriculum Vitae

Name: Jwaher Abdullah Ibrahim Almulhem .

Education

(2014- 2017)	*Candidate in Biomedical and health Informatics PhD* *Dissertation Title: Layperson Perceptions and Attitudes towards National Electronic Health Record Introduction in Saudi Arabia*	*University of Wisconsin-Milwaukee USA*	*GPA: 3.9 out of 4*
(2012- 2014)	*Master of science in Health Care Informatics* *Thesis Title: Importance of Medical Informatics in Medical Students' Curricula in Saudi Arabia*	*University of Wisconsin-Milwaukee USA*	*GPA: 4 out of 4*
(2006- 2010)	*Bachelor of Health Information Management and Technology*	*University of Dammam Saudi Arabia*	*GPA: 4.85 out of 5*

Out- of -class activities

[7 weeks in 2003]	**- Summer training course in English and Computer in Prince Mohammad Bin Fahad Program for Qualifying and Employing Saudi Youths.**
[1st Jul 2004 - 8th Aug.2004]	**- Summer training course in English and Computer in Prince Mohammad Bin Fahad Program for Qualifying and Employing Saudi Youths.**
[25th June 2005 - 4th Aug.2005]	**- Summer training course in English and Computer in Prince Mohammad Bin Fahad Program for Qualifying and Employing Saudi Youths.**
[18th June 2006 - 27th Jul.2006]	**- Summer training course in the development of life skills in Prince Mohammad Bin Fahad Program for Qualifying and Employing Saudi Youths.**

Interest

- **Health information system.**
- **Medical informatics research**
- **Quality of health care.**

Other Activities

- **Attended the Saudi e-Health Conference in Riyadh 2008.**
- **Attended the First Health Informatics Forum in the Easter Region 2009.**
- **Attended the Big Data and Bioinformatics Conference in Boston, MA, USA 2016.**