OUTPATIENTS' ATTITUDES TOWARDS ELECTRONIC PERSONAL HEALTH RECORDS

ASSESSING OUTPATIENTS' ATTITUDES AND EXPECTATIONS TOWARDS ELECTRONIC PERSONAL HEALTH RECORDS (ePHR) SYSTEMS IN SECONDARY AND TERTIARY HOSPITALS IN RIYADH, SAUDI ARABIA

BY

OHOUD SAAD ALHAMMAD, B.Sc.

A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment
of the Requirements for the Degree Master of Science in eHealth

McMaster University

McMaster University MASTER OF SCIENCE IN EHEALTH (2017) Hamilton, Ontario

TITLE: Assessing Outpatients’ Attitudes And Expectations Towards Electronic Personal Health Records (ePHR) Systems In Secondary And Tertiary Hospitals In Riyadh, Saudi Arabia

AUTHOR: Ohoud Saad Alhammad, B.Sc. (McMaster University)

SUPERVISOR: Dr. Ann McKibbon, MLS, PhD FMLA, and Professor Emeritus, Department of Health Research Methods, Evidence and Impact

NUMBER OF PAGES: xii, 121

Supervisory Committee

Assessing Outpatients' Attitudes And Expectations Towards Electronic Personal Health Records (ePHR) Systems In Secondary And Tertiary Hospitals In Riyadh, Saudi Arabia

By

Ohoud Saad Alhammad, B.Sc.

Supervisory Committee

Dr. Ann McKibbon, MLS, PhD FMLA – **Supervisor**

Professor Emeritus, Department of Health Research Methods, Evidence and Impact

Dr. Norman Archer, M.S., PhD - **Committee Member**

Professor Emeritus, Information Systems, DeGroote School of Business

Dr. David Chan, MD, CCFP, MSc, FCFP- **Committee Member**

Professor Emeritus, Department of Family Medicine

Lay Abstract

This study is the first report of Saudi patients in the literature on electronic personal health records (ePHRs). It investigates patients' attitudes and expectations regarding ePHRs in Saudi Arabia. It also gives insights about addressing the gap between the interest and the utilization of ePHRs by presenting information about patients' preferences for ePHR features and activities. More research is needed to explore the ePHR privacy concerns of patients and the key factors in improving the use of ePHRs among specific populations.

Abstract

This study is the first report of Saudi patients in the literature on electronic personal health records (ePHRs). It investigates patients' attitudes and expectations regarding ePHRs in Saudi Arabia. It also gives insights about addressing the gap between the interest and the utilization of ePHRs by presenting information about patients' preferences for ePHR features and activities. The findings show higher interest rates in ePHR use compared to other studies with similar sample frame in developed countries. They also indicate high levels of perceived usefulness of ePHRs on patients' health and healthcare. More research is needed to explore the ePHR privacy concerns of patients and the key factors in improving the use of ePHRs among specific populations such as the elderly and those patients with chronic disease.

Dedication

For all studying mothers,

"It always seems impossible until it's done"
(Nelson Mandela)

And

For my great blessing, my children: Ibrahim, Laila, and Saad,

One day you will dedicate a book for me.

Acknowledgements

Several people left their marks on the journey of conducting this research. In this space, I would like to express my greatest gratitude to everyone who contributed in a way or another to the completion of this thesis. Special thanks go to:

- Dr. Ann McKibbon, MLS, PhD FMLA, for her kindness and patience and for providing insights and expertise that greatly assisted the research
- Dr. Norman Archer, M.S., PhD and Dr. David Chan, MD, CCFP, MSc, FCFP for their valuable feedback
- Dr. Amr Jamal, MBBS, SBFM, ABFM, MRCGP, and Haya Alhammad, BSc, for their crucial role during the data collection
- Iris Kehler for her support and guidance throughout the eHealth program
- my children, Ibrahim, Laila, and Saad, for understanding why sometimes I cannot play with them and for allowing a quiet time for me to finish my work
- my beloved husband Dr. Abdullah Alhammad for his continued support and love throughout the journey of this research and within my own life
- my dear father Saad Alhammad and dear mother Dr. Laila Alanzan for their endless love and encouragement and for their multiple trips to Canada to support me
- my brother, sisters, and family-in-law for supporting and taking care of my children
- my friends who filled my days in Canada with laughter, joy, and enthusiasm
- and finally, to the participants for their valuable time

This study was funded by King Saud University.

Table of Contents

List of Figures

List of Tables

List of Abbreviations and Symbols

Abbreviation	The meaning
CAD	Canadian Dollar
CHI	Consumer Health Informatics
EHR	Electronic Health Records
ENT	Ear, Nose and Throat
ePHRs	Electronic Personal Health Records
FOSS	Free and open source software
HIPPA	Health Insurance Portability and Accountability Act
iPad	Apple® tablet
KAUH	King Abdulaziz University Hospital
KFMC	King Fahad Medical City
KKUH	King Khalid University Hospital
KSA	Kingdom of Saudi Arabia
KSMC	King Saud Medical City
KSUMC	King Saud University Medical City
MOH	Ministry of Health
PDT	Problem, Diagnosis and Treatment
SR	Saudi Riyal
U.K.	United Kingdom

Chapter 1: Introduction

In the early 1990s, some health professionals envisioned a new form of health informatics that they thought might empower patients and transform them into functional elements in healthcare (Demiris, 2016; Ferguson, 2003). This new concept of informatics was named consumer health informatics (CHI) and was defined by Ferguson as “the study, development, and implementation of computer and telecommunications applications and interfaces designed to be used by health consumers” (Demiris, 2016; Ferguson, 2003). More detailed definition of CHI was presented by the American Medical Informatics Association, which stated that CHI is “a subspecialty in medical informatics which studies from a patient/consumer perspective the use of electronic information and communication to improve medical outcomes and the healthcare decision-making process” (American Medical Informatics Association, 2016).

The patients’ desire to be part of their health decision-making helped in disseminating the concept of CHI (Abaidoo & Larweh, 2014). Some health professionals saw this patient involvement as a potential means for saving health costs and empowering individuals to be active partners in their health care (Department of Health, 2008; Greenhalgh, Hinder, Stramer, Bratan, & Russell, 2010). These consumer health technologies can be used by healthy individuals who want to prevent diseases and maintain their health status. The technologies can also be used by patients who want to treat and self-manage their conditions (Demiris, 2016; Or & Karsh, 2009). Some examples of CHI tools are smartphone applications, self-management systems, electronic personal health records (ePHRs), patient portals and peer interaction systems (Abaidoo & Larweh, 2014).

ePHRs are consumer health tools that have the potential to transform the current healthcare model that is disease focused to a new healthcare model that motivates patients' involvement and engagement (Greenhalgh et al., 2010). According to the Markle Foundation in its report in 2003, an ePHR system is "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" (Markle Foundation, 2003). ePHRs have shown positive results in improving and facilitating the delivery of quality healthcare to consumers (Bouri & Ravi, 2014; Genitsaridi, Kondylakis, Koumakis, Marias, & Tsiknakis, 2015; Shah et al., 2015).

There has been an increase in the number of ePHR studies that have investigated this rapidly expanding area since its origin in the 1990s. However, most ePHRs were not designed according to users' needs and preferences (Archer et al., 2011; Chomutare, Fernandez-Luque, Arsand, & Hartvigsen, 2011; Greenhalgh et al., 2010; Johansen & Henriksen, 2014). In fact, to be adopted by health consumers, it is crucial to understand the users' perspectives and attitudes towards ePHRs (Greenhalgh et al., 2010). Based on the Kaelber et al paper, there is a lack of research about heath consumers' attitudes towards ePHRs and the adoption of such inventions (Kaelber, Jha, Johnston, Middleton, & Bates, 2008; Yau, Williams, & Brown, 2011). Moreover, a considerable number of studies have called for further research about assessing users' preferences regarding ePHR features and functions to address the gap between the interest and the utilization of these technologies. Although most studies showed a positive interest in using ePHRs, other studies found low utilization of the same technology (Greenhalgh et al., 2010; Johansen & Henriksen, 2014; Patel et al., 2012; Tang, Ash, Bates, Overhage, & Sands, 2006; Wagner et al., 2012). Understanding consumers' perceptions and preferences may help in increasing the use of ePHRs and enhancing the design and the functionality of these electronic records and hence alleviating the barriers to adoption (Curtis, Cheng, Rose, & Tsai, 2011; Johansen & Henriksen, 2014; Tang et al., 2006).

The consumer perspectives have been well studied in developed countries such as Canada, United States (U.S.), and United Kingdom (U.K.) (Ant Ozok, Wu, Garrido, Pronovost, & Gurses, 2014; Cocosila & Archer, 2014; Luchenski et al., 2013; McInnes et al., 2011). To date, no studies have discussed the consumers' perception towards ePHRs in the Kingdom of Saudi Arabia (KSA). This thesis intended to assess outpatients' attitudes and perceptions toward ePHRs in secondary and tertiary hospitals in Riyadh, KSA.

Chapter 2: Literature Review

In this chapter, the history and the types of ePHRs are described, and ePHR security, privacy, and costs are discussed. Moreover, the benefits of ePHRs and the barriers to adopting this technology are explained.

2.1. ePHR history and categories:

2.1.1. History

The concept of personal health records is not new. People have often created ways to keep their medical summaries in one place to be easily accessed and used. These ways were of a low-technology nature and basically consisted of collecting all or most of the person's paper-based medical documents such as physician notes, laboratory reports, personal medical diaries, and pregnancy notes in files or binders. Furthermore, parents often saved their children's medical documents such as immunizations records and development sheets in baby books to track their children's growth and health. Some people carried wallets that had medical contacts and specific emergency health information such as blood types and allergies (Noblin, Wan, & Fottler, 2012).

This non-technological accumulation of medical documents became electronic when people, especially those with chronic illnesses, started to use simple computer programs such as word processors and spreadsheets to enter their personal health information and maintain their health histories. With the invention of electronic storage devices such as CDs and flash stick memories, people started to save their electronic health histories and personal health information in these devices to be accessible when needed. More advanced ePHRs were enabled when web-based applications became available to maintain online emergency and other medical records in which individuals manually entered their health information to be accessed by physicians in emergency situations (Lober et al., 2006; Noblin et al., 2012).

Other applications that had the same concept of ePHRs were patient portals, which were initiated and managed by large health organizations in the late 1990s. Although developed early, these portals did not become popular until several years later (Demiris, 2016; Halamka, Mandl, & Tang, 2008).

The concept of ePHRs is patient-centric. The Markle Foundation in 2003 defined an ePHR system 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" (Markle Foundation, 2003). In 2006, Google and Microsoft established their own versions of ePHRs (Demiris, 2016). In 2009, the federal government in U.S. introduced an incentive program for healthcare providers which was named the Meaningful Use Program. This incentive program encouraged healthcare providers to adopt electronic health record systems (EHRs) and other health information technologies in their institutions (Demiris, 2016). One of the criteria of the Meaningful Use Program was the engagement of patients and families in their healthcare. This Meaningful Use incentive program motivated health professionals to explore ways to involve health consumers in the healthcare process. As a result, many healthcare providers in U.S. adopted ePHRs and patient portals (Demiris, 2016).

2.1.2. ePHR categories

ePHRs can be classified into three categories based on their architectural design: standalone, tethered, and integrated ePHRs (Detmer, Bloomrosen, Raymond, & Tang, 2008; Genitsaridi et al., 2015; Steele, Min, & Lo, ; Tang et al., 2006). The standalone or free-standing ePHRs require their users to manually input and update their health records. These applications are usually internet-based personal computer based applications. Some of these applications allow users to organize and store their information for free, while others charge a fee. These standalone ePHRs can be accessed anytime and anywhere, and some allow users to download the data on storage devices such as flash stick memories or CDs (Detmer et al., 2008).

Based on the challenges of manual data entry in the free-standing ePHRs, physicians may question the accuracy, the validity, the completeness of these records, and the consequences of incorrect information on the treatment process (Detmer et al., 2008; Witry, Doucette, Daly, Levy, & Chrischilles, 2010). In fact, some physicians have assumed that patients might not be consistent in creating and updating their files online (Witry et al., 2010). Some studies suggested that these standalone personal health records, which serve as repositories of patients' health data, might not be beneficial in helping patients to manage their health (Johansen & Henriksen, 2014). Moreover, some types of these standalone records might be lost or destroyed with the loss of personal computers (Detmer et al., 2008).

Integrated or interconnected ePHRs are web-based ePHRs that collect the patient's medical or health information from different sources such as providers' EHRs, insurance claims, pharmacy records, wearable devices, and home diagnostic tools. This automated entry can eliminate the re-entry of the data by consumers and thus eliminating the duplication of information. These types of ePHRs can be shared with health providers and may provide more comprehensive records about patients. Consumers may also have the ability to input their information in some sections in these first two types of ePHRs. Moreover, integrated ePHRs can be used as communication tools between providers and their patients. The integrated tools also have the potential to reduce medical errors and improve the healthcare quality and efficiency (Detmer et al., 2008).

Tethered ePHRs are web-based ePHRs that are linked to one source of medical information and provide consumers with access to some sections of their EHRs through web portals (Detmer et al., 2008; Tang et al., 2006). This source of data is usually a specific healthcare organization health system (e.g., an EHR) or database. These tethered ePHRs may allow users to order medication refills, book follow-up appointments, and communicate with their health providers via secure messaging systems or e-mails. In these ePHRs, clinicians control all of the patients' data, and patients are allowed to only view the data without modifying or changing them. However, a number of tethered ePHRs allow users to add or annotate some sections in their medical records (Abaidoo & Larweh, 2014; Detmer et al., 2008).

The ideal ePHR should hold a lifetime comprehensive health record that is collected from all of the patient's health-related sources. Each piece of information should be labeled by the source that provided it (Tang et al., 2006). Based on the literature, the category that has the most potential effect in empowering and strengthening consumers to manage their health and transforming them to active healthcare partners is the integrated ePHRs. These ePHRs have shared access by both providers and patients (Detmer et al., 2008; Johansen & Henriksen, 2014; Tang et al., 2006). Integrated ePHRs help ensure the completeness, the depth, the accessibility, and the portability of patient's medical information (Detmer et al., 2008).

2.2. ePHR Security and privacy

Security and privacy are significant issues that are associated with every type of electronic health application, including ePHRs. ePHRs may provide more means of protection to consumer's health information than traditional paper-based records through the use of password-protected applications and audit tracking. However, the potential risk of invading the privacy of paper-based records is relatively low since these records are physically stored in specific places, unlike ePHRs that might be shared electronically among multiple places (Kaelber et al., 2008).

The U.S. Health Insurance Portability and Accountability Act (HIPPA), which was established in 1996, clarifies the legal protection for ePHR privacy and security in the U.S. HIPPA regulates only the "covered entities" such as health plans and healthcare providers. As a result, some issues cannot be addressed and regulated by HIPPA. For example, some new ePHRs are not covered by HIPPA since their developers are not considered covered entities. For this reason, there is a need for regulations that can address these ePHRs uncovered entities (Kahn, Aulakh, & Bosworth, 2009). However, a new ePHR is usually covered by the privacy and security regulations of the organization that is offering it (MAXIMUS Federal Services, 2012; U.S. Department of Health & Human Services, 2016).

In a number of studies, health providers showed a concern about the privacy and the security of ePHRs, especially for stigmatized conditions such as HIV (McInnes et al., 2011; Witry et al., 2010). Contrary to the views of physicians, most patients with stigmatized conditions in these studies did not see a difference in ePHR privacy concerns between their conditions and other conditions such as diabetes (McInnes et al., 2011).

Similarly, in some studies, most of the users of ePHR were not concerned about the privacy and security of their health information. For example, two-thirds of consumers were concerned about these privacy and security issues (Archer et al., 2011; California HealthCare Foundation, 2016). In fact, the literature showed that frequent users of healthcare services including patients with chronic and acute conditions are less concerned about the privacy and the security of their health information online than are the health providers (Archer et al., 2011; Hassol et al., 2004). Some studies suggested that receiving reminders and education through ePHRs would be more secure than receiving them through messages or e-mails (McInnes et al., 2011).

Sharing personal health information with the individual’s health providers and family is one of the most important and desirable features of ePHRs. The fact that some ePHRs do not allow consumers to control or filter shared information may inhibit some patients from using such features (Cushman, Froomkin, Cava, Abril, & Goodman, 2010).

Moreover, some privacy issues are associated with ePHRs that are connected with personal health monitoring devices. Some people perceive these types of ePHRs connected to monitoring devices such as 24-hour surveillance systems that can invade an individual’s privacy (Cushman et al., 2010). In addition, some studies showed that vulnerable people might have some privacy issues regarding the use of ePHRs. For example, elderly and people with mental illnesses might have impairments in judgment that might hinder them from making good decisions regarding the collection and the storage of their health information (Cushman et al., 2010).

Data security issues may also arise with ePHRs since they collect, store, and exchange personal health information (Cushman et al., 2010). Exchanging personal data among different health providers requires ePHR platforms to be highly secured and protected (Cushman et al., 2010). Furthermore, privacy and security issues arise from ePHRs that have social networking and online communities features (Cushman et al., 2010).

Authentication might be also a challenge in the ePHR world. Authentification involves who controls sharing and accessing personal health information in ePHRs. Authentication is very important in some types of ePHRs such as integrated ePHRs where multiple health providers use and exchange personal health information from one person. For other types of ePHRs such as standalone ones, it is difficult to authenticate a patient. This may affect the patient's privacy since the unauthenticated information may be a unique identifier of the patient (Tang et al., 2006).

2.3. ePHR architecture and functionality

In this section, the architecture and the functionality of ePHRs will be discussed. ePHR systems can be divided into three major segments: data, infrastructure, and applications. Data are the types of information that are being processed, exchanged, analyzed, and stored in ePHRs. Infrastructure is the computing systems and platforms that are exchanging, processing, analyzing, and storing patients' health data such as software packages, functions, and websites. Lastly, applications are the computing system capabilities that depend on infrastructure and data to perform certain tasks on healthcare data. Exchanging and transactional capabilities such as requesting medication refills and scheduling appointments are examples of ePHR applications (Kaelber et al., 2008).

According to the literature, the ideal ePHR should be able to perform several features to be successfully adopted by consumers (Genitsaridi et al., 2015; Jones et al., 1999; Kahn et al., 2009). The first feature is that ePHRs should use free and open source software (FOSS). This feature is needed to free consumers from any financial restrictions in using ePHRs, including the costs and information distribution restrictions (Genitsaridi et al., 2015). With this FOSS capability, consumers can perform many actions without limitations such as copying and redistributing their information (Genitsaridi et al., 2015).

Moreover, ePHRs should have a web-based nature. This web-based feature may promote the portability and the accessibility of ePHRs to be used anytime and anywhere from any computer that is connected to the Internet and has a browser (Genitsaridi et al., 2015; Kahn et al., 2009). Web-based systems can also allow users to access their ePHRs through mobile devices such as smartphones and tablets (Genitsaridi et al., 2015). Therefore, this feature of being web-based enhances usage flexibility and the interoperability of ePHRs, thus eliminating the need to download or install additional software (Archer et al., 2011; Genitsaridi et al., 2015; Tobacman et al., 2004).

A recent study recommended that the ePHR development process should be based on edge computer technologies to ensure its maintainability, expandability, and interoperability. This development process will likely enhance the healthcare services quality (Genitsaridi et al., 2015). More importantly, ePHRs should be guided by high-quality standards to be widely recognized as a high-quality product. In fact, three recognized standards were established to certify the design and architecture of ePHRs: the International Organization for Standardization (ISO) (Genitsaridi et al., 2015; the International Organization for Standardization, 2014), the Personal Health Record System Functional Model by Health Level Seven (HL7) organization (Genitsaridi et al., 2015; Health Level Seven International, 2016), and the Meaningful Use program by U.S. Office of National Coordinator for Health Information Technology (ONC) (Genitsaridi et al., 2015; Health information technology, 2014). The following paragraph has a brief description of these three standardization efforts.

ISO has established different standard series that can be applied to ePHRs. Some of their standards provide guidance in evaluating electronic products' processes and activities. Other ISO standard series set criteria for the characteristics of successful electronic products and their human-interaction status including the security, efficiency, satisfaction, usability, portability, and maintainability of the digital product (Genitsaridi et al., 2015; International Organization for Standardization, 2014).

The HL7 staff has created a functional model that provides guidance for developing a successful ePHR (Genitsaridi et al., 2015; Health Level Seven International, 2016).

The Meaningful Use program is a program that sets criteria to allow hospitals and health providers to receive incentives for adopting EHR technology. One of their criteria is to engage patients and families in their healthcare by different means including providing patients with clinical summaries and electronic copies of their health information (Genitsaridi et al., 2015; Health information technology, 2014).

Different studies have looked into the types of personal information and functions that should be included in ePHRs (Archer et al., 2011; Genitsaridi et al., 2015; Jones et al., 1999; Kahn et al., 2009; Tang et al., 2006; Witry et al., 2010). In general, ePHR functions can be categorized into five groups (Genitsaridi et al., 2015). The first group is called Problem, Diagnosis, and Treatment (PDT), or information collection group, and it includes all the basic health information such as the patient's past medical history, current health problems and diagnosis, treatment plans, procedures, and medications (Archer et al., 2011; Genitsaridi et al., 2015; Witry et al., 2010). Recording the patients' health problems and allergies, and recording the treatment process and procedures are two examples of PDT functions that should be included in ePHRs (Genitsaridi et al., 2015). The type and the nature of the patient's health problem(s) will likely determine the types of ePHR functions one prefers (Archer et al., 2011). Although some studies showed that many people prefer to see different types of information in their ePHRs, only a few patients agreed to include their psychological and social problems in these records (Jones et al., 1999). ePHRs with comprehensive patients' health records are believed to be useful to both physicians and patients (Archer et al., 2011).

The second group of functions encompasses all the functions and services that help consumers in monitoring and following their own health parameters such as prevention and wellness reminders (Genitsaridi et al., 2015; Tang et al., 2006). These services are called self-management or self-health monitoring functions, and they include all the functions that allow patients to record or track their own health activities (Archer et al., 2011; Genitsaridi et al., 2015; Kaelber et al., 2008).

The third group of services is called communication management or information sharing and exchange group (Archer et al., 2011; Genitsaridi et al., 2015).

It includes all the functions and the services that allow patients to manage their communications with the health team. Scheduling appointments, sending messages to health professionals, renewing prescriptions, and processing claims and payments are all communication management services that should be included in ePHR records (Genitsaridi et al., 2015; Johansen & Henriksen, 2014; Tang et al., 2006).

The fourth group includes all the services and functions that are related to the security of ePHRs. Functions such as authentication, authorization, audit, delegation and data security are examples of security and access control services (Genitsaridi et al., 2015). According to the literature, some functions in the security and access control group are rarely found in current ePHRs. For example, the delegation of access functions that help patients to give access to certain data in their ePHRs to specific health providers is often lacking (Genitsaridi et al., 2015). These types of functions and services are crucial in useful ePHRs (Genitsaridi et al., 2015).

The fifth and the last group of functions is called intelligence factors group, and it includes the functions that provide intelligent behavior actions in ePHRs. Services and functions such as educational resources, data presentations, data exports that output the data in useful formats, data filters, and decision support functions are examples of intelligence factors group that should be included in ePHRs (Genitsaridi et al., 2015).

Some studies suggested that ePHRs should include all the information that is relevant to an individual's health such as information about family members, caregivers, and information about home and work environments (Tang et al., 2006). All of this information should be explained and displayed in a way that can be digested by health consumers (Archer et al., 2011; Earnest, Ross, Wittevrongel, Moore, & Lin, 2004; Noblin et al., 2012; Segall et al., 2011; Tang et al., 2006). ePHR records that encompass all of these features and information may have a remarkable effect on transforming patients into active partners in healthcare (Kahn et al., 2009).

2.4. ePHR Policies and Costs

The literature suggested that ePHR records have a great potential in improving the quality and reducing the costs of healthcare services (Detmer et al., 2008; Greenhalgh et al., 2010). Organizations are hoping that empowering consumers to manage their own health by providing them with more health information and guidance may eventually increase the healthcare quality and hence may reduce costs in healthcare (Abaidoo & Larweh, 2014).

Healthcare providers might see that adopting ePHRs would help in promoting their institutions in the marketplace as good competitors in certain healthcare settings. Incentives might play a great role in encouraging healthcare providers to adopt ePHRs (Tang et al., 2006). For this reason, governments in many countries might have a significant role in promoting the adoption of ePHRs by health providers. One of the ways likely to increase use is to establish standards for ePHR infrastructures, features, and contents. Another way is to provide incentives or tax deductions to providers who implement ePHRs in their organizations (Tang et al., 2006).

2.5. ePHR benefits

Despite the limited evidence supporting the benefits of ePHRs, the literature showed numerous potential benefits of ePHR records in creating new models of care that depend on patients' participation (Czaja et al., 2015; Ralston et al., 2009). This model might lead to improvements in healthcare services utilization and chronic diseases management (Czaja et al., 2015; Tang et al., 2006). Moreover, different studies reported potential benefits of ePHR records in decreasing the errors and enhancing patient's experience in healthcare (Chang et al., 2004; Detmer et al., 2008; Kahn et al., 2009; Turner, Klaman, & Shea, 2016). Examples of these benefits include empowering patients to improve their own health, reducing administrative costs, and enhancing the patient-provider communication. In this section, the potential benefits of ePHRs will be explained in terms of ePHR benefits on the patient-provider communication, patients' education and lifestyle, and overall healthcare benefits (Jones et al., 1999; Kahn et al., 2009).

2.5.1. ePHR Benefits to providers and the nature of patient-provider communication

Even though some physicians expressed concerns about ePHR effects on the patient-provider relationship (Yau et al., 2011), a study showed that the access to an online ePHR enabled patients to gain more trust and confidence in their physicians (Fisher, Bhavnani, & Winfield, 2009). That access made patients feel empowered and involved as active partners with their doctors (Bird & Walji, 1986; Fisher et al., 2009; Jones et al., 1999; Markle Foundation, 2003; Noblin et al., 2012; Tomson, 1985; Witry et al., 2010). Improving patient-provider communication is believed to be one of the major potential benefits that ePHRs might have on healthcare (Archer et al., 2011; Jones et al., 1999; Noblin et al., 2012; Tang et al., 2006; Yau et al., 2011). This belief might stem from the idea that patients could contact their health providers to inquire about their online personal data to better understand it (Yau et al., 2011). This process can enable an ongoing continuous connection between the physician and his/her patients (Tang et al., 2006). A paper showed an increase in patients' communication through the email system with their health providers' clinics after implementing a web portal to help patients in self-managing their conditions (Archer et al., 2011). Additionally, ePHRs might improve the efficiency of the patient-provider relationship and free physicians from un-needed face-to-face communication (Tang et al., 2006). Another study showed a reduction in clinic visits and telephone calls among patients who used ePHRs (Zhou, Garrido, Chin, Wiesenthal, & Liang, 2007).

Besides the patient-provider communication benefits, physicians may also benefit in other domains from ePHRs in their practice. For example, in emergency situations, the access to a patient's ePHR records might be crucial to manage the health problem when the patient's hospital or clinic record is not available (Abaidoo & Larweh, 2014; Witry et al., 2010). ePHRs that combine information from different healthcare centers could serve as comprehensive tools that might be important to healthcare providers (Abaidoo & Larweh, 2014). In a study that investigated physicians' attitudes towards patient-held records, half of the physician sample thought that integrated patient records contained critical information about their patients (Jones et al., 1999). Obtaining more data about the patient might help physicians to make better decisions (Tang et al., 2006). Another study showed that family physicians believed that ePHRs could lead to positive changes in healthcare (Yau et al., 2011).

However, several concerns were raised by physicians about using ePHRs. One of the concerns was related to the data management of patients' online information.

Physicians were concerned about the security, privacy, and backup of patients' information while using these types of electronic systems (Cushman et al., 2010; McInnes et al., 2011; Witry et al., 2010; Yau et al., 2011). Moreover, some clinicians showed concerns about the quality of the information included in ePHRs since physicians might record less information on electronic charts that might be accessible to patients (Archer et al., 2011; Yau et al., 2011). Physicians believe that some patients might develop unnecessary anxiety from misinterpreting their electronic records. This anxiety might also develop from the absence of the traditional face-to-face communication between the doctor and his or her patients (Yau et al., 2011). However, some studies showed that the lack of face-to-face communication was not a concern for patients who used information and communication technology (Abaidoo & Larweh, 2014; Akesson, Saveman, & Nilsson, 2007; Chen, Garrido, Chock, Okawa, & Liang, 2009; McInnes et al., 2011).

In addition, physicians expressed concerns regarding the accuracy and the liability of data in ePHRs that allow consumers to input their own health information (Archer et al., 2011; Cushman et al., 2010; Tang et al., 2006; Witry et al., 2010). The use of inaccurate or incomplete health data might harm the patient and subject the physician to legal charges (Cushman et al., 2010; Detmer et al., 2008; Tang et al., 2006).

Another concern was about the practice management while using ePHRs. Using ePHRs might lead to an increase in physicians' responsibilities and workloads and a decrease in patients' visits, especially when ePHRs are used as an electronic outreach for disease screening that might lead to unmanageable workloads (Detmer et al., 2008; McInnes et al., 2011; Yau et al., 2011). In addition, the current billing models might not compensate physicians for this new workload (Archer et al., 2011; Detmer et al., 2008; McInnes et al., 2011; Yau et al., 2011). Moreover, doctors expressed concerns about their responsibilities in ePHRs and the guardianship of patients' data (Yau et al., 2011). In a different study, clinicians showed some concerns that ePHRs might promote drug abuse. In this study, family physicians were concerned that ePHRs may allow patients to inappropriately obtain prescriptions for narcotic drugs (Witry et al., 2010).

Physicians saw that integrating ePHRs with hospital or clinic EHRs might have a great value in promoting the adoption of ePHRs by physicians (Yau et al., 2011). In addition, proving the added value of such technologies to health practices, without being a burden in cost and time, might also be significant in adopting ePHRs by health providers (Detmer et al., 2008; Segall et al., 2011; Yau et al., 2011). Some studies suggested that physicians were not familiar with ePHRs and their potential benefits (Greenhalgh et al., 2010; Weitzman, Kaci, & Mandl, 2009; Wynia & Dunn, 2010). This unfamiliarity might hinder the adoption of ePHRs by physicians (Witry et al., 2010). It might also affect their desire to promote ePHR use among patients (Witry et al., 2010). For this reason, some studies called for educating physicians about the benefits of ePHRs in empowering patients to gain control over their health (Tang et al., 2006). Moreover, some studies suggested that both patients and physicians should learn to trust each other to support this technology (Tang et al., 2006). Physicians should teach their patients how to input their health information accurately in ePHRs, so physicians can use this information appropriately (Tang et al., 2006).

2.5.2. Patients education and lifestyle benefits

ePHR records could be a source of education for both patients and clinicians (Johansen & Henriksen, 2014; Markle Foundation, 2003). ePHR records which allow patients to input their information could help physicians to learn more about their patients for better decision-making process (Archer et al., 2011).

One of the potential benefits of ePHRs is that patients could have access to valid trustworthy health information and knowledge (Tang et al., 2006). Consumers could use this knowledge to improve their health conditions and to promote improvement in the quality of their lives (Kahn et al., 2009; Tang et al., 2006). Some clinicians believed that ePHRs might generate better health outcomes and encourage patients to be more involved in their health (Witry et al., 2010).

Moreover, the literature showed that ePHR records have a great potential to be used for electronic outreach and social marketing (McInnes et al., 2011). For example, ePHRs could be an efficient tool in educating patients about disease screening, especially because some physicians report that the traditional way of repeatedly asking patients to screen seemed to have lost its effectiveness (McInnes et al., 2011). In a study, patients revealed that receiving messages electronically gave them the flexibility of accessing these outreach messages as much as they wished at any time (McInnes et al., 2011). Patients also noted that these messages should be designed and presented in a simple way that could be easily digested by people with low literacy levels (McInnes et al., 2011). Furthermore, some patients found that receiving electronic messages about screening for diseases such as HIV was acceptable and useful (McInnes et al., 2011). Consumers were motivated to receive education and more information about their health using the Internet as a medium, and physicians found that medium to be a great way in reinforcing doctors' recommendations (McInnes et al., 2011).

Studies showed that patients with chronic diseases and disabilities were more interested in using and adopting ePHRs that would enable them to access their health information and monitor their health (Archer et al., 2011; D. B. Lafky & T. A. Horan, 2008; Markle Foundation, 2003; Tang et al., 2006; Winkelman, Leonard, & Rossos, 2005). A study reported that patients who practiced self-management were highly interested in using ePHRs especially in emergency situations (Archer et al., 2011; Winkelman et al., 2005). Patient-provider communication and patient engagement in health are critical components of effective self-management efforts (Heisler, Bouknight, Hayward, Smith, & Kerr, 2002; Noblin et al., 2012). Patients who were involved in their health were able to be active partners with the health team to manage their illness, improve medication adherence, and produce better health outcomes (Archer et al., 2011; Tang et al., 2006).

A number of studies emphasized the potential benefits of ePHR records in helping consumers managing their conditions (Archer et al., 2011; Delbanco et al., 2012; Hess et al., 2007; Jerden & Weinehall, 2004; Johansen & Henriksen, 2014). Some patients declared that they would be able to manage and monitor their illnesses at home if they had access to their medical information online (Noblin et al., 2012). Providing patients with chronic disease with access to their records would allow them to record, edit, and track their health measurements in a conjunction with their health team for better management of the disease (Demiris et al., 2008; Tang et al., 2006). Monitoring the disease signs and symptoms could help in early detection and treatment of serious conditions (Demiris et al., 2008; Tang et al., 2006). Some patients reported changes in their lifestyles including better exercise and diet after six months of using ePHRs (Archer et al., 2011; Jerden & Weinehall, 2004). Patients also reported increased control over their conditions and adherence to medications after one year of using ePHRs (Delbanco et al., 2012). Participants who used an ePHR portal that was created to help patients self-manage diabetes reported that the reminder systems in the portal were useful and helpful (Hess et al., 2007). A study by Archer et al showed improvements in patients understanding as a result of patients' access to their laboratory test results and the patient-provider communication through ePHRs (Archer et al., 2011). A paper by Johansen and Henriksen found enhancements in patients' satisfaction levels as they felt safer and motivated to take care of their illnesses (Johansen & Henriksen, 2014). Moreover, some studies reported slight positive changes in hypertension and diabetes measures after using ePHR records (Johansen & Henriksen, 2014; Tenforde, Jain, & Hickner, 2011; Wagner et al., 2012). A study that measured the patients' satisfaction about ePHRs found good utilization and adoption results and positive attitudes towards ePHRs (Silvestre, Sue, & Allen, 2009).

Most ePHRs were not designed according to users preferences and personal self-management practices (Archer et al., 2011; Chomutare et al., 2011; Johansen & Henriksen, 2014). As a result, these ePHRs do not necessarily support self-management (Archer et al., 2011; Chomutare et al., 2011; Greenhalgh et al., 2010; Johansen & Henriksen, 2014). For that reason, some studies showed poor adoption of ePHRs (Greenhalgh et al., 2010; Johansen & Henriksen, 2014; Wen, Kreps, Zhu, & Miller, 2010). Assessing the needs of patients with chronic disease is crucial to designing successful ePHRs that could be easily adopted (Archer et al., 2011).

Moreover, some studies showed that providing patients with ePHRs without educating them about the use of this technology would affect the degree of the improvements in patients' satisfaction, health services utilization, and other health outcomes (Archer et al., 2011; Wagner et al., 2012; Winkelman et al., 2005).

2.5.3. Overall healthcare benefits

In addition to ePHR benefits to physicians and patients, ePHR records could benefit healthcare payers and the purchasers in decreasing the overall costs of medications and chronic disease management costs (Curtis et al., 2011; Tang et al., 2006). Moreover, the use of ePHR records may help health institutions in decreasing the physicians' workload and the time need for scheduling and follow-up appointments (Curtis et al., 2011). To sum up, ePHRs promoted the concept of the continuity of care since they facilitated the access to patients' health information by different health organizations (Curtis et al., 2011).

2.6. ePHR barriers to adoption

Some studies showed that providing consumers with access to their health information was not enough to produce changes in their health outcomes (Wagner et al., 2012). A number of studies reported a great interest in using ePHR records but with low rates of utilization (Ancker, Silver, & Kaushal, 2014; Greenhalgh et al., 2010; Jeffs, Nossar, Bailey, Smith, & Chey, 1994; Jones et al., 1999; Kaelber et al., 2008; Roblin, Houston, Allison, Joski, & Becker, 2009; Segall et al., 2011; Weitzman et al., 2009; Wen et al., 2010; Wynia & Dunn, 2010). More papers showed that although patients perceive the importance of ePHRs, they might experience some challenges in using this technology (Segall et al., 2011). According to the literature, a couple of factors might be associated with promoting the use and the adoption of ePHRs (Archer et al., 2011; Greenhalgh et al., 2010; Jian et al., 2012; Johansen & Henriksen, 2014; Tang et al., 2006; Wagner et al., 2012).

One factor is in assessing potential users' needs and attitudes regarding ePHRs in order to design an ePHR tool that can be tailored to their demands. The literature showed that health outcome improvements were sometimes associated with tools that were tailored and personalized to user preferences (Archer et al., 2011; Gibbons et al., 2009). Some studies showed that most current ePHRs were not designed and developed according to users' needs, and this might contribute to ePHR records being abandoned or not adopted (Archer et al., 2011; Chomutare et al., 2011; Greenhalgh et al., 2010; Johansen & Henriksen, 2014; McInnes et al., 2011). Assessing the needs process should include all the related aspects of individuals who might be affected by ePHRs such as patients' attitudes and needs, as well as physicians' time value and work routines (Greenhalgh et al., 2010; Jian et al., 2012; McInnes et al., 2011). In a study that investigated the factors that affect the adoption of ePHRs, authors found that users' intentions and perceived usefulness of ePHRs would have major impacts on their adoption of ePHR records (Jian et al., 2012).

The adoption of any similar technology requires users to acquire Internet access and to be familiar with using computers to address their needs (Kahn et al., 2009). The availability of Internet access and fair computer competency are crucial in promoting ePHRs usage and adoption (Ancker et al., 2014; Kahn et al., 2009). In studies that investigated users experience while using ePHRs, authors found that most patients experienced difficulties while trying to view and manage their data through ePHRs (Ancker et al., 2014; Archer et al., 2011; Greenhalgh et al., 2010; Hess et al., 2007; Hibbard et al., 2008; Segall et al., 2011; Tang et al., 2006; Tobacman et al., 2004). These difficulties were often associated with the design and user interaction aspects of these electronic records (Greenhalgh et al., 2010; Segall et al., 2011). To increase the adoption of ePHRs, patients should have the educational and technical support that would help them overcome the technology barrier of using ePHRs (Archer et al., 2011; Kahn et al., 2009; Segall et al., 2011). Increasing the usability of ePHRs would likely have a major impact on its adoption (Archer et al., 2011; Greenhalgh et al., 2010; Pagliari, Detmer, & Singleton, 2007; Segall et al., 2011; Tang et al., 2006). In addition to that, integrating ePHRs in users' daily lives would probably improve the sustainability of ePHRs (Kahn et al., 2009). For example, allowing patients to access their personal health records through their mobile phones would likely increase the usage of this technology (Kahn et al., 2009).

Other factors that might affect the adoption of ePHRs are patients' lack of trust of their providers (Ancker et al., 2014; Archer et al., 2011; Detmer et al., 2008; Lyles et al., 2013), and patients' health literacy levels and their ability to interpret the received online information and use it to promote their own health and wellbeing (Kahn et al., 2009; Noblin et al., 2012; Segall et al., 2011). Some studies suggested that patients' understanding of online health information was a barrier that should be addressed to achieve the optimal benefits of ePHRs (Archer et al., 2011; Kim et al., 2009; Noblin et al., 2012; Segall et al., 2011).

A study suggested that health education should be started as early as elementary school years and that students should be introduced to simple ways and tools that could promote and manage their health (Tang et al., 2006). Moreover, this study recommended that medical schools should include in their curriculum EHR and ePHR education, and different ways to encourage and motivate patients to adopt these technologies (Tang et al., 2006). Providers' lack of awareness and preparedness to ePHRs might hinder the patients' adoption to such technology (Archer et al., 2011).

Furthermore, studies suggested that patient information in ePHRs should be presented in a clear simple way that could be understandable by the target population (Archer et al., 2011; Noblin et al., 2012; Segall et al., 2011; Tang et al., 2006). A study showed that patients prefer to see their information presented as a summary instead of a full record (Jones et al., 1999).

Another element that might increase the adoption of ePHRs is integrating these records with the clinicians' EHRs to provide a comprehensive source of health information to patients and physicians (Archer et al., 2011; Johansen & Henriksen, 2014; Kahn et al., 2009; Winkelman et al., 2005; Yau et al., 2011). Some studies showed low uptake of ePHRs that were not linked to hospitals' EHRs (Greenhalgh et al., 2010). In these studies, patients reported that they were disappointed because they expected to access and view their complete medical records in an ePHR (Greenhalgh et al., 2010). The potential benefits of integrated ePHRs probably outweigh the benefits of standalone ones. ePHRs that are integrated to physician EHRs could have more valuable information and features, such as maintenance and backup, for patients than other types of ePHRs (Tang et al., 2006).

In addition, designing social networks and forums within ePHRs were believed to have great impacts on changing and supporting users' behaviors through the power of peer support (Archer et al., 2011; Eysenbach, 2008; Kahn et al., 2009). This design might motivate patients to use and adopt ePHRs to engage with support groups and gain experience from other patients who have similar conditions (Kahn et al., 2009).

Furthermore, creating technical and interoperability standards that could guide the design, development, and accessibility of ePHRs might promote use and adoption of these records (Detmer et al., 2008; Kahn et al., 2009). The absence of these technical standards has likely led to a slow adoption of ePHRs among providers and patients (Detmer et al., 2008; Kahn et al., 2009).

Lastly, understanding and investigating the reasons behind the failure of some existing ePHRs and the barriers to ePHR use are crucial in promoting the adoption of this technology (Greenhalgh et al., 2010; Kaelber et al., 2008; Segall et al., 2011). Measuring the sustainability or the degree to which a technology continues to be accessed by the users could be a significant indicator of ePHR success (Archer et al., 2011). Studies suggested that the support of health stakeholders and patients would promote the use of ePHRs in health institutions, thus probably increasing the adoption of these records (Curtis et al., 2011; Roblin et al., 2009). Moreover, literature recommends that education and research are critical elements in increasing ePHR adoption (Tang et al., 2006).

In conclusion, literature showed a great potential of ePHR records in shifting the healthcare focus from physician-centered care to patient-centered care in which health consumers act as partners to promote and manage their health. However, the adoption of ePHRs is associated with several barriers that might hinder ePHR ability to reach their optimal benefits. Lack of trust and technical standards, security and privacy, usability, and health literacy are some of the barriers that should be addressed to promote the use and the adoption of ePHR records.

Chapter 3: Methods

In this chapter, the design of the study, development of the survey, and the research ethics approval processes in Canada and KSA are described.

3.1. Study design

This cross-sectional descriptive study was conducted in four secondary and tertiary care hospitals in Riyadh, KSA. A survey was designed to assess adult outpatients' attitudes and perceptions toward ePHRs. The study took place in the waiting areas of the hospitals.

3.2. Study setting

3.2.1. Kingdom of Saudi Arabia (KSA)

KSA is a developing country that is located in Asia and has a total population of 31,540,000 (World Health Organization (WHO), 2016). Comes in the third place after China and India, KSA is considered to be the largest developing country and has contributed to the global improvement movement (Markle Foundation, 2003).

Since the establishment of KSA, public health and disease control have been considered to be the top priorities of the country (Ministry of Health - KSA (MOH), 2016a; Patel et al., 2011). In 1925, King Abdulaziz, the founder of KSA, created the first public health department in Mecca. In the same year, the Public Health and Ambulance unit was founded and helped in building different health centers for citizens (Ministry of Health - KSA (MOH), 2016a). During the past decades, the government of KSA has exerted major efforts to improve the quality of healthcare services (Bouri & Ravi, 2014). As a result, the number of hospitals and medical institutions has increased dramatically in the country (Bouri & Ravi, 2014).

The major reason for the early need to establish a health department stemmed from the need to care for Hajj and Umrah performers. Hajj is an Islamic pilgrimage event that happens annually in Mecca. At Hajj season, large numbers of people making pilgrimages come from more than 183 countries to perform Hajj (Markle Foundation, 2003). The Saudi General Authority for Statistics revealed that the total number of pilgrimages in 2016 was 1,862,909 (General Authority for Statistics - KSA, 2016). The existence of these large numbers of people in small areas could generate various health risks such as infections, skin disorders, and food-related diseases and injuries. This threat created a need to design an effective health infrastructure that could help in preventing and controlling such risks (Ministry of Health - KSA (MOH), 2016a). This infrastructure was established and included 177 primary medical clinics and 27 hospitals to serve people in the Hajj period (Markle Foundation, 2003).

Health care services, which are provided free of charge to Saudi citizens, are primarily provided by the Ministry of Health (Ministry of Health - KSA (MOH), 2016a). Recently, the MOH has followed a new delivery care model that reinforces the integration of health services throughout KSA (Markle Foundation, 2003). The ministry vision is to “improve the equability, standards, availability and quality of care in the Kingdom of Saudi Arabia” (Ministry of Health - KSA (MOH), 2016a).

To fulfill this vision, the MOH has created a 5-year plan that includes electronic health as a significant factor in enabling the main vision (Ministry of Health - KSA (MOH), 2016a). For this reason, MOH has created a 5-year eHealth strategy that aligns closely with MOH goals. The eHealth strategy calls for “A safe, quality health system, based on Patient Centric Care guided by standards, enabled by eHealth” (Ministry of Health - KSA (MOH), 2016b).

3.2.2. Hospitals

The four hospitals included in the study were King Fahad Medical City (KFMC), King Khalid University Hospital (KKUH), King Abdulaziz University Hospital (KAUH), and King Saud Medical City (KSMC). These hospitals were selected to ensure responses and opinions from a variety of participants. These secondary and tertiary care hospitals serve a culturally and socioeconomically diverse patient population. Moreover, the hospitals accept referrals from various hospitals and centers from all regions of KSA. All care, including medications, is free of charge for eligible Saudi patients.

KKUH and KAUH are part of, and managed by, King Saud University Medical City – The Ministry of Education, whereas KFMC and KSMC are managed by the MOH. Each of these hospitals had completely implemented an EHR system that is being used by its staff and professionals. The following is a brief description of each hospital and its current status of adopting ePHRs.

3.2.2.1. King Fahad Medical City

KFMC, which consists of four hospitals, has a total capacity of 1095 beds. It is a tertiary care hospital that is considered to be one of the largest and most advanced medical centers in the Middle East (KFMC, 2016).

The health informatics department in KFMC launched a pilot version of a patient portal on the hospital's website in 2015. This version was available for selected patients. A newer version was released in 2016. With this new version, all patients are able to view their upcoming appointments, medications, radiology summaries, and laboratory requests. However, patients are not able to request any services through this portal. Patients are also able to access this portal through an App that can be downloaded on smart phones.

3.2.2.2. King Khalid University Hospital

KKUH is part of King Saud University Medical City, which is managed by the Saudi Ministry of Education. It is a tertiary care hospital that has a total capacity of 800 beds (KKUH, 2016).

3.2.2.3. King Abdulaziz University Hospital

This university hospital was the first educational hospital in KSA. It is a tertiary care hospital that hosts one of the leading diabetic centers in the region. It is part of King Saud University Medical City and is managed by the Saudi Ministry of Education (KAUH, 2016).

King Saud University Medical City had recently implemented a new EHR system that connects its hospitals. However, no patients' portals or ePHRs has been implemented in these hospitals.

3.2.2.4. King Saud Medical City

This secondary care hospital was established in 1956. It consists of five hospitals with a capacity of more than 1200 beds. Lately, KSMC launched a beta version of its new website. With this version, patients have the ability to book appointments online. For the future, the hospital aims to automate all patient and staff services through this portal (KSMC, 2016).

Moreover, the MOH, which manages KSMC services, has a portal that can be accessed through the MOH website. This portal allows health consumers to send complaints, appreciations, inquiries, recommendations and suggestions to any department in the MOH (Ministry of Health - KSA (MOH), 2016b). People can also learn about different diseases and health conditions through this portal that serves as valid health information source and is monitored by MOH. Consumers can also receive reminders about upcoming vaccinations for their children (Ministry of Health - KSA (MOH), 2016b).

3.3. MREB and hospital approvals

This study was approved by the McMaster Research Ethics Board on May 4, 2015. The document number is 2015 081. In addition, the investigator was approved by the Institutional Review Boards of each hospital to collect data from the outpatients in the waiting areas (Appendix 1).

3.4. Survey design

The survey questions were developed based on a study about consumers' perspectives on health information exchange and personal health records by Patel in 2011 with permission from the author (Patel et al., 2011). A later version of the survey was designed in which some questions not relevant to this study were deleted to shorten the survey. Other questions were added to investigate the sociocultural background of the participants. This version of the survey was reviewed by experts in electronic health and health informatics from McMaster University and King Saud University (Appendix 2).

The survey was translated to Arabic, the official language of the participants (Appendix 3). After that, it was piloted with 14 individuals who met the criteria of the study participants, except that the setting was not the hospital's waiting area. For this pilot stage, the investigator used snowball sampling to recruit participants (Goodman, 1960). The snowball sampling started with the investigator's personal contacts and radiated from there to include 14 adults from different age groups. The main aim for this pilot stage was to test the length, the clarity, the wording, the format, and the content of the survey. Eight of these 14 individuals used the paper-based survey, while the other six used the iPad to fill out the electronic survey. A final version was produced after reviewing the comments and the recommendations of the pilot participants. Finally, the survey was back translated to English to assess the accuracy and consistency of the questions before administration (Appendix 4).

3.4.1. Survey domains

The survey questions were divided into four sections or domains: general demographic questions, health-related questions, Internet use questions, and personal health record questions.

The general demographic questions included questions about the setting, the region of residence, the age group, the educational level, and the household income. The health-related questions included questions about the participant's health status, annual clinic visits, the use of prescribed medications, and the presence of chronic disease(s). Moreover, the other health-related questions investigated the participant's healthcare experience such as the patient's understanding of the physician's verbal instructions and other written materials, and the participant's satisfaction with the provided care. Following this section, there were questions about the patient's access and use of the Internet and his/her level of concern about the privacy of the shared health information online. The last domain investigated the participant's attitudes and expectations towards personal health records, including the types of information and activities that are most likely to be accessed by the patients using an ePHR, the expected frequency of ePHR usage, and the expected potential benefits associated with the use of an ePHR. The questions were multiple choice questions, yes/no questions, and 5-point Likert-like style questions.

3.4.2. Survey administration and tools

The investigator approached the outpatients while they were waiting for their appointments in the clinics' waiting areas of each hospital. First, the investigator introduced herself to the participant and then handed to the participant the letter of information that included all the elements of informed consent, information about the study, the names of investigators, and their affiliations and contacts (Appendix 5). Similar to the survey questions, this letter of information was administered in Arabic and was also back translated to English to ensure the accuracy and consistency of the information (Appendix 6 & 7). After that, the patient was asked to choose between two forms of self-administered questionnaires: online or paper-based surveys.

Participants received café gift certificates as compensation for their participation. The café gift certificate was worth 20 Saudi Riyals (about 7 Canadian Dollars). To make it easier for participants, this card allowed the participant to buy a cup of beverage and a snack from off-site or existing café shops in each hospital. The participant was eligible to receive the gift certificate once he/she read the letter of information and started filling out the survey, which means that he/she consented to participate in the study. Even the patients who decided to withdraw before completing the survey received gift certificates from the investigator. The Oral Recruiting script that describes the oral communication with the participants is attached (Appendix 8).

QuestionPro was used to administer the online questionnaire through the iPad. It is an online survey platform that supports Arabic language. It also allows the surveyor to administer offline mobile surveys through the iPad application. These offline responses are seamlessly synced with QuestionPro once the iPad is connected to the Internet. This feature helped the investigator to survey patients in the hospital's waiting areas where there was no Internet access available. The only way to access the online questionnaire was through the iPad that was with the investigator. This would ensure that the participant was physically visiting the hospital at the time of the study and met the study inclusion criteria.

3.4.3. Privacy, confidentiality, and the security of data

This was an anonymous survey. No identifiable personal information or personal health information was collected, so the anonymity of participants was maintained during the data collection, storage, and dissemination. As a result, the collected data could not be linked to participants' identities. Moreover, the healthcare team including the participant's physician and nurse did not have any access to the collected data. Only the researchers could view and analyze the data. The data analyses were performed using a password-protected computer, and the data were analyzed collectively and not case by case, so the participant's identity could not be known during the data analysis since no one, even the researchers, knew which answers were for whom. The researchers kept the information that was collected confidential. Any data from this study, which will be shared or published, will be the combined data of all participants, thus protecting their anonymity.

3.4.3.1 Paper-based survey

The collected paper-based survey responses were kept in a locked cabinet until the researchers transferred the data on the papers to an Excel spread sheet in a password-protected computer. Only the researchers knew the password and had access to this computer and the locked cabinet. After transferring the data from the papers to the password-protected computer, these papers were destroyed using a paper-shredder.

3.4.3.2 QuestionPro and Online survey

The team that works on QuestionPro, the online survey platform, is committed to the confidentiality and integrity of all the information within the system. To ensure the platform's security, the data centers of QuestionPro are monitored twenty-four hours a day, seven days a week. QuestionPro employs the concept of least privilege. In other words, qualified employees are allowed access to privileged areas of the system only when such access is necessary for the operation of QuestionPro business functions. All customer data, including the data of end users, is logically separated by account-based rules that require the entry of a unique username and password with each logon. Only the researchers had access to this study's username, password, and the participants' data. The collected online data were transferred to an Excel spread sheet and saved in a password-protected computer. Only the researchers had access to this computer. A month after the data collection period, all the collected data in the QuestionPro account were destroyed and the account was deleted. An overview of QuestionPro security measures is in Appendix 9 (QuestionPro, 2016).

The iPad, which was used for the online survey, was covered with a privacy screen protector that blackened the screen to the people who were looking at it from the sides of the tablet. With this protector, only the person holding the iPad was able to see the online survey. However, to ensure a better confidentiality with both online and paper-based surveys, outpatients sometimes were asked to sit in a corner that had no patients in, to assure that their privacy was protected and no other patients were looking at the answers.

Once the study has been completed, an archive of the data, without any identifiable information, will be maintained for approximately ten years to conduct similar research in different regions in KSA to produce results that can present a general idea about Saudis preferences with respect to ePHRs. After approximately ten years, the data will be deleted and destroyed. All of these privacy and confidentiality information were explained to participants and were written in the information letter.

3.4.4 Participation and Withdrawal:

This was a cross-sectional study in which outpatients were invited to participate one time, and there was no need for on-going consent. After the investigator introduced herself, she handed a letter of information to the participant that had all the elements of the informed consent. If the participant completed the survey, he/she was assumed to have consented. For the electronic copy of the survey using QuestionPro tool, the same letter of information was presented as an introduction to the online survey. If the participant completed the survey, he/she was assumed to have consented.

The letter of information clarified the withdrawal rights for participants. Furthermore, these rights were explained orally by the investigator to participants (Appendixes 5 & 8). The participant had the right to withdraw from the survey at any time without penalty. If he/she started completed the survey and then decided to stop answering the questions, the investigator thanked the participant for his/her time and would not try to encourage the participant to complete the survey. The uncompleted/withdrawn paper-based surveys were destroyed and not used by the investigator in the analysis of the thesis. However, for the online survey, once the participant had submitted the survey, his/her responses could not be withdrawn from the study because the researcher would not be able to identify which responses were his/hers. In other words, once the participant entered his/her information into the database, the researcher would no longer be able to withdraw the participant from the study. If the participant withdrew from the survey without completing it, he/she was still able to receive a gift certificate, which would be handed to the participant by the investigator in person.

3.4.5 Potential risks and benefits of participating

It was not likely that there would be any serious harm associated with completing the survey. However, the patients may have felt uncomfortable filing this survey while they were waiting anxiously for their appointments. The participants may also have been concerned about their privacy and reputation while participating in a survey in a waiting area in the hospital setting. They may have been afraid that the care they were receiving in the hospital might be affected negatively if they responded to the survey and their healthcare team knew about the answers. The outpatients may also have felt demeaned or marginalized when they answered some questions in the survey. They may have felt that they didn’t have time to fill this survey, or they have felt afraid that this survey was collecting personal information about them.

Besides the clarification in the information letter, the investigator clarified to the patients all the above-mentioned risks that might be associated with participating in the study, and presented more information about the participation and withdrawal policies, the privacy, and the security of the study methods and tools to overcome these risks (Appendix 8).

If the outpatient chose to participate using the paper-based survey and worried about not having enough time to complete it, the patient was allowed to keep the letter of information and the paper-based survey with him/her, and complete the survey after the appointment. However, if the participant chose to use the electronic survey but was worried about the time, he/she would have to wait until after the appointment to respond to the survey. The researcher could not leave the iPad with patients and no login information was provided to patients. Furthermore, participants were being informed that it was not compulsory to answer all questions, and there was no any penalty for skipping or not answering questions.

There were no direct personal benefits to outpatients for participating in this study. The participant may have felt the satisfaction of knowing that he/she had provided some information to potentially help in conducting research that might contribute in improving the quality and the future of healthcare in KSA.

Chapter 4: Analyses

The responses were coded in the input phase to facilitate and speed up the data transfer from the paper forms to the computer (Appendix 10). The dataset was reviewed and checked four times to make sure that the data input was correct. Each paper-based survey was given a number that matched the Excel sheet row number of the survey to make it easier to find specific responses in the case of missing data or inaccurate data input. Before the analyses take place, the investigator cleaned the data and deleted uncompleted surveys from the dataset. The listwise approach was used in cleaning the dataset in which the researcher took off or deleted the surveys that had missing values or unanswered questions. Once all the information had been entered and cleaned in Excel, the dataset was transferred to RStudio and decoded.

The main outcome in this study arose from examining the outpatients' potential interest in using ePHRs. The participants who reported that they would use an ePHR every 6 months or more often (once weekly, once monthly, or once every 3 to 6 months) were defined as potential users of ePHRs; while outpatients who indicated that they would use ePHRs less frequently (once a year, rarely or not at all) were defined as not interested in using ePHRs.

The researchers explored the descriptive statistics of all variables to summarize the collected data and to describe the characteristics of participants. RStudio version 0.98.490, Java Gui for R (JGR) version 1.7-16, and Microsoft Excel version 14.4.9, and Apple® iPad were used for data collection, manipulation, and analysis. All the data manipulation and analysis were performed using MacBook Pro with Mac OS X version 10.6.8.

Chapter 5: Results

The data collection took approximately 3 months (June – Sept 2015). The following is a description of the study results.

5.1. Respondents

Out of 1296 individuals who were approached, 506 responded to the survey. Of these 506 responded surveys, 66 incomplete surveys were eliminated. Approximately 61% (n=790) of potential outpatients refused to participate in the study.

The survey analysis included 440 surveys. Of the 440 respondents, 119 were outpatients of KFMC, 116 were outpatients of KKUH, 101 were outpatients of KAUH, and 104 were outpatients of KSMC (Table 1). Approximately 15% (n=67) of the 440 participants used the iPad to respond to the electronic survey, while the other 85% (n=373) preferred to use the paper-based questionnaire. Data collection took place in different outpatient clinics including: internal medicine clinic, women health clinic, primary health clinic, dermatology clinic, ear nose and throat (ENT) clinic, ophthalmology clinic, endocrine/diabetic clinic, cardiac clinic, plastic surgery clinic, oncology clinic, and emergency room and pharmacy waiting areas.

Although the participants came from diverse locations, the majority (81.8%) came from the central region of KSA. Other participants came from the north region (8.6%), the south region (5.2%), the east region (2.5%), and the west region (1.8%).

Over 84% of the study participants were less than 51 years old. Almost 16% were in their 50s or older (Table 1).

Approximately half of the participants (49.7%) had at least a university or a graduate degree, while the other half had no degrees or had only an elementary (13.4%), intermediate (7.3%), or secondary (29.5%) school degree. The largest group of the participants (39.2%) had a monthly household income between 3,000 and 9,999 Saudi Riyals. About a quarter (25.7) of the participants had a monthly income of less than 3,000 SR, and another quarter (27%) had an income between 10,000 and 19,999 SR a month. Only about 8% of the participants had an income of more than 20,000 SR a month (Table 1).

Table 1: Respondent demographic characteristics (n=440)

Characteristic	n	%
Hospital		
KFMC	119	27.0
KKUH	116	26.4
KAUH	101	23.0
KSMC	104	23.6
Region		
Central	360	81.8
North	38	8.6
South	23	5.2
East	11	2.5
West	8	1.8
Age		
18-30	194	44.1
31-50	176	40
51-60	47	10.7
61+	23	5.2
Education		
Elementary or less	59	13.4
Intermediate	32	7.3
Secondary	130	29.5
University	192	43.6
Graduate	27	6.1
Income in SR		
Less than 3000	113	25.7
3000 - 9999	173	39.3
10000 - 19999	119	27
20000 - 49999	26	5.9
50000+	9	2

The majority of participants (93%) rated their health status as excellent (18%), very good (45.9%), or good (29.1%); whereas less than the tenth of them (7%) believed they had fair or poor health status. Only 34.3% of the study sample reported having a chronic medical condition, and more than half of the respondents (64.1%) were taking prescribed medications (Table 2).

Table 2: Respondents health-related characteristics (n=440)

Characteristic	n	%
Self-rated health status		
Excellent	79	18
Very good	202	45.9
Good	128	29.1
Fair	21	4.8
Poor	10	2.3
Chronic medical condition		
Yes	151	34.3
No	289	65.7
Taking prescribed medication		
Yes	282	64.1
No	158	35.9
Frequency of problems understanding doctor's verbal communication		
Always	4	0.9
Often	26	5.9
Sometimes	128	29.1
Occasionally	105	23.9
Never	177	40.2
Frequency of problems understanding written medical information		
Always	28	6.4
Often	40	9.1
Sometimes	135	30.7
Occasionally	103	23.4
Never	134	30.5
Satisfied with quality of health care received in past 5 years		
Very Satisfied	125	28.4
Somewhat satisfied	175	39.8
Neutral	58	13.2
Somewhat dissatisfied	56	12.7
Very dissatisfied	26	5.9

Over half of the participants (53%) stated that they sometimes or occasionally had a problem understanding their physician's verbal communication, while 40% of them did not report any such difficulties. Similarly, half of the respondents (54.1%)

reported that they sometimes or occasionally had difficulties in understanding written medical information. Almost 70% of the study sample indicated that they were very satisfied or somewhat satisfied with the quality of the healthcare received in the past five years (Table 2).

The study sample reported an average of 4.6 visits to primary care facilities, 3.6 visits to specialist healthcare providers, 2.1 visits to emergency rooms, and 0.8 admissions that lasted at least overnight in the hospital in the year 2014. Almost 75% of the respondents visited their primary healthcare providers less than 5 times, visited the specialist less than 4 times, and visited the emergency room less than 3 times during that time. The maximum number of visits reported by a participant in this study was 104 visits for the primary care facility, 60 visits for the specialist healthcare provider, 30 visits for emergency rooms, and 35 admissions to the hospital in 2014 (Table 3).

Table 3: Number of visits to healthcare providers in the past year 2014 (n=440)

Facility	Mean	St. Deviation	Minimum	Maximum	25th Percentile	75th Percentile
Primary care	4.6	8.9	0	104	1	5
Specialist	3.6	6.9	0	60	0	4
ER	2.1	4.1	0	30	0	3
Admissions	0.8	2.3	0	35	0	1

The majority of the respondents (88.9%) reported having Internet access, with more than three-quarters (78.4%) using the Internet once or several times a day. Less than half of the study sample (44.3%) revealed that they use the Internet to look for health information. Around 36% reported that they use the Internet for health purposes once a week or once a month, while around a fifth of the respondents

(18.9%) claimed that they use the Internet for health purposes at least once daily (Table 4).

5.2. Outpatient attitudes and usage of personal health records

Approximately 70% of the respondents (n=297) showed an interest in using the Internet and the computer to manage their healthcare. Only 1.6% of participants expressed no interest in accessing their personal health information and regulating their healthcare through the Internet, while 3.9% of respondents were neutral about this matter (Table 5).

Table 4: Respondent Internet-related characteristics (n=440)

Characteristic	n	%
Internet access available		
Yes	391	88.9
No	49	11.1
Frequency of Internet use		
Several times a day	306	69.5
About once daily	39	8.9
Once weekly	21	4.8
Once monthly	11	2.5
Rarely or not at all	63	14.3
Frequency of Internet use for health purposes		
Several times a day	48	10.9
About once daily	35	8
Once weekly	80	18.2
Once monthly	82	18.6
Rarely or not at all	195	44.3

Table 5: Outpatients' interest in using Internet to manage their health (n=440)

I am interested in using the computer to go online and use the Internet to manage my healthcare	N	%
Strongly agree	297	67.5
Agree	119	27.0
Neutral	17	3.9
Disagree	6	1.4
Strongly disagree	1	0.2

Almost three-quarters (75.7%) of the respondents stated that they would view their health information and use the services offered through ePHRs at least once a week (36.8%) or a month (38.9%). A fifth of the participants (21.4%) reported that they would manage their health information through an ePHR once every three to six months, while only 2.3% of the study sample revealed that they would use an ePHR once annually to view or manage their health information. Less than 1% of the subjects (n=3) stated that they would rarely or never use the services offered through ePHRs (Table 6).

Table 6: Frequency of potentially using an ePHR (n=440)

How often do you think you would view and manage your personal health record	n	%
Once a week	162	36.8
Once a month	171	38.9
Once every 3-6 months	94	21.4
Once a year	10	2.3
Rarely or not at all	3	0.7

5.3. Outpatient preferences related to content and features of ePHRs

The results showed that participants wanted to have access to different health-related information within their personal health records (Figure 1) (Table 7). There was a great interest in accessing test results such as blood tests and x-rays in an ePHR by the majority of the respondents (90.5%). Other types of health information that outpatients were highly interested in accessing included medical problems (81.8%), current and previous medications (73%), list of doctors and health care providers seen by the patient (61.4%), surgeries and medical procedures that the patient had (60.5%), medical visits (57%), and information from health monitoring devices (55.9%). Less than half of the respondents expressed an interest in accessing their allergy information (%45%), immunization records (46.8%), and family histories (44.8%). Only 33.6% (n=148) of the respondents showed an interest in accessing information about lifestyle choices such as exercise and smoking (Table 7).

Table 7: Outpatients' preferences of ePHR contents (n=440)

Which of the following types of health information would you like to have as part of your personal health record?	n	%
My allergies	198	45
Test results (e.g. blood tests, X-rays)	398	90.5
Immunization records	206	46.8
Medication I have taken or am currently taking	321	73
List of doctors and health care providers I have seen	270	61.4
Family history of health problems	197	44.8
Medical problems	360	81.8
Medical visits, including visits to the emergency room	251	57
Surgeries and medical procedures that I have had	266	60.5
Lifestyle choices (e.g., exercise, smoking history)	148	33.6
Information from devices that help me monitor my health (e.g., glucose from a diabetes meter)	246	55.9

Other respondents declared that they would like their ePHRs to be in two languages (Arabic and English) and to be comprehensive and contain all the patient’s information from birth to the present time, including dental visits. Some outpatients showed an interest in learning more about certain health conditions and complications through ePHRs such as heart diseases, hypothyroidism, obesity, asthma, pregnancy, and diabetes. Moreover, others were interested in knowing more about their treatment plans, side effects, complications, medication administration methods, prescription expiry dates alerts, and new available treatment plans. Other respondents showed an interest in accessing information about new treatment plans for specific conditions and the hospitals and health centers that have experts in dealing with such conditions. Patients expressed an interest in accessing information about promoting the quality of life of patients for who have certain chronic health conditions such as diabetes. Other patients were interested in accessing some administrative information and services such as requesting sick-leave notes. Some participants suggested that the ePHR login codes should not use the patient's name; instead it should use the patient's file number so the patient would not be identified by anyone who could access the file (Table 8).

Table 8: Specific ePHR contents that were reported by the respondents (n=440)

Other contents reported by the participants:
• A complete patient history from the birth to the present time or death, including the dental visits
• Available clinics and the methods of booking appointments
• Comprehensive information about specific health conditions with treatment options
• Clear explanation of the case
• Information about appointments, tests, and new treatments for my case, and different doctors' opinions about my case
• Information about heart diseases
• Information about hypothyroidism and its treatment. I can't find answers about its causes and other treatments different than the thyroxin
• Information about medications and their complications
• Information about physical health and obesity and its complications
• Information about pregnancy complications
• Information about sick-leaves
• Information about the side effects of treatments
• Information about the surgical operations
• Information about the test results with the interpretations of each test
• Information about the types of the surgical operations I underwent
• Information about the ways of administering the medications
• Information about Asthma medications and treatment tools
• Medication expiry dates alerts and refills
• Physicians' reports about my case
• Please use the patient's file number as identification for the electronic file, and don't show or use the patient's name, so the patient will not be recognizable by anyone who could access the electronic file.
• Recommendations about other centers and hospitals that have better treatment options and plans for my case
• Some health recommendations to promote the health of the patients. For example, a diabetic person would like to learn more about the recommended daily walking duration etc.
• The diseases and the symptoms
• The reports should be in English and Arabic

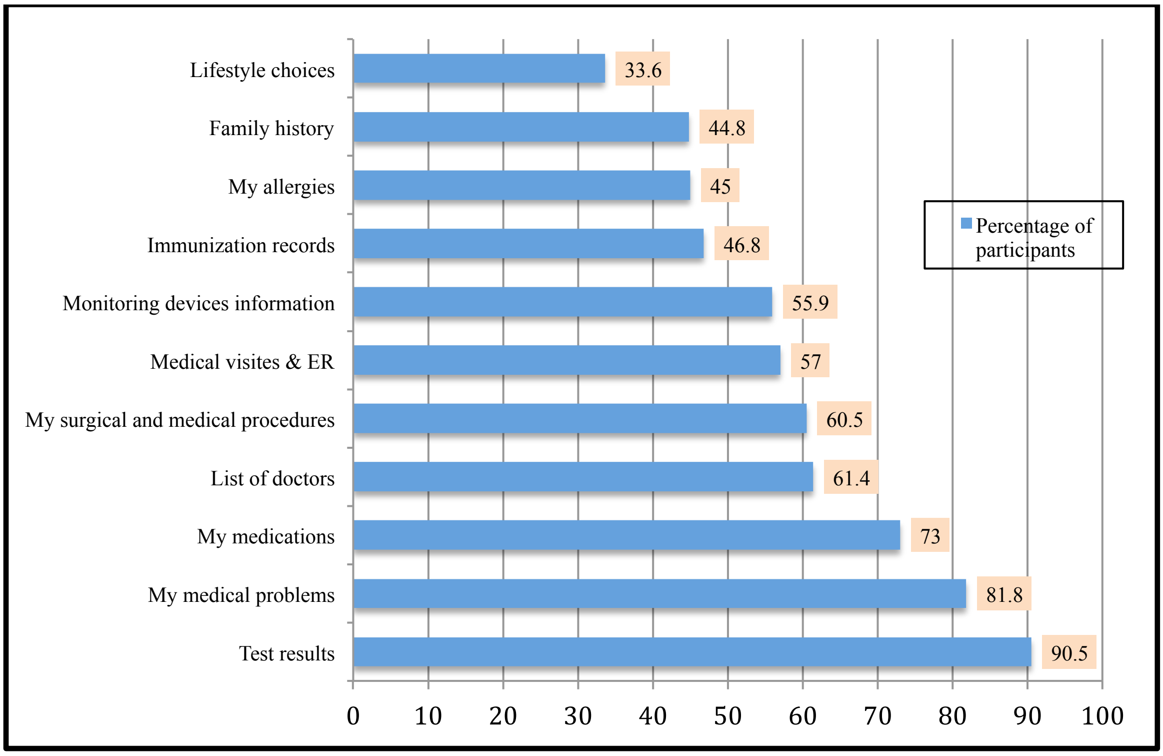


Figure 1: Types of health information participants interested in accessing in ePHRs (%)(n=440).

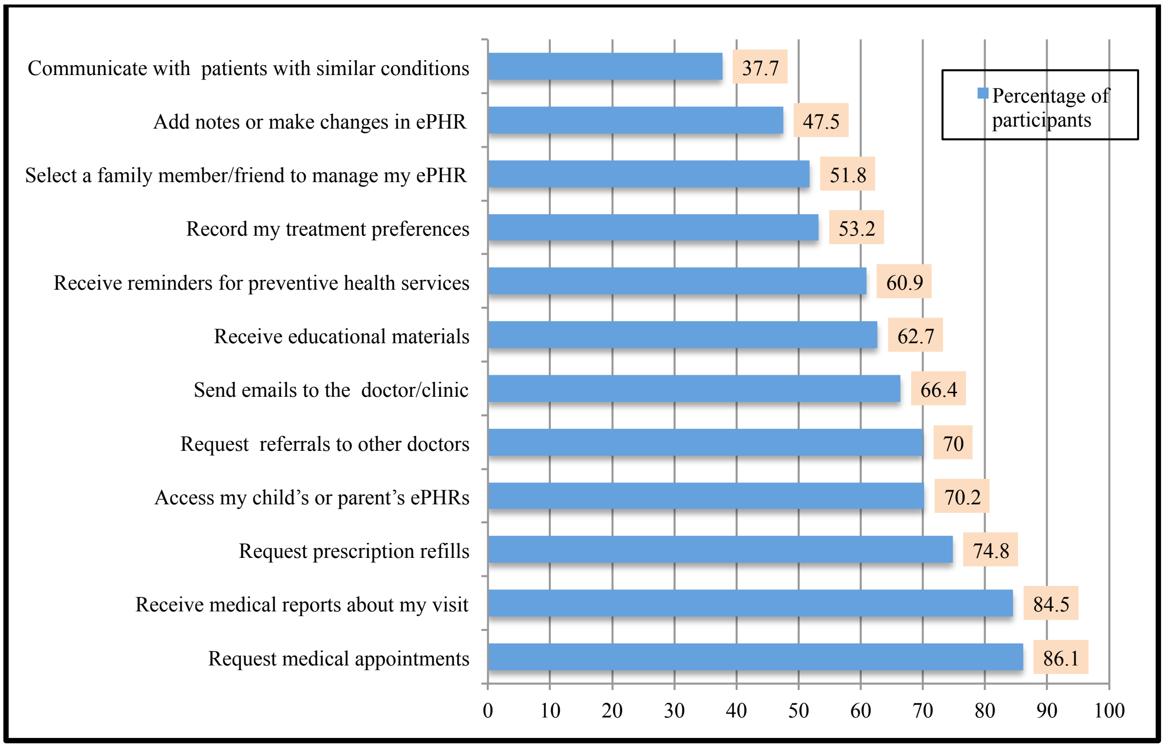


Figure 2: Outpatient preferences of ePHR features and activities (n=440)

The majority of participants were interested in being able to request medical appointments (86.1%) and medical reports (84.5%) using their ePHRs. Almost three-quarters (74.8%) of the respondents showed an interest in requesting medication refills online through ePHRs. Other activities that respondents were eager to use in ePHRs were requesting referrals (70%), accessing ePHRs by their first-degree relatives and caretakers (70.2%), receiving educational materials (62.7%) and preventive health services reminders (60.9%), and contacting their health providers electronically (66.4%). Approximately half of the participating outpatients were interested in adding notes or changes to their ePHRs (47.5%), and recording their treatment preferences (53.2%) and their selection of their primary caretakers in case of an emergency (51.8%). The activity that had the least interest to the participants was communicating with support groups or other people who have similar health problems (37.7%) (Figure 2) (Table 9).

Table 9: Outpatients' preferences of ePHR features and activities (n=440)

Which of the following activities would you like to do on the Internet?	n	%
Receive a report from my doctor about my visit	372	84.5
Add my own notes or make changes to information in my patient health record	209	47.5
Request medical appointments	379	86.1
Request referrals to other doctors	308	70
Request prescription refills	329	74.8
Send emails to my doctor or his/her practice with my medical questions	292	66.4
Receive reminders for preventive health services (e.g. flu shots)	268	60.9
Access my child’s or parent’s medical record if I am their primary caretaker	309	70.2
Communicate with other people with similar health problems (e.g. support groups)	166	37.7
Receive educational materials related to my health	276	62.7
Record my treatment preferences	234	53.2
Record my selection of a family member or friend to manage my health care when I am not able to	228	51.8

Some outpatients expressed an interest in accessing specific activities such as measuring their blood glucose level using the computer or the cell-phone and uploading the result directly to the patient's file, consulting psychological medical services through ePHRs, receiving updates about the available case-specific treatments in the world, and receiving referrals to hospitals and health centers that are specialized in treating specific conditions. Other respondents suggested that all the networks of MOH hospitals should be united, and that the patient could access ePHRs while travelling or being away from the hospital that has the patient’s file (Table 10).

Table 10: Specific ePHR activities that were reported by the participants (n=440)

Other activities reported by the participants:
• Accessing ePHRs while travelling or being away from the hospital that has my files • Measuring the glucose level using the computer or the cell-phone, and then uploading the result directly to the patient's file • My rights • Proper referrals to best hospitals and centers that are specialist in treating specific cases • Psychological consultation for me or for my family member • Send the newest updates of the available treatments in the world • The MOH network in all hospitals should be united

5.4. Outpatient perceptions regarding potential benefits and use of ePHRs

The majority of the respondents believed that using ePHRs would be associated with improvements in their satisfaction (89.8%) and the overall quality of their healthcare (91.6%). They also believed that using ePHRs might improve their understanding of their physician’s explanations (90.2%) and their overall health status (88%). A great number of participants reported that using ePHRs might improve their sense of control over their healthcare (86.4%), and their ability to make decisions about their medical care as a team with their physicians (85.7%). Almost three-quarters of respondents believed that the security and the privacy of their medical information (75%) and the safety of their care (74.8%) would improve with the use of ePHRs. However, over one-fifth of the participants believed that using ePHRs would have no effect on the security and the privacy of their medical information (21.8%) and the safety of their healthcare (20.7%). More than half of the participants (61.1%) believed that using ePHRs would eliminate their worries about their healthcare, while 34.5% saw that this would have no effect on their concerns about their healthcare (Table 11).

Table 11: Perceptions about the potential benefits of using ePHRs (n=440)

What effect do you think being able to view and manage (e.g. making appointments) your electronic personal health record will have on:	Improve n (%)	No effect n (%)	Worsen n (%)
The security and the privacy of my medical information	330(75)	96(21.8%)	14(3.2)
Understanding my doctor's explanations and advice	397(90.2)	40(9.1)	3(0.7)
My understanding of my own health	387(88)	48(10.9)	5(1.1)
My sense of control over my own healthcare	380(86.4)	56(12.7)	4(0.9)
The ability of my doctor(s) and I to make decisions about my medical care together as a team	377(85.7)	58(13.2)	5(1.1)
My worries about my own healthcare	269(61.1)	152(34.5)	19(4.3)
The safety of my care (e.g. medical errors)	329(74.8)	91(20.7)	20(4.5)
My satisfaction with my health care	395(89.8)	41(9.3)	4(0.9)
The overall quality of my healthcare	403(91.6)	35(8)	2(0.5)

5.5. Outpatient preferences and concerns regarding the privacy of sharing their health information online and through ePHRs

Approximately 30% of the respondents expressed no concerns about the privacy of personal health information that was shared online. About 67% showed different levels of concerns about the privacy of their personal health information online, with about 33% who were very concerned or not very concerned, and 37% were concerned or somewhat concerned (Table 12).

The majority of the respondents would be willing to give their primary physicians (77%) and other health professionals who provide them with medical care (79.3%) permission to view their ePHRs. More than half of the respondents (64.3%) were willing to give permission to designated family members and friends to access ePHRs, while fewer people showed a willingness to share that access with employers (17.5%) and government officials (17%). About 5% (n=23) of the participants were not willing to give permission to anyone to view their information in ePHRs (Table 13).

Table 12: Level of concern about the privacy of shared personal information on the Internet (n=440)

How concerned are you about the privacy of personal health information that is shared over the internet?	n	%
Very concerned	48	10.9%
Not very concerned	116	26.4%
Concerned	28	6.4%
Somewhat concerned	117	26.6%
Not concerned	131	29.8%

Table 13: Outpatients' preferences of giving access to some people to view ePHRs (n=440)

Who would you give permission to view information in your electronic personal health record?	n	%
Designated family members or friends	283	64.3%
My primary care doctor	339	77%
Other doctors or healthcare providers who care for me (in clinic, the ER or the hospital)	349	79.3%
Government officials	77	17.5%
My employer	75	17%
I would not give anyone permission	23	5.2%

Chapter 6: Discussion

To our knowledge, this study is the first to assess the perceptions of the Saudi population regarding ePHR features and potential use. Although the majority of the sample came from the central region of KSA, some participants came from diverse geographic backgrounds and different regions in KSA as the study settings serve all regions of KSA. More than three-quarters of the participants were less than 51 years old and had a minimum monthly income of 3000 SR. Almost half of the study sample had at least a university degree.

The majority of the respondents (93%) rated their health status as excellent, very good or good. More than a quarter (34.3%) of the sample reported having a chronic disease and more than half of the respondents (64.1%) were taking prescribed medications. Approximately, half of the participants had difficulties understanding their physicians' verbal communication (53%) and other written medical information (54.1%). However, the majority of the sample (68.2%) were satisfied with the quality of the healthcare received in the past five years.

The vast majority of the participants were frequent Internet users who use the Internet at least once daily, and almost half of the sample reported using the Internet to inquire for health purposes.

The results revealed that the majority of the sample (94.5%) were interested in using ePHRs to manage their health, with more than three-quarters of them interested in using this technology at least once a month. This high rate of interest in using ePHRs is higher than some rates reported in other studies with similar sample frame in developed countries (Noblin et al., 2012; Patel et al., 2011; Patel et al., 2012).

Studies showed that although participants show interest in potentially adopting ePHRs, the actual use of these records is not widespread (Kaelber, Jha, Johnston, Middleton, & Bates, 2008). To address the gap between the interest and the utilization of ePHRs by patients, the literature suggested looking into the types of data that might attract patients to adopt these records (Patel et al., 2012). In this study, participants reported that they would like to access different types of health information in their ePHRs. They were highly interested in accessing test results such as x-ray and blood test results. This finding was consistent with other studies that showed that test results were the most popular features that potential ePHR users were interested in (Curtis et al., 2011). Beside test results, participants were interested in accessing their medical problems, current and previous medications, doctors' list, surgeries and medical procedures, and allergies and immunization records. These types of information were also reported in the literature as patients were interested in accessing them in ePHRs (Segall et al., 2011). The type of information that had the least interest for inclusion in ePHRs was lifestyle choices such as exercise and smoking habit information.

Some participants in this study declared that they would like their ePHRs to be comprehensive and to contain all the patient's health-related information from birth to the present time. Likewise, some studies suggested that ePHRs should include all the information that are relevant to an individual's health such as information about family members, caregivers, and information about home and work environments (Tang et al., 2006). Other patients suggested that all MOH hospitals' records should be combined together so that the patient can access his/her complete medical information anywhere anytime. Several studies suggested that ePHRs should be integrated in hospital EHRs to provide a comprehensive source of health information to the patient and clinicians (Archer et al., 2011; Johansen & Henriksen, 2014; Kahn et al., 2009; Winkelman et al., 2005; Yau et al., 2011). ePHRs with comprehensive patients' health records are believed to be useful to both physicians and patients (Archer et al., 2011). Other studies stressed that the information in ePHRs should be explained and displayed in a way that is understandable to health consumers (Archer et al., 2011; Earnest et al., 2004; Noblin et al., 2012; Segall et al., 2011; Tang et al., 2006).

Some respondents revealed that they would like to learn more about some health conditions and complications through ePHRs. As the literature shows, an ePHR can serve as an educational tool that provides patients with access to valid trustworthy health information and knowledge (Tang et al., 2006). Consumers could use this knowledge to improve their health conditions and to promote the quality of their lives (Kahn et al., 2009; Tang et al., 2006). Some physicians believed that ePHRs might empower patients and motivate them to be more involved in their health (Witry et al., 2010).

Furthermore, participants showed an interest in accessing different services in ePHRs. There was a high interest in being able to request medical appointments and reports, referrals, medication refills, educational materials, and preventive medical services alerts in ePHRs. More than half of the patients were also interested in contacting their physicians through ePHRs and authorizing their caretakers to access their personal health information. Moreover, almost half of the sample was interested in adding notes and changes and recording their treatment preferences in ePHRs. This finding is consistent with the literature that showed that health consumers were also interested in contacting their physicians and accessing their medical reports (Segall et al., 2011).

Some patients suggested that they would like to be able to measure some health parameters through the use of ePHRs. For example, one patient revealed that he would like to be able to measure his blood glucose level using a computer or a smartphone, and then upload the result directly to his ePHR. Other patients reported that they would like to be able to consult psychological medical services through ePHRs. Similar to previous studies, the service that had the least interest to the participants was communicating with support groups or other people who have similar health problems (Segall et al., 2011).

The vast majority of the respondents believed that ePHRs are associated with improvements in different health-related outcomes. Patients believed that ePHRs could improve their satisfaction levels and the quality of healthcare. They also believed that ePHRs could lead to enhancements in their overall health status and their understanding of physicians’ instructions. Patients also expected to see improvements in their sense of control and their ability to make decisions regarding their health with the use of an ePHR. Some studies concluded that perceived usefulness of ePHR might positively influence the adoption of these records (Jian et al., 2012).

Most of the respondents expressed concerns regarding the privacy of the health information shared online. However, almost three-quarters of the sample believed that ePHRs would improve the security and the privacy of their health information and enhance the safety of their healthcare. Some participants suggested that the ePHR login codes should not use the patient’s name; instead, it should use the patient’s file number so the patient will not be identified by anyone who could access the file. A study showed that actual ePHR users were less concerned about the privacy and security of their health information compared to potential users and health professionals (Archer et al., 2011; California HealthCare Foundation, 2016).

Finally, more than three-quarters of the participants reported that they would be willing to share their records with their primary physicians or other members of their care team; whereas, in another study, only half of the participants were willing to share their ePHR data with their family physicians or other health providers (Curtis, Cheng, Rose, & Tsai, 2011). Moreover, approximately 65% of the respondents were willing to share their ePHR with designated family members and friends. In another study, less than half of the patients were willing to share their records with a family member (Curtis, Cheng, Rose, & Tsai, 2011). The findings also showed less interest in sharing personal health data with government officials and employers.

Chapter 7: Strength and Limitations

To our knowledge, this study is the first in assessing patients' attitudes and expectations regarding ePHR use in KSA. It is also the first study in KSA to examine consumers' preferences regarding ePHR features and services. One of the main strengths of the study is the large number of participants who came from diverse backgrounds and regions. Furthermore, this study presents new valuable findings to the literature and Saudi health institutions regarding outpatients' attitudes towards ePHR uses and features. Although KSA is considered to be a developing country, these participants showed more enthusiasm for ePHRs than some studies done in more developed countries. Our study reported high levels of perceived usefulness of ePHR that may lead to improving the use of these records according to the literature.

Although the patients came from diverse backgrounds and regions in KSA, the characteristics of the sample might not resemble the characteristics of the Saudi population. For this reason, the results of this study may not be generalized to the Saudi population. In an effort to improve the generalizability, researchers included different major hospitals that serve not only the central region but also all regions of KSA. In addition, the authors surveyed patients from different medical departments such as dermatology, ophthalmology, cardiac, and renal health departments, strengthening the possibility of having a broad-based sample.

Translating the survey questions to another language might affect the meaning of the questions. However, the researchers back-translated the letter of information and the survey to ensure the consistency and the accuracy of the information. Despite these limitations, this study may provide guidance to other studies and present valuable findings that could be useful in addressing the gap between the interest in ePHRs and their utilization.

Chapter 8: Conclusion

This study is the first in examining patients' attitudes and expectations regarding ePHRs in KSA. Participants showed higher levels of interest in using ePHRs than other studies in developed countries. More than three-quarters of the participants were interested in using ePHRs at least once a month. Moreover, respondents were highly interested in accessing imaging and blood test results in ePHRs. They also were interested in viewing other health information in ePHRs such as current and previous medications, doctors' list, health conditions, surgeries and medical procedures, and allergies and immunization records. In addition, respondents were extremely interested in requesting medical appointments, reports, medication refills, and referrals through ePHRs. They also showed an interest in using an ePHR as an educational tool to learn about specific health conditions.

This study presented high levels of perceived usefulness of ePHR potential benefits to the individual's health and the healthcare systems. Although patients showed some concerns about the privacy and the security of their information online, most patients believed that ePHRs could improve the safety and the security of healthcare data. Patients were willing to share their ePHRs with their physicians and some designated family members and friends.

Finally, further research is needed to investigate ePHR privacy and security concerns of patients and the factors that may influence the adoption of these records. Moreover, future studies should look into the adoption of ePHRs by specific populations such as elderly and chronic disease patients who may need specialized assistance to overcome different obstacles that hinder them from using ePHRs. More importantly, identifying the key factors that may improve the sustainability and the continuity of ePHR use by patients should be investigated.

References

Abaidoo, B., & Larweh, B. T. (2014). Consumer health informatics: The application of ICT in improving patient-provider partnership for a better health care. *Online Journal of Public Health Informatics, 6*(2), e188.

Akesson, K. M., Saveman, B. I., & Nilsson, G. (2007). Health care consumers' experiences of information communication technology--a summary of literature. *International Journal of Medical Informatics, 76*(9), 633-645.

AMIA . (2016). *Consumer health informatics.* Retrieved Oct/03, 2016, from https://www.amia.org/applications-informatics/consumer-health-informatics

Ancker, J. S., Silver, M., & Kaushal, R. (2014). Rapid growth in use of personal health records in new york, 2012-2013. *Journal of General Internal Medicine, 29*(6), 850-854.

Ant Ozok, A., Wu, H., Garrido, M., Pronovost, P. J., & Gurses, A. P. (2014). Usability and perceived usefulness of personal health records for preventive health care: A case study focusing on patients' and primary care providers' perspectives. *Applied Ergonomics, 45*(3), 613-628.

Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbon, K. A., & Straus, S. E. (2011). Personal health records: A scoping review. *Journal of the American Medical Informatics Association : JAMIA, 18*(4), 515-522.

Baldry, M., Cheal, C., Fisher, B., Gillett, M., & Huet, V. (1986). Giving patients their own records in general practice: Experience of patients and staff. *British Medical Journal (Clinical Research Ed.), 292*(6520), 596-598.

Bird, A. P., & Walji, M. T. (1986). Our patients have access to their medical records. *British Medical Journal (Clinical Research Ed.), 292*(6520), 595-596.

Bouri, N., & Ravi, S. (2014). Going mobile: How mobile personal health records can improve health care during emergencies. *JMIR mHealth and uHealth, 2*(1), e8.

California HealthCare Foundation (Lake Research Partners). (2016). *Consumers and health information technology: A national survey.* Retrieved Oct/26, 2016, from http://www.chcf.org/publications/2010/04/consumers-and-health-information-technology-a-national-survey

Chang, B. L., Bakken, S., Brown, S. S., Houston, T. K., Kreps, G. L., Kukafka, R., et al. (2004). Bridging the digital divide: Reaching vulnerable populations. *Journal of the American Medical Informatics Association : JAMIA, 11*(6), 448-457.

Chen, C., Garrido, T., Chock, D., Okawa, G., & Liang, L. (2009). The kaiser permanente electronic health record: Transforming and streamlining modalities of care. *Health Affairs (Project Hope), 28*(2), 323-333.

Chomutare, T., Fernandez-Luque, L., Arsand, E., & Hartvigsen, G. (2011). Features of mobile diabetes applications: Review of the literature and analysis of current applications compared against evidence-based guidelines. *Journal of Medical Internet Research, 13*(3), e65.

Cocosila, M., & Archer, N. (2014). Perceptions of chronically ill and healthy consumers about electronic personal health records: A comparative empirical investigation. *BMJ Open, 4*(7), e005304-2014-005304.

Curtis, J., Cheng, S., Rose, K., & Tsai, O. (2011). Promoting adoption, usability, and research for personal health records in Canada: The MyChart experience. *Healthcare Management Forum, 24*(3), 149-154.

Cushman, R., Froomkin, A. M., Cava, A., Abril, P., & Goodman, K. W. (2010). Ethical, legal and social issues for personal health records and applications. *Journal of Biomedical Informatics, 43*(5 Suppl), S51-5.

Czaja, S. J., Zarcadoolas, C., Vaughon, W. L., Lee, C. C., Rockoff, M. L., & Levy, J. (2015). The usability of electronic personal health record systems for an underserved adult population. *Human Factors, 57*(3), 491-506.

Delbanco, T., Walker, J., Bell, S. K., Darer, J. D., Elmore, J. G., Farag, N., et al. (2012). Inviting patients to read their doctors' notes: A quasi-experimental study and a look ahead. *Annals of Internal Medicine, 157*(7), 461-470.

Demiris, G. (2016). Consumer health informatics: Past, present, and future of a rapidly evolving domain. *Yearbook of Medical Informatics, Suppl 1*, S42-7.

Demiris, G., Afrin, L. B., Speedie, S., Courtney, K. L., Sondhi, M., Vimarlund, V., et al. (2008). Patient-centered applications: Use of information technology to promote disease management and wellness. A white paper by the AMIA knowledge in motion working group. *Journal of the American Medical Informatics Association: JAMIA, 15*(1), 8-13.

Department of Health. (2008). *NHS next stage review: Our vision for primary and community care* No. 10096) U.K. Department of Health.

Detmer, D., Bloomrosen, M., Raymond, B., & Tang, P. (2008). Integrated personal health records: Transformative tools for consumer-centric care. *BMC Medical Informatics and Decision Making, 8*, 45-6947-8-45.

Earnest, M. A., Ross, S. E., Wittevrongel, L., Moore, L. A., & Lin, C. T. (2004). Use of a patient-accessible electronic medical record in a practice for congestive heart failure: Patient and physician experiences. *Journal of the American Medical Informatics Association: JAMIA, 11*(5), 410-417.

Eysenbach, G. (2008). Medicine 2.0: Social networking, collaboration, participation, apomediation, and openness. *Journal of Medical Internet Research, 10*(3), e22.

Ferguson, T. (2003). *The Ferguson report: Doctom's FAQ.* Retrieved Oct/26, 2016, from http://www.fergusonreport.com/articles/tfr07-03.htm

Fisher, B., Bhavnani, V., & Winfield, M. (2009). How patients use access to their full health records: A qualitative study of patients in general practice. *Journal of the Royal Society of Medicine, 102*(12), 539-544.

General Authority for Statistics - KSA. (2016). *Limited to actual haj.* Retrieved Oct/29, 2016, from http://www.stats.gov.sa/en/28

Genitsaridi, I., Kondylakis, H., Koumakis, L., Marias, K., & Tsiknakis, M. (2015). Evaluation of personal health record systems through the lenses of EC research projects. *Computers in Biology and Medicine, 59*, 175-185.

Gibbons, M. C., Wilson, R. F., Samal, L., Lehman, C. U., Dickersin, K., Lehmann, H. P., et al. (2009). Impact of consumer health informatics applications. *Evidence report/technology Assessment, (188)*(188), 1-546.

Goodman, L. (1960). Snowball sampling. *The Annals of Mathematical Statistics*, 148--170.

Green, B. B., Cook, A. J., Ralston, J. D., Fishman, P. A., Catz, S. L., Carlson, J., et al. (2008). Effectiveness of home blood pressure monitoring, web communication, and pharmacist care on hypertension control: A randomized controlled trial. *JAMA, 299*(24), 2857-2867.

Greenhalgh, T., Hinder, S., Stramer, K., Bratan, T., & Russell, J. (2010). Adoption, non-adoption, and abandonment of a personal electronic health record: Case study of HealthSpace. *BMJ (Clinical Research Ed.), 341*, c5814.

Halamka, J. D., Mandl, K. D., & Tang, P. C. (2008). Early experiences with personal health records. *Journal of the American Medical Informatics Association: JAMIA, 15*(1), 1-7.

Hassol, A., Walker, J. M., Kidder, D., Rokita, K., Young, D., Pierdon, S., et al. (2004). Patient experiences and attitudes about access to a patient electronic health care record and linked web messaging. *Journal of the American Medical Informatics Association: JAMIA, 11*(6), 505-513.

Health information technology. (2014). *What is meaningful use?* Retrieved Oct/26, 2016, from https://www.healthit.gov/providers-professionals/ehr-incentives-certification

Health Level Seven International. (2016). *PHR-S FM personal health record system functional model (PHR-S FM).* Retrieved Oct/26, 2016, from http://www.hl7.org/implement/standards/product_brief.cfm?product_id=88

Heisler, M., Bouknight, R. R., Hayward, R. A., Smith, D. M., & Kerr, E. A. (2002). The relative importance of physician communication, participatory decision making, and patient understanding in diabetes self-management. *Journal of General Internal Medicine, 17*(4), 243-252.

Hess, R., Bryce, C. L., Paone, S., Fischer, G., McTigue, K. M., Olshansky, E., et al. (2007). Exploring challenges and potentials of personal health records in diabetes self-management: Implementation and initial assessment. *Telemedicine Journal and e-Health : The Official Journal of the American Telemedicine Association, 13*(5), 509-517.

Hibbard, J. H., Greene, J., Becker, E. R., Roblin, D., Painter, M. W., Perez, D. J., et al. (2008). Racial/ethnic disparities and consumer activation in health. *Health Affairs (Project Hope), 27*(5), 1442-1453.

International Organization for Standardization. (2014). *iso/iec 25000:2005.* Retrieved Oct/26, 2016, from http://www.iso.org/iso/iso_catalogue/catalogue_tc/catalogue_detail.htm?csnumber=35683

Jeffs, D., Nossar, V., Bailey, F., Smith, W., & Chey, T. (1994). Retention and use of personal health records: A population-based study. *Journal of Paediatrics and Child Health, 30*(3), 248-252.

Jerden, L., & Weinehall, L. (2004). Does a patient-held health record give rise to lifestyle changes? A study in clinical practice. *Family Practice, 21*(6), 651-653.

Jian, W. S., Syed-Abdul, S., Sood, S. P., Lee, P., Hsu, M. H., Ho, C. H., et al. (2012). Factors influencing consumer adoption of USB-based personal health records in Taiwan. *BMC Health Services Research, 12*, 277-6963-12-277.

Johansen, M. A., & Henriksen, E. (2014). The evolution of personal health records and their role for self-management: A literature review. *Studies in Health Technology and Informatics, 205*, 458-462.

Jones, R., McConville, J., Mason, D., Macpherson, L., Naven, L., & McEwen, J. (1999). Attitudes towards, and utility of, an integrated medical-dental patient-held record in primary care. *The British Journal of General Practice : The Journal of the Royal College of General Practitioners, 49*(442), 368-373.

Kaelber, D. C., Jha, A. K., Johnston, D., Middleton, B., & Bates, D. W. (2008). A research agenda for personal health records (PHRs). *Journal of the American Medical Informatics Association : JAMIA, 15*(6), 729-736.

Kahn, J. S., Aulakh, V., & Bosworth, A. (2009). What it takes: Characteristics of the ideal personal health record. *Health Affairs (Project Hope), 28*(2), 369-376.

KAUH. (2016). *About us.* Retrieved Oct/29, 2016, from https://medicine.ksu.edu.sa/en/node/1247

KFMC. (2016). *About us.* Retrieved Oct\29, 2016, from https://www.kfmc.med.sa/#about

Kim, E. H., Stolyar, A., Lober, W. B., Herbaugh, A. L., Shinstrom, S. E., Zierler, B. K., et al. (2009). Challenges to using an electronic personal health record by a low-income elderly population. *Journal of Medical Internet Research, 11*(4), e44.

KKUH. (2016). *About us.* Retrieved Oct/29, 2016, from http://medicine.ksu.edu.sa/en/content/vision-mission-values

KSMC. (2016). *About city.* Retrieved Oct/29, 2016, from https://www.ksmc.med.sa/en/about/Pages/default.aspx

Lafky, D. B. & Horan, T. A. (2008). Prospective personal health record use among different user groups: Results of a multi-wave study. *Hawaii International Conference on System Sciences, Proceedings of the 41st Annual,* pp. 233-233.

Lober, W. B., Zierler, B., Herbaugh, A., Shinstrom, S. E., Stolyar, A., Kim, E. H., et al. (2006). Barriers to the use of a personal health record by an elderly population. *AMIA .Annual Symposium Proceedings. AMIA Symposium,* , 514-518.

Luchenski, S. A., Reed, J. E., Marston, C., Papoutsi, C., Majeed, A., & Bell, D. (2013). Patient and public views on electronic health records and their uses in the united kingdom: Cross-sectional survey. *Journal of Medical Internet Research, 15*(8), e160.

Lyles, C. R., Sarkar, U., Ralston, J. D., Adler, N., Schillinger, D., Moffet, H. H., et al. (2013). Patient-provider communication and trust in relation to use of an online patient portal among diabetes patients: The diabetes and aging study. *Journal of the American Medical Informatics Association : JAMIA, 20*(6), 1128-1131.

Markle Foundation. (2003). *The personal health working group final report.* Markle Connecting for Health.

MAXIMUS Federal Services. (2012). *Non-HIPAA covered entities: Privacy and security policies and practices of PHR vendors and related entities report.* MAXIMUS Federal Services.

McInnes, D. K., Solomon, J. L., Bokhour, B. G., Asch, S. M., Ross, D., Nazi, K. M., et al. (2011). Use of electronic personal health record systems to encourage HIV screening: An exploratory study of patient and provider perspectives. *BMC Research Notes, 4*, 295-0500-4-295.

Ministry of Health - KSA. (2016). *About the ministry.* Retrieved Oct/29, 2016, from http://www.moh.gov.sa/en/Pages/Default.aspx

Ministry of Health - KSA. (2016). *eHealth national plan* . Retrieved Oct/29, 2016, from http://www.moh.gov.sa/en/Ministry/nehs/Pages/default.aspx

Noblin, A. M., Wan, T. T., & Fottler, M. (2012). The impact of health literacy on a patient's decision to adopt a personal health record. *Perspectives in Health Information Management, 9*, 1-13.

Or, C. K., & Karsh, B. T. (2009). A systematic review of patient acceptance of consumer health information technology. *Journal of the American Medical Informatics Association : JAMIA, 16*(4), 550-560.

Pagliari, C., Detmer, D., & Singleton, P. (2007). Potential of electronic personal health records. *BMJ (Clinical Research Ed.), 335*(7615), 330-333.

Patel, V. N., Dhopeshwarkar, R. V., Edwards, A., Barron, Y., Likourezos, A., Burd, L., et al. (2011). Low-income, ethnically diverse consumers' perspective on health information exchange and personal health records. *Informatics for Health & Social Care, 36*(4), 233-252.

Patel, V. N., Dhopeshwarkar, R. V., Edwards, A., Barron, Y., Sparenborg, J., & Kaushal, R. (2012). Consumer support for health information exchange and personal health records: A regional health information organization survey. *Journal of Medical Systems, 36*(3), 1043-1052.

QuestionPro. (2016). *How it works.* Retrieved May/1, 2015, from http://www.questionpro.com/

Rainie, L. (2016). *Testimony to the national committee on vital and health statistic.* Retrieved Oct/26, 2016, from http://www.pewinternet.org/2001/01/11/testimony-to-the-national-committee-on-vital-and-health-statistics/

Ralston, J. D., Hirsch, I. B., Hoath, J., Mullen, M., Cheadle, A., & Goldberg, H. I. (2009). Web-based collaborative care for type 2 diabetes: A pilot randomized trial. *Diabetes Care, 32*(2), 234-239.

Roblin, D. W., Houston, T. K., 2nd, Allison, J. J., Joski, P. J., & Becker, E. R. (2009). Disparities in use of a personal health record in a managed care organization. *Journal of the American Medical Informatics Association : JAMIA, 16*(5), 683-689.

Segall, N., Saville, J. G., L'Engle, P., Carlson, B., Wright, M. C., Schulman, K., et al. (2011). Usability evaluation of a personal health record. *AMIA ...Annual Symposium Proceedings. AMIA Symposium, 2011*, 1233-1242.

Shah, S. G., Fitton, R., Hannan, A., Fisher, B., Young, T., & Barnett, J. (2015). Accessing personal medical records online: A means to what ends? *International Journal of Medical Informatics, 84*(2), 111-118.

Silvestre, A. L., Sue, V. M., & Allen, J. Y. (2009). If you build it, will they come? the Kaiser Permanente model of online health care. *Health Affairs (Project Hope), 28*(2), 334-344.

Steele, ,Robert, Min, ,Kyongho, & Lo, ,Amanda. Personal health record architectures: Technology infrastructure implications and dependencies.

Tang, P. C., Ash, J. S., Bates, D. W., Overhage, J. M., & Sands, D. Z. (2006). Personal health records: Definitions, benefits, and strategies for overcoming barriers to adoption. *Journal of the American Medical Informatics Association : JAMIA, 13*(2), 121-126.

Tenforde, M., Jain, A., & Hickner, J. (2011). The value of personal health records for chronic disease management: What do we know? *Family Medicine, 43*(5), 351-354.

The U.S. Department of Health and Human Services (HHS). (2015). *Personal health records and the HIPPA privacy rule*. https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/special/healthit/phrs.pdf

Tobacman, J. K., Kissinger, P., Wells, M., Prokuski, J., Hoyer, M., McPherson, P., et al. (2004). Implementation of personal health records by case managers in a VAMC general medicine clinic. *Patient Education and Counseling, 54*(1), 27-33.

Tomson, P. (1985). Sharing problem cards with patients. *The Journal of the Royal College of General Practitioners, 35*(280), 534-535.

Turner, K., Klaman, S. L., & Shea, C. M. (2016). Personal health records for people living with HIV: A review. *AIDS Care, 28*(9), 1181-1187.

U.S. Department of Health & Human Services. (2016). *Health information privacy.* Retrieved Oct/26, 2016, from http://www.hhs.gov/hipaa/index.html

Wagner, P. J., Dias, J., Howard, S., Kintziger, K. W., Hudson, M. F., Seol, Y. H., et al. (2012). Personal health records and hypertension control: A randomized trial. *Journal of the American Medical Informatics Association : JAMIA, 19*(4), 626-634.

Weitzman, E. R., Kaci, L., & Mandl, K. D. (2009). Acceptability of a personally controlled health record in a community-based setting: Implications for policy and design. *Journal of Medical Internet Research, 11*(2), e14.

Wen, K. Y., Kreps, G., Zhu, F., & Miller, S. (2010). Consumers' perceptions about and use of the internet for personal health records and health information exchange: Analysis of the 2007 health information national trends survey. *Journal of Medical Internet Research, 12*(4), e73.

Winkelman, W. J., Leonard, K. J., & Rossos, P. G. (2005). Patient-perceived usefulness of online electronic medical records: Employing grounded theory in the development of information and communication technologies for use by patients living with chronic illness. *Journal of the American Medical Informatics Association : JAMIA, 12*(3), 306-314.

Witry, M. J., Doucette, W. R., Daly, J. M., Levy, B. T., & Chrischilles, E. A. (2010). Family physician perceptions of personal health records. *Perspectives in Health Information Management, 7*, 1d.

World Health Organization. (2016). *Countries: Saudi Arabia.* Retrieved Oct/29, 2016, from http://www.who.int/countries/sau/en

Wynia, M., & Dunn, K. (2010). Dreams and nightmares: Practical and ethical issues for patients and physicians using personal health records. *The Journal of Law, Medicine & Ethics : A Journal of the American Society of Law, Medicine & Ethics, 38*(1), 64-73.

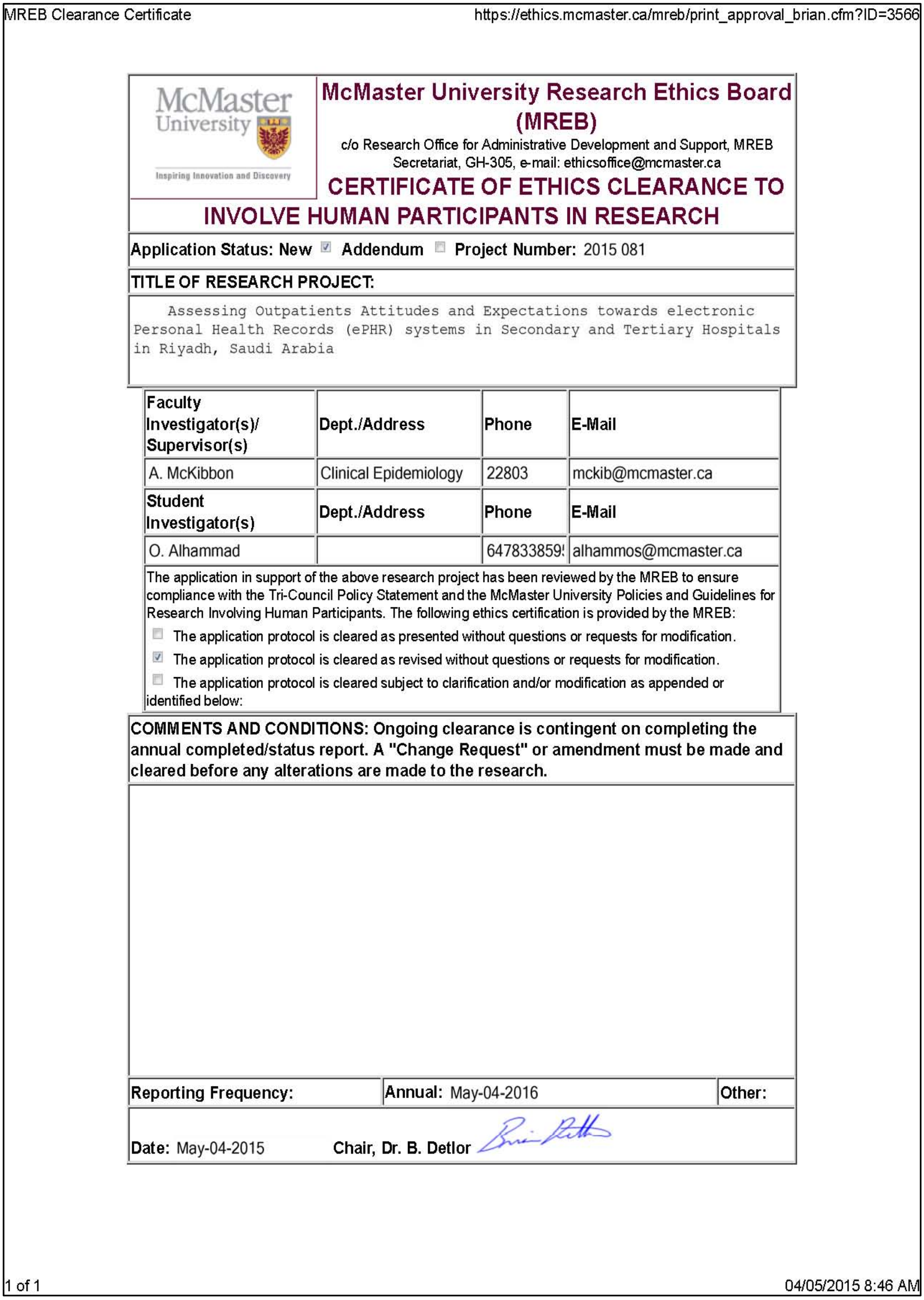
Yau, G. L., Williams, A. S., & Brown, J. B. (2011). Family physicians' perspectives on personal health records: Qualitative study. *Canadian Family Physician Medecin De Famille Canadien, 57*(5), e178-84.

Zhou, Y. Y., Garrido, T., Chin, H. L., Wiesenthal, A. M., & Liang, L. L. (2007). Patient access to an electronic health record with secure messaging: Impact on primary care utilization. *The American Journal of Managed Care, 13*(7), 418-424.

Appendices

Appendix 1: Ethics Board Clearances

1- McMaster University Research Ethics Board Clearance



MREB Clearance Certificate https://ethics.mcmaster.ca/mreb/print_approval_brian.cfm?ID=3566

McMaster University
Inspiring Innovation and Discovery

McMaster University Research Ethics Board (MREB)

c/o Research Office for Administrative Development and Support, MREB Secretariat, GH-305, e-mail: ethicsoffice@mcmaster.ca

CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN PARTICIPANTS IN RESEARCH

Application Status: New ☑ **Addendum** ☐ **Project Number:** 2015 081

TITLE OF RESEARCH PROJECT:

Assessing Outpatients Attitudes and Expectations towards electronic Personal Health Records (ePHR) systems in Secondary and Tertiary Hospitals in Riyadh, Saudi Arabia

Faculty Investigator(s)/ Supervisor(s)	**Dept./Address**	**Phone**	**E-Mail**
A. McKibbon	Clinical Epidemiology	22803	mckib@mcmaster.ca
Student Investigator(s)	**Dept./Address**	**Phone**	**E-Mail**
O. Alhammad		647833859	alhammos@mcmaster.ca

The application in support of the above research project has been reviewed by the MREB to ensure compliance with the Tri-Council Policy Statement and the McMaster University Policies and Guidelines for Research Involving Human Participants. The following ethics certification is provided by the MREB:

☐ The application protocol is cleared as presented without questions or requests for modification.

☑ The application protocol is cleared as revised without questions or requests for modification.

☐ The application protocol is cleared subject to clarification and/or modification as appended or identified below:

COMMENTS AND CONDITIONS: Ongoing clearance is contingent on completing the annual completed/status report. A "Change Request" or amendment must be made and cleared before any alterations are made to the research.

Reporting Frequency: **Annual:** May-04-2016 **Other:**

Date: May-04-2015 **Chair, Dr. B. Detlor** Brian Detlor

1 of 1 04/05/2015 8:46 AM

2- King Saud University Medical City Institutional Review Board Clearance
(King Khalid University Hospital and King Abdulaziz University Hospital)

جامعة الملك سعود (034)
هاتف +966 11 467 00 11
فاكس +966 11 467 24 39

المملكة العربية السعودية
ص.ب 7805 الرياض 11472
www.ksu.edu.sa

جامعة الملك سعود
King Saud University

كلية الطب
ومستشفى الملك خالد الجامعي

10.09.2015 (26.11.1436)
Ref. No. 15/0336/IRB

Ms. Ohoud Alhammad
Master Student
McMaster University, Canada –eHealth Master Program
Teaching Assistant in KSU College of Applied Medical Sciences
Community Health Departtment

Subject: **Research Project No. E-15-1605**

Project Title: "Assessing Outpatients' Attitudes and Expectations towards electronic Personal Health records (ePHR) Systems in secondary and tertiary hospitals in Riyadh, Saudi Arabia"

Dear Ms. Alhammad,

I am pleased to inform you that your above-mentioned research project was reviewed by the Institutional Review Board on 10 September 2015 (26 Dhual-Qa'dah 1436). The project was **approved**. Work on this project may begin.

We wish you success in your research and request you to keep the IRB informed about the progress and final outcome of the study in a regular basis. Please quote the project number shown above in any future correspondence or follow-ups related to this study.

If you have any question, please feel free to contact me.

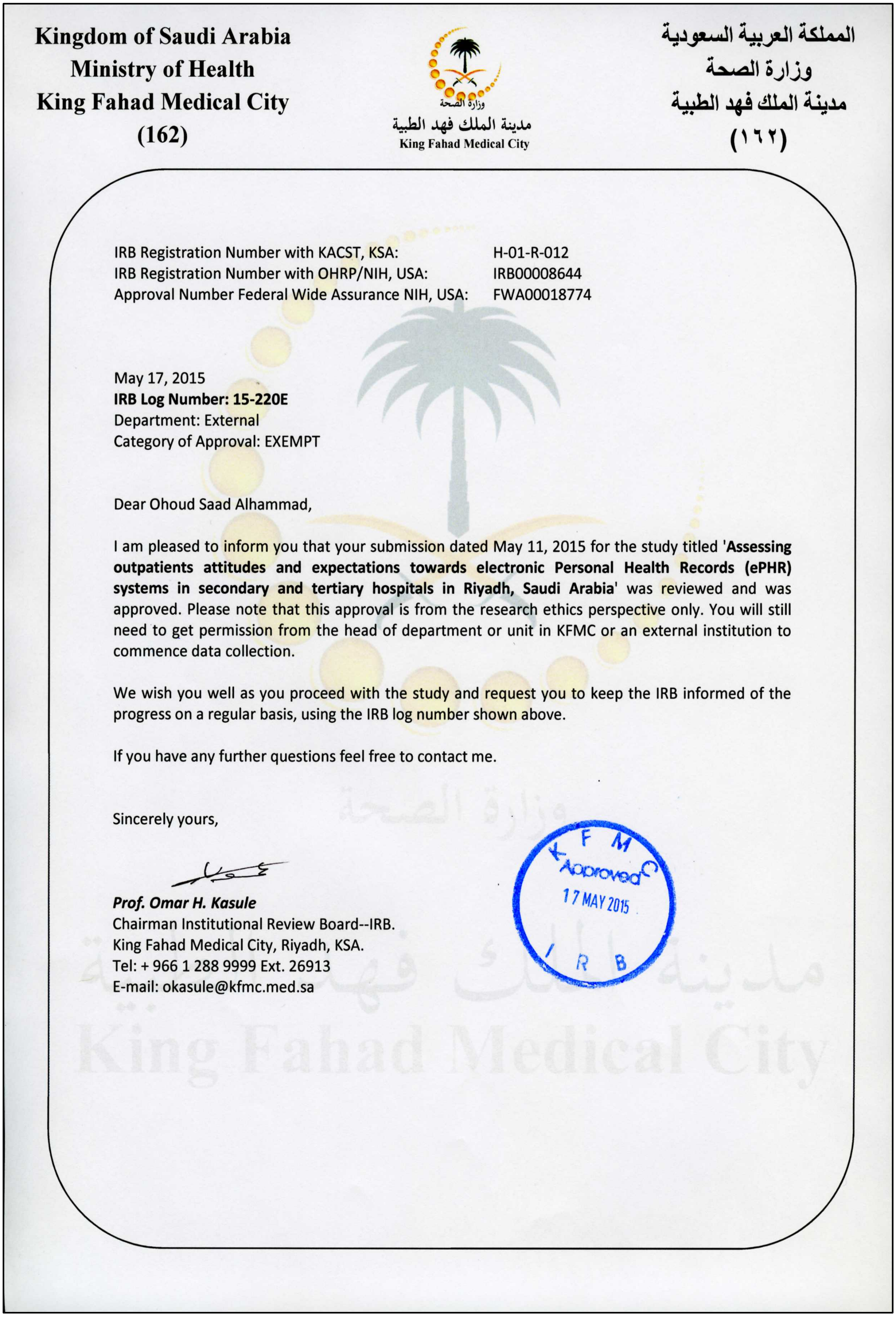
Thank you!

Sincerely yours,

Prof. Khalid M. Al-Faleh
Chairman, Institutional Review Board
King Saud University College of Medicine
P.O. Box 7805 Riyadh 11472 K.S.A.
E-mail: kfaleh@ksu.edu.sa

/braezell
الرقم
التاريخ
المرفقات

3- King Fahad Medical City Institutional Review Board Clearance



Kingdom of Saudi Arabia
Ministry of Health
King Fahad Medical City
(162)

وزارة الصحة
مدينة الملك فهد الطبية
King Fahad Medical City

المملكة العربية السعودية
وزارة الصحة
مدينة الملك فهد الطبية
(١٦٢)

IRB Registration Number with KACST, KSA:	H-01-R-012
IRB Registration Number with OHRP/NIH, USA:	IRB00008644
Approval Number Federal Wide Assurance NIH, USA:	FWA00018774

May 17, 2015
IRB Log Number: 15-220E
Department: External
Category of Approval: EXEMPT

Dear Ohoud Saad Alhammad,

I am pleased to inform you that your submission dated May 11, 2015 for the study titled '**Assessing outpatients attitudes and expectations towards electronic Personal Health Records (ePHR) systems in secondary and tertiary hospitals in Riyadh, Saudi Arabia**' was reviewed and was approved. Please note that this approval is from the research ethics perspective only. You will still need to get permission from the head of department or unit in KFMC or an external institution to commence data collection.

We wish you well as you proceed with the study and request you to keep the IRB informed of the progress on a regular basis, using the IRB log number shown above.

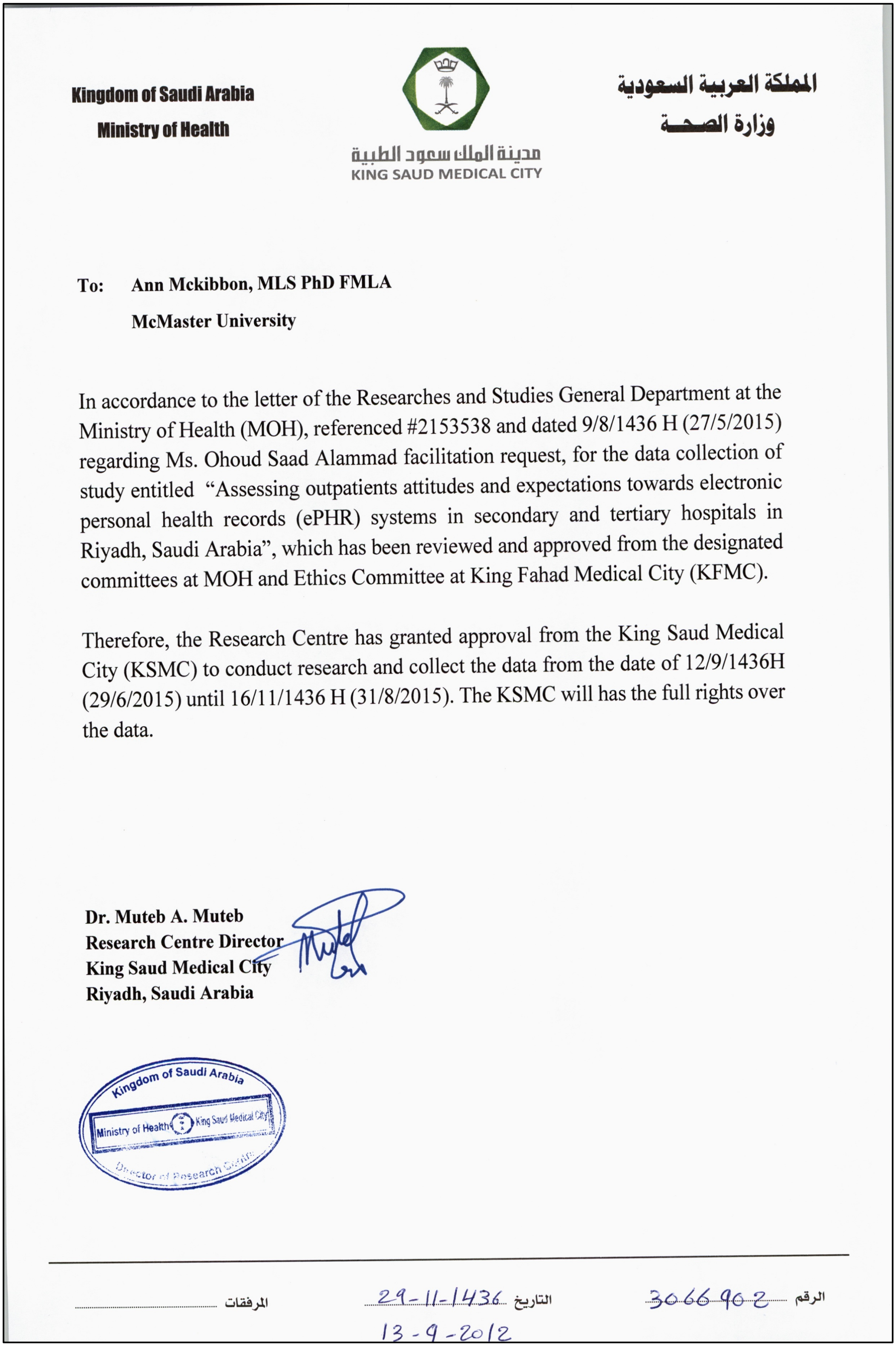
If you have any further questions feel free to contact me.

Sincerely yours,

Prof. Omar H. Kasule
Chairman Institutional Review Board--IRB.
King Fahad Medical City, Riyadh, KSA.
Tel: + 966 1 288 9999 Ext. 26913
E-mail: okasule@kfmc.med.sa

KFMC
Approved
17 MAY 2015
IRB

4- King Saud Medical City Institutional Review Board Clearance



Kingdom of Saudi Arabia
Ministry of Health

مدينة الملك سعود الطبية
KING SAUD MEDICAL CITY

المملكة العربية السعودية
وزارة الصحة

To: **Ann Mckibbon, MLS PhD FMLA**
McMaster University

In accordance to the letter of the Researches and Studies General Department at the Ministry of Health (MOH), referenced #2153538 and dated 9/8/1436 H (27/5/2015) regarding Ms. Ohoud Saad Alammad facilitation request, for the data collection of study entitled "Assessing outpatients attitudes and expectations towards electronic personal health records (ePHR) systems in secondary and tertiary hospitals in Riyadh, Saudi Arabia", which has been reviewed and approved from the designated committees at MOH and Ethics Committee at King Fahad Medical City (KFMC).

Therefore, the Research Centre has granted approval from the King Saud Medical City (KSMC) to conduct research and collect the data from the date of 12/9/1436H (29/6/2015) until 16/11/1436 H (31/8/2015). The KSMC will has the full rights over the data.

Dr. Muteb A. Muteb
Research Centre Director
King Saud Medical City
Riyadh, Saudi Arabia

Director of Research Centre

الرقم 3066902 التاريخ 29-11-1436 المرفقات
13-9-2012

Appendix 2: The Study Survey

If you feel uncomfortable with answering any of the questions, you do not have to and you will not be penalized

Demographic questions: this information will be used only in summary form; it will not be used to identify you individually.

Please check the appropriate answer for your response:

1. What is the hospital you are attending today?
   - ○ King Abdulaziz University Hospital
   - ○ King Khalid University Hospital
   - ○ King Fahad Medical City
   - ○ King Saud Medical City

2. Where do you live in Saudi Arabia?
   - ○ Central region
   - ○ East region
   - ○ North region
   - ○ West region
   - ○ South region

3. How old are you?
   - ○ 19 – 30
   - ○ 31 – 50
   - ○ 51 – 60
   - ○ 61+

4. What is your highest grade or level of school you have completed?
   - ○ Elementary school or less
   - ○ Intermediate school
   - ○ Secondary school
   - ○ University graduate
   - ○ Graduate degree

5. What is the best estimate of your monthly household income (riyal)?
   - ○ Less than 3000
   - ○ 3000 – 9999
   - ○ 10,009 – 19,999
   - ○ 20,000 – 49,999
   - ○ 50,000 or more

Health related questions:

6. In general, how would you rate your overall health?
   - ○ Excellent
   - ○ Very good
   - ○ Good
   - ○ Fair
   - ○ Poor

7. Are you being treated for any chronic disease or medical problem such as high blood pressure, diabetes, heart or lung disease, or a mental health problem?
   - ○ Yes
   - ○ No

8. Are you taking medication(s) prescribed by a doctor?
   - ○ Yes
   - ○ No

9. Approximately, how many visits in the **past year** have you had with the following healthcare providers or facilities?

	Number of visits in past year
○ Primary healthcare (doctors, nurses)	
○ Specialist (e.g. heart doctor, skin doctor etc.)	
○ Emergency room	
○ Hospital (stayed at least overnight)	

10. How often do you have problems understanding your doctors when they are talking to you about your health?

○ Always ○ Often ○ Sometimes ○ Occasionally ○ Never

11. How often do you have problems understanding written medical information (such as forms, or pamphlets) from your doctor or doctor's clinic?

○ Always ○ Often ○ Sometimes ○ Occasionally ○ Never

12. Overall how satisfied are you with the quality of health care service you have received in the past 5 years?

○ Very satisfied ○ Neutral ○ Very dissatisfied
○ Somewhat satisfied ○ Somewhat dissatisfied

Internet use questions:

13. Do you have a computer with Internet access available for use, either at home or work or another location?

○ Yes ○ No

14. How often do you go on line and use the Internet?

○ Several times a day ○ Once monthly
○ About once daily ○ Rarely or not at all
○ Once weekly

15. How often do you use the Internet for health purposes?

○ Several times a day ○ Once monthly
○ About once daily ○ Rarely or not at all
○ Once weekly

16. How concerned are you about the privacy of personal health information that is shared over the Internet?

○ Very concerned ○ Concerned ○ Somewhat concerned
○ Not very concerned ○ Not concerned

<u>Personal health record questions:</u> an electronic personal health record is like a paper medical record except this is created, stored, and viewed on computers. It is primarily used by you to view your health information and manage you healthcare (like make appointments and see blood test results) on the Internet.

17. Please indicate how strongly you agree or disagree with the following statement:
I am interested in using the computer to go online and use the Internet to manage my healthcare (view my health information/or do activities like making appointments)

○ Strongly agree ○ Agree ○ Neutral ○ Disagree ○ Strongly disagree

18. Which of the following types of health information would you like to have as part of your personal health record? **<u>Please check all that apply:</u>**
    - ○ My allergies
    - ○ Test results (e.g. blood tests, X-rays)
    - ○ Immunization records
    - ○ Medication I have taken or am currently taking
    - ○ List of doctors and health care providers I have seen
    - ○ Family history of health problems
    - ○ Medical problems
    - ○ Medical visits, including visits to the emergency room
    - ○ Surgeries and medical procedures that I have had
    - ○ Lifestyle choices (e.g., exercise, smoking history)
    - ○ Information from devices that help me monitor my health (e.g., glucose from a diabetes meter)
    - ○ Other health information specify ____________________

19. Which of the following activities would you like to do on the Internet? **<u>Please check all that apply:</u>**
    - ○ Receive a report from my doctor about my visit
    - ○ Add my own notes or make changes to information in my patient health record
    - ○ Request medical appointments
    - ○ Request referrals to other doctors
    - ○ Request prescription refills
    - ○ Send emails to my doctor or his/her practice with my medical questions
    - ○ Receive reminders for preventive health services (e.g. flu shots)
    - ○ Access my child's or parent's medical record if I am their primary caretaker
    - ○ Communicate with other people with similar health problems (e.g. support groups)
    - ○ Receive educational materials related to my health

  - Record my treatment preferences
  - Record my selection of a family member or friend to manage my health care when I am not able to.
  - Other activities. Specify:____________

20. How often do you think you would view your personal health record or do the activities listed above?
    - Once a week
    - Once a month
    - Once every 3 -6 months
    - Once a year
    - Rarely or not at all

21. What effect do you think being able to view and manage (e.g. making appointments) your electronic personal health record will have on the following:

	Improve	No effect	Worsen
a. The security and the privacy of my medical information			
b. Understanding my doctor's explanations and advice			
c. My understanding of my own health			
d. My sense of control over my own healthcare			
e. The ability of my doctor(s) and I to make decisions about my medical care together as a team			
f. My worries about my own healthcare			
g. The safety of my care (e.g. medical errors)			
h. My satisfaction with my health care			
i. The overall quality of my healthcare			

22. Who would you give permission to view information in your electronic personal health record? **<u>Please check all that apply:</u>**
    - Designated family members or friends
    - My primary care doctor
    - Other doctors or healthcare providers who care for me (in clinic, the ER or the hospital)
    - Government officials
    - My employer
    - I would not give anyone permission

Thank you very much for completing this survey!

Appendix 3: The Study Survey in Arabic

استبيان التقارير الطبية الشخصيه الالكترونيه

يمكنك عدم الاجابه على بعض الأسئلة اذا كنت تشعر بعدم ارتياح من الاجابه عليها ولن تكون هناك عواقب جراء ذلك.

الأسئلةالعامة :هذه المعلومات ستستخدمكمجموعة,ولن تستخدم للتعريف بك شخصياً.
أرجو اختيار الاجابة المناسبة لحالتك:

1. ما هو المستشفى الذي تزوره اليوم؟

○ مستشفى الملك عبدالعزيز الجامعي ○ مدينة الملك سعود الطبية
○ مستشفى الملك خالد الجامعي ○ مدينة الملك فهد الطبية

2. أين تعيش في المملكة العربية السعودية؟

○ الوسطى ○ الشمالية ○ الجنوبيه ○ الشرقيه ○ الغربيه

3. كم عمرك؟

○ 18 30 ○ 31 50 ○ 51 60 ○ أكبر من 60

4. ماهو أعلى مستوى تعليمي أكملته؟

○ الابتدائية أو أقل ○ المتوسطة ○ الثانوية ○ الجامعيه ○ دراسات عليا

5. ماهو أحسن تقدير لدخل منزلك الشهري؟

○ 3000 أو أقل ○ 3000 9,999 ○ 10,000 19,999
○ 20,000 49,999 ○ أكثر من 50,000

الاسئلة الصحية:

6. بصفة عامة ماهو تقييمك لصحتك؟

○ ممتازة ○ جيدة جداً ○ جيدة ○ مقبوله ○ ضعيفه

7. هل أنت تعالج من مرض مزمن مثل ارتفاع ضغط الدم، السكري، أمراض القلب؟

○ نعم ○ لا

8. هل تأخذ أدوية موصوفة من طبيب؟

○ نعم ○ لا

9. تقريباً, كم عدد زياراتك العام الماضي لموفري الخدمة الصحية الآتية؟

	عدد الزيارات في العام الماضي
○ رعاية صحية أولية (مثل الطبيب العام أو ممرضة)	
○ طبيب أخصائي (مثل طبيب قلب,طبيب جلدية)	
○ الطوارئ	
○ المستشفى (تم تنويمك لليلة واحده على الأقل)	

10. هل تجد صعوبة في فهم طبيبك عندما يتحدث معك عن صحتك؟

○ دائماً ○ غالباً ○ أحياناً ○ نادراً ○ أبداً

11. هل تجد صعوبة في فهم المعلومات الطبية المكتوبة مثل الكتيبات والاستمارات الطبية في عيادة الطبيب؟

○ دائماً ○ غالباً ○ أحياناً ○ نادراً ○ أبداً

12. بصفة عامة,ماهو مدى رضاك عن جودة الخدمة الصحية المقدمة لك في الخمس سنوات الماضية؟

○ راضٍ جداً ○ محايد ○ غير راضٍ جداً
○ نوعاً ما راض ○ نوعاً ما غير راض

13. هل يوجد لديك كمبيوتر موصول بالانترنت في البيت أو العمل أو أي مكان آخر؟

○ نعم ○ لا

14. كم مرة تستخدم الانترنت؟

○ مرات عديدة في اليوم ○ مرة واحدة في اليوم ○ نادراً أو لا أستخدمه أبداً
○ مرة واحدة في الاسبوع ○ مرة واحدة في الشهر

15. كم مرة تستخدم الانترنت لأغراض صحيه؟

○ مرات عديدة في اليوم ○ مرة واحدة في اليوم ○ نادراً أو لا أستخدمه أبداً
○ مرة واحدة في الاسبوع ○ مرة واحدة في الشهر

16. ماهو مدى قلقك من خصوصية المعلومات الصحية الشخصية التي تشارك عبر الانترنت؟

○ تقلقني جداً ○ نوعا ما تقلقني ○ لا تقلقني أبداً
○ تقلقني ○ لست قلقاً كثيراً

أسئلة التقارير الطبية: التقارير الشخصية الطبية الالكترونية هي مثل التقارير الطبية العادية ولكنها تُنشأ وتتحفظ وتثرى على الكمبيوتر. غالباً, تستخدم من قبلك لترى معلوماتك الصحية ولتنظيم رعايتك الصحية مثل طلب المواعيد ورؤية نتائج تحاليل الدم على الانترنت

17.ما مدى موافقتك للعبارة التالية:

أنا مهتم باستخدام الكمبيوتر والانترنت لتنظيم رعايتي الصحية (مثل رؤية معلوماتي الصحية,او طلب مواعيد)

○ اوافق بشدة ○ اوافق ○ محايد ○ لا أوافق ○ لا أوافق بشدة

18.ماهي أنواع المعلومات الصحية التي تود الحصول عليها في تقاريرك الصحية الشخصية الالكترونية:أرجو اختيار جميع الأجوبة المناسبة

○ الحساسية
○ نتائج التحاليل (مثل الدم والأشعة)
○ التطعيمات
○ الأدوية السابقة والتي استخدمها حالياً
○ قائمة بأسماء الأطباء وموفري الخدمة الصحية الذين أزورهم
○ التاريخ الطبي للعائلة
○ مشاكلي وأمراضي الصحية
○ زياراتي الطبية من ضمنها زياراتي للطوارئ
○ العمليات والاجراءات الطبية التي أجريتها
○ سلوكي الصحي (مثل الرياضة , التدخين)
○ معلومات من الأجهزة التي أستخدمها لتنظيم صحتي مثل جهاز قياس السكر بالدم
○ معلومات صحية أخرى، أرجو التحديد ______________________

19.أي من الأعمال التالية تود أن تفعلها على الانترنت؟ أرجو اختيار جميع الأجوبة المناسبة

○ استلام تقرير من الطبيب عن زيارتي
○ وضع ملاحظاتي الشخصية أو تغيير بعض المعلومات الصحية في تقاريري الالكترونية
○ طلب مواعيد صحية
○ طلب تحويل لأطباء آخرين
○ طلب اعادة تعبئة للأدوية
○ ارسال أسئلة عن صحتي عبر البريد الالكتروني لطبيبي أو لعيادته
○ استلام تذكيرات عن خدمات الوقاية الصحية مثل تطعيمات الانفلونزا
○ رؤية التقارير الطبية الخاصة بطفلي أو والدي أو والدتي في حالة أني المسؤول الأول عن رعايتهم

○ التواصل مع المرضى الذين يعانون من نفس المشكلة الصحية مثل مجموعات الدعم الصحية
○ الحصول على مواد تعليمية لها علاقة بحالتي الصحية
○ حفظ مفضلاتي العلاجية
○ تسجيل اختياري من العائلة أو الأصدقاء القادر على تنظيم حالتي الصحية في حال عدم مقدرتي على ذلك
○ أعمال أخرى، أرجو التحديد ________________

20.كم مرة باعتقادك سوف تستخدم أو ترى تقاريرك الشخصية الالكترونية أو تعمل أي من الأعمال المشار اليها في السؤال السابق؟

○ مرة في الاسبوع ○ مرة كل 3 6 شهور ○ نادراً أو لن استخدمه أبداً
○ مرة في الشهر ○ مرة بالسنة

21.ما الأثر المترتب على مشاهدتك وتنظيمك لتقاريرك الطبية الشخصية الالكترونية على الأمور التالية:

		سيتحسن	لا يوجد أثر	سيصبح أسوأ
1	أمان وخصوصية معلوماتي الصحية			
2	فهم شرح ونصائح طبيبي			
3	فهمي لحالتي الطبية			
4	احساسي بمدى تحكمي عن رعايتي الصحية			
5	مقدرتي على أخذ قراراتي الصحية بالتعاون مع الأطباء لنعمل كفريق واحد			
6	مخاوفي من رعايتي الصحية			
7	أمان الرعاية الصحية المقدمة لي (مثل الأخطاء الطبية)			
8	مدى رضاي عن رعايتي الصحية			
9	الجودة الاجمالية لرعايتي الصحية			

22.من الذي ستسمح له بمشاهدة تقاريرك الصحية الالكترونية؟ أرجو اختيار جميع الأجوبة المناسبة.

○ بعض أفراد العائلة أو الأصدقاء
○ جهات حكومية
○ جهة العمل الخاصة بي
○ طبيبي الرئيسي
○ أطباء آخرين يوفرون لي الرعاية الصحية (مثل في الطوارئ أو المستشفيات)
○ لن أسمح لأي أحد بمشاهدتها

Appendix 4: Back Translation Of The Survey

Answering these questions is optional and there will be no consequences on not answering any question.

General questions

This information will be used as a group and will not be used as personal identifications.

Please select the appropriate answer for your situation:

1- Which Hospital are you visiting today?
  - ○ King Fahad Medical city
  - ○ King Khalid University Hospital
  - ○ King Abdulaziz University Hospital
  - ○ King Saud Medical City

2- Where are you living in Saudi Arabia:
  - ○ Central
  - ○ Western
  - ○ Eastern
  - ○ North
  - ○ South

3- How old are you?
  - ○ 18 -30
  - ○ 31 – 50
  - ○ 50 – 60
  - ○ older than 60

4- What is your level of education?
  - ○ Elementary or less
  - ○ Intermediate school
  - ○ Secondary School
  - ○ Bachelor
  - ○ Higher education

5- What is your monthly income?
  - ○ 3,000 SAR or less
  - ○ 3,000 – 9,999
  - ○ 10,000 – 19,999
  - ○ 20,000 – 49,999
  - ○ More than 50.000.

Health questions

6. What best describes your health status:
   - Excellent
   - Very good
   - Good
   - Average.
   - Poor.

7. Are you being treated from chronic disease e.g. hypertension, diabetes or heart disease.
   - Yes
   - No

8. Are you taking prescribed medications?
   - Yes
   - No

9. Last year, how many times did you visit the following health care institutes:

	Number of visits
Primary healthcare e.g. family doctors, nurses	
Specialist e.g. heart doctor, skin doctor	
Emergency room	
Hospital (stayed an overnight at least)	

10. Do you have any difficulty understanding your physician when he/she speaks to you about your health?
    - Always
    - Often
    - Sometimes
    - Rarely
    - Never.

11- Do you have any difficulty understanding written medical information e.g. booklets or brochures in the doctor clinic.

- Always
- Often
- Sometimes
- Rarely
- Never

12- In general, what is the extent of your satisfaction with the quality of health service provided to you in the past five years?

○ Very satisfied
○ Somewhat satisfied
○ Neutral
○ Somewhat unsatisfied
○ Very unsatisfied

13. Do you have a computer connected to the Internet at home, work or anywhere else?
○ Yes
○ No

14. How often do you use the Internet?
○ Several times a day.
○ Once a day
○ Once a week.
○ Once a month.
○ Rarely or never

15. How many times have used the Internet for the purposes of health?
○ Several times a day.
○ Once a day
○ Once a week.
○ Once a month.
○ Rarely or never

16. What is the extent of your concern of personal health information privacy that are shared online?
○ Very worried.
○ Somewhat worried
○ A lttle bit worried
○ Worried
○ Not worried

Medical reports questions:

Personal electronic medical reports are like regular medical reports but are created, saved and seen on your computer. Often used by you to see your health information and to regulate your health care, such as appointments and laboratory results online.

17. To what extent you agree to the following:
I'm interested in using the computer and the Internet to organize my care and health (such as viewing my health records and scheduling my appointments)

o Strongly agree.
o Agree
o Neutral
o Disagree
o Strongly Disagree.

18. What are the types of health information you would like to get in the electronic personal health reports: Please select all the appropriate answers:
o Allergy.
o Test results (e.g. laboratory and radiology)
o Vaccinations
o Previous and current medications.
o List of doctors and health care providers whom I visit
o Family medical history
o My current and chronic diseases
o My medical visits, including emergency visits.
o Surgeries and procedures I had.
o My lifestyle health (e.g. exercise and smoking).
o Information from the devices that I use to organize my health, such as blood glucose cheker machine.
o Other health information: please specify………

19. Which of the following would you like to do on the Internet? Choose all the right answers;

o Rceive reports from the doctor about my visit
o Write my personal observations or change some of the electronic health information in my reports
o Request medical appointments
o Request referal to other physicians
o Request refill medication
o Send questions through email about my health to my family physician or clinic.
o Receive reminders for preventive health services such as flu vaccinations
o Access my family and parents medical reports, if I am primarily responsible for their care
o Communicate with patients who suffer from the same health problem such as health support groups
o Access to educational materials related to my health problem.
o Remember my favorite treatment plans.
o Optionaly recording a family member or a friend to organize my health incase I am was not able to
o Others, please specify …….

20. How many times do you think you will use or see your electronic personal health reports or do any of the activities referred to in the previous question?
    - Once a week.
    - Once a month.
    - Once every 3 – 6 months.
    - Once a year.
    - Rarely or never.

21. The resulting impacts of viewing your personal electronic medical reports on your organization and the following matters:

	Improve (1)	No impact (2)	Worsen (3)
j. Security and privacy of health records			
k. Understand my physician recommendations			
l. Understand my health situation			
m. |My feeling of how I am controlling my healthcare			
n. My ability to take decision about my health care in collaboration with the physicians.			
o. The fears from health care			
p. Safety of health services provided to me (such as medical mistakes)			
q. My satisfaction about my health care.			
r. The quality of the health care provided to me			

22. Who will you allow to access your health records? Select all the appropriate answers;

- Some family members or friends
- Government agencies
- My employer
- The main physician
- Other physicians who provide healthcare to me (such as in an emergency or hospital)
- I will not allow any one to see it

Appendix 5: Letter Of Information/ Consent

A Study of/about: Assessing Outpatients Attitudes and Expectations towards ePHR in Secondary and Tertiary Hospitals in Riyadh

Principal Investigator:	**Student Investigator:**
Dr. Ann McKibbon	Ohoud Alhammad
Department of Health Sciences	Department of Health Sciences
McMaster University	McMaster University
Hamilton, Ontario, Canada	Hamilton, Ontario, Canada
+1(905) 525-9140 ext. 22803	**+1(647) 833-8595 or +966 500559055**
E-mail: mckib@mcmaster.ca	E-mail: alhammos@mcmaster.ca

Research Sponsor: Saudi Cultural Bureau in Canada/ King Saud University in Saudi Arabia

Purpose of the Study:
You are invited to take part in this study on outpatients' attitudes and expectations regarding electronic personal health records (ePHR). We are hoping to learn about the potential of using this type of technology in Saudi Arabian healthcare. This is an external research study, and it is not undertaken by the hospital but it had been approved by the Saudi Ministry of Health and the hospital's Institutional Review Board.

Procedures involved in the Research:
You will be asked to complete a survey that has questions about your background and your preferences in using electronic personal health records. The survey will take approximately 10 - 15 minutes. You may choose to complete a paper-based or an electronic survey. The tool that is used for the electronic survey is QuestionPro. To ensure its security, the data centers of QuestionPro are monitored twenty-four hours a day, seven days a week. QuestionPro employs the concept of least privilege—qualified employees are allowed access to privileged areas of the system only when such access is necessary for the operation of QuestionPro business functions. All customer data, including the data of end users, is logically separated by account-based rules that require the entry of a unique username and password with each logon. Only the researchers will have an access to this study's username, password, and the participants' information.

Risks:
It is not likely that there will be any serious harm associated with completing this survey. However, you may feel uncomfortable filing this survey while you are waiting anxiously for your appointment. You may also be concerned about your privacy and reputation when participating in a survey in a waiting area in the hospital setting. You may feel afraid that the care you are receiving in the hospital will be affected negatively if you respond to the survey and your healthcare team knows about your answers. You may also feel demeaned or marginalized when you answer some

questions in the survey. You may feel that you don't have time to fill this survey, or you may be afraid that this survey is collecting personal information about you.

If you choose to participate using the paper-based survey but you are worried about not having enough time to complete it, you can keep the Letter of Information and the paper-based survey with you, and complete the survey after you have had your appointment. If you choose to use the electronic survey and would like to start it after your appointment, please ask me after your appointment to give you the iPad to fill the electronic survey in the waiting area. The researcher can't leave the iPad with the patients and no logon information will be provided.

This is an anonymous survey, and no personal information or personal health information is being collected. Your information can't be linked to your identity since no identifiable personal information will be collected. Your healthcare team including your physician and nurse will have no access to the collected information. Only the researchers will have the access to the collected data. All the data will be analyzed collectively and not case by case, so your reputation will not be affected when the data will be analyzed since no one will know, even the researchers, which answers are yours.

The iPad that is used for the online survey is covered with a privacy screen protector that will blacken the screen to the people looking to it from the sides of the iPad. With this protector, only the holder of the iPad can see the online survey questions. However, to ensure your confidentiality with both online and paper-based surveys, you may be asked to sit in a corner that has no patients in, to ensure that your privacy is protected and that no other patient is looking to your answers.

If you feel uncomfortable with answering any of the questions, you don't have to and you will not be penalized.

Benefits:
The research will not benefit you directly. We hope that what is learned as a result of this study will help us to better understand your preferences and the type of activities you would like to do in your electronic personal health record. You will receive a gift certificate as a compensation for your time in answering this survey.

Confidentiality
You are participating in this research anonymously. No one including us will know that you participated. The information you provide will be kept in a locked cabinet until the researchers transfer the data in the survey papers to a password protected computer. Only the researchers know the password and have access to this computer and locked cabinet. Once the study has been completed, an archive of the data, without identifying information, will be maintained for approximately 10 years to conduct similar research in different regions in Saudi Arabia to produce results that can give us a general idea about Saudis preferences in electronic personal health records. And after approximately 10 years, the data will be deleted and destroyed.

Participation and Withdrawal:

It is your choice to be part of the study or not. If you decide to be part of the study, you can stop the survey at any time. If you are filling a paper-based survey, your survey paper will be destroyed using paper shredder and will not be included in the study after your withdrawal. But once you are filling the online survey, your answers will be put into a database and will not be identifiable to you. This means that once you have submitted your online survey, your responses cannot be withdrawn from the study because we will not be able to identify which responses are yours. That means that once your information is entered into the database, you will no longer be able to withdraw from the study. If you withdraw from the survey without completing it, you will still receive a gift certificate worth 20 Saudi riyals, which I will give to you in person.

The researchers will keep the information that is collected confidential. Any data from this study which will be shared or published will be the combined data of all participants. That means it will be reported for the whole group not for individual persons.

I expect to have this study completed by approximately December 2015. If you would like a brief summary of the results, please send me an email and a summary will be sent to you once the study is completed.

Questions about the Study:

If you have questions or need more information about the study itself, please contact me at:

alhammos@mcmaster.ca

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. You can ask the researcher to use the iPad to send an email to McMaster Research Ethics Board Secretariat if you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
C/o Research Office for Administrative Development and Support
E-mail: ethicsoffice@mcmaster.ca

Appendix 6: The Letter of Information In Arabic

معلومات عن الدراسة

اسم الدراسة: تقييم سلوكيات وتوقعات مرضى العيادات الخارجية تجاه التقارير الطبية الشخصية الالكترونية في مستشفيات الرعاية الثانية والتخصصية

.

المشرف:	**الطالب الباحث:**
د. آن ميكيبون	عهود الحماد
قسم العلوم الصحية جامعة مكماستر	قسم العلوم الصحية جامعة مكماستر
هاملتون ، اونتاريو ، كندا	هاملتون ، اونتاريو ، كندا
1905525140+تحويلة: 22803	+ 16478338595
mckib@mcmaster.ca البريد الالكتروني:	alhammos@mcmaster.ca البريد الالكتروني:

الداعم للبحث: الملحقية الثقافية السعودية بكندا ، جامعة الملك سعود.
الغرض من الدراسة: أنت مدعو للمشاركة في بحث تقييم سلوكيات وتوقعات مرضى العيادات الخارجية تجاه التقارير الطبية الشخصية الالكترونية، حيث أننا نطمح لمعرفة إمكانية استخدام هذه التكنواوجيا في الخدمة هذا البحث ليس تابع للمستشفى ولكن تمت الموافقه عليه من قبل وزارة الصحية في المملكة العربية السعودية. الصحة ولجنة الأخلاقيات العلميه بالمستشفى.

الطرق المستخدمة في البحث: سيطلب منك تعبئة استبيان يحتوي على أسئلة عن اهتمامك في استخدام التقارير الطبية الشخصية الالكترونية. اكمال هذا الاستبيان سيأخذ من وقتك 10 15 دقيقة ويمكنك الإختيار بين اكمال الاستبيان الورقي أو الالكتروني. الأداة المستخدمة للاستبيان الالكتروني هي كويسشن برو. هذه الآداة آمنه حيث أن مركز بياناتها مراقب 24 ساعة خلال 7 أيام في الاسبوع. بعض الموظفين الأكفاء فقط هم من يُسمح لهم بالدخول على البيانات في حالة الحاجة لحل أي عمليات متعلقة بأعمال كويسشن برو. جميع بيانات المستهلكين المستخدمين تُحفظ تحت حسابات تتطلب اسم مستخدم وكلمة سر للدخول اليها. الباحثون فقط هم من سيتخدمون حساب هذا الاستبيان واسم المستخدم وكلمة السر للدخول لبيانات المشاركين.

المخاطر:
من غير المتوقع أن يكون هناك أي ضرر ناتج عن اجابتك للأسئلة.ولكن قد تشعر بعدم الارتياح من اكمال هذا الاستبيان وأنت تنتظر موعدك بقلق. وقد تفكر أيضاً في سمعتك وخصوصيتك عند اكمالك للاستبيان في غرف الانتظار في المستشفى.كما قد تعتقد أن الرعاية الصحية المقدمة لك ستتأثر سلبياً عند اجابتك على الاستبيان ومعرفة الفريق الطبي عن اجاباتك.و قد تشعر بالضعف عند اجابتك عن بعض الأسئلة. وقد تعتقد أن الوقت لا يسعك لاكمال الاستبيان أو قد تكون قلقاً من أن هذا الاستبيان يجمع معلومات خاصة وشخصية عنك.
اذا كنت قد اخترت اكمال الاستبيان الورقي ولكنك قلق بأن الوقت لن يسعك لاكماله فإنه يمكنك الاحتفاظ بورقة المعلومات هذه وبالاستبيان الورقي واكماله حين انتهائك من موعدك. وإن كنت قد اخترت أن تبدأ الاستبيان الالكتروني بعد موعدك، أرجو منك أن تسألني بعد انتهاء الموعد لكي أعطيك الكمبيوتر الكفي (الأيباد) لتكمل الاستبيان الالكتروني في غرفة الانتظار حيث أن الباحث لا يستطيع ترك الكمبيوتر الكفي (الأيباد) مع المشاركين، ولن يتم اعطاء أي معلومات للدخول للاستبيان الالكتروني الا عن طريق الأيباد.
ستكمل هذا الاستبيان كشخصية مجهولة حيث أنه لا يوجد معلومات شخصية أو طبية خاصة يتم جمعها في هذا البحث. هويتك لن تُكتشف أو تُعرف من المعلومات التي قدمتها، وذلك لأن الاستبيان لا يجمع معلومات خاصه تُعرّف عن هوية المشارك. لن يعرف فريقك الطبي الذي يشمل طبيبك وممرضك عن المعلومات التي قدمتها في الاستبيان. الباحثون هم فقط من يستطيع الاطلاع على البيانات التي تم جمعها. جميع المعلومات سيتم تحليلها كمجموعة وليس كحالة فردية لكل مريض، لذلك فإن سمعتك لن تتأثر عند تحليل هذه المعلومات ولن يعرف أحد حتى الباحثون أي الاجابات كانت اجاباتك.
شاشة الأيباد المستخدم للاستبيان الالكتروني مغطاة بغلاف واقي يتيح الخصوصية لمستخدم الأيباد وذلك بتعتيم الشاشه لمن ينظر اليها من الجوانب. بواسطة هذا الغلاف الواقي للشاشه حامل ومستخدم الأيباد هو فقط من يستطيع النظر لأسئلة الاستبيان الالكتروني. ولكن لحماية خصوصيتك أكثر قد يُطلب منك عند تعبئة الاستبيان

الورقي أو الالكتروني أن تجلس في مكان آخر في غرفة الانتظار حتى لا يسترق أحد النظر الى اجاباتك.كما يمكنك عدم الاجابه على بعض الأسئلة إذا شعرت بعدم الارتياح لها ولن يكون هناك أي تبعات أو عواقب لذلك.

الفوائد:
هذا البحث لن يقدم لك فائدة مباشرة. ولكننا نطمح في الإستفادة من نتائج هذه الدراسة لفهم اهتمامك في استخدام تقاريرك الطبية الشخصية الالكترونية، ومعرفة نوع الأنشطة التي تود استخدامها في هذه التقارير. ستحصل على بطاقة هدية كتعويض عن وقتك في الإجابة عن هذا الاستبيان.

الخصوصية:
انت تشارك في هذا البحث كشخصية مجهولة. لن يستطيع احد وحتى الباحثون كشف هوية المشاركين. المعلومات التي ستقدمها ستحفظ في درج مكتب بقفل لن يستطيع فتحه الا الباحثون، الى أن يتم نقل المعلومات التي في الاستبيان الورقي إلى كمبيوتر مقفل برقم سري. الباحثون فقط هم من لديهم هذا الرقم السري وهم فقط من سيطلع على البيانات. ستحفظ المعلومات الخالية من أي معرفات شخصيه لمدة عشر سنوات بعد الانتهاء من هذه الدراسة. حيث أنه سيتم استخدامها في عمل دراسات أخرى تساعدنا على فهم اهتمام السعوديين في استخدام التقارير الطبية الشخصية الالكترونية. بعد ذلك سيتم حذف و إتلاف جميع المعلومات المحفوظة في الكمبيوتر.

المشاركة والانسحاب:
مشاركتك في هذا البحث هي راجعة لمشيئتك. إذا اخترت المشاركة فإنه يمكنك التوقف عن اكمال الاستبيان في أي وقت. اذا كنت قد أكملت الاستبيان الورقي فإن أوراق استبيانك سيتم اتلافها عن طريق آلة تمزيق الورق وقت انسحابك من المشاركة ولن يتم ادخال بياناتك ضمن هذا البحث. ولكن اذا أجبت الاستبيان الالكتروني فإنه لن يمكننا سحب واتلاف اجاباتك التي قدمتها، وذلك لأنه لايمكننا معرفة أي من المعلومات المقدمة من جميع المشاركين هي اجاباتك. هذا يعني أنه لن يتم سحب مشاركتك من البحث في هذه الحالة. حتى عند انسحابك من الدراسة قبل اكمال الاستبيان ستحصل على بطاقة هدية بقيمة 20 ريال سعودي ستقدم اليك شخصياً من قبل الطالب الباحث.
معلومات المشاركين ستعامل وتستخدم بسرية تامة. المعلومات التي سيتم نشرها في المجلات والمؤتمرات العلمية ستكون البيانات التي تم تحليلها كمجموعة وليس كحالات فرديه. كما وأن من المتوقع الانتهاء من هذه الدراسة في شهر ديسمبر من عام 2015م. أرجو ارسال بريد الكتروني اذا أردت الحصول على ملخص عن نتائج هذه الدراسة، وسيتم ارسال ملخص لك حالما ينتهي البحث.
أسئلة عن البحث: اذا كان لديك سؤال أو أردت الحصول على معلومات إضافية عن البحث، ارجو مراسلتي على:

alhammos@mcmaster.ca

تم مراجعة وموافقة هذه الدراسة من قبل لجنة اخلاقيات البحث في جامعة مكماستر. اذا كان لديك أسئلة عن حقوقك كمشارك أو عن طريقة اجراء هذا البحث، ارجو التواصل مع :
سكرتير لجنة اخلاقيات البحث بجامعة مكماستر
هاتف: +9055259140تحويلة 23142
مكتب البحث للشؤون الإدارية للتطوير والدعم
البريد الالكتروني
:ethicsoffice@mcmaster.ca

Appendix 7: Back Translation Of The Letter of Information

INFORMATION ABOUT THE STUDY

Supporting the research: Saudi Cultural Bureau in Canada, King Saud University.

Purpose of the study: You are invited to participate in a study about the behaviors and expectations of outpatients toward personal electronic medical reports, in which we invastigate to know the possibility of using this technology in health services in the Kingdom of Saudi Arabia. This research is not carried by the hospital, but was approved by the Ministry of Health and the Committee of Scientific Ethics Board in the hospital .

The methods used in the study: You will be asked to fill in a questionnaire containing questions about your interest in using personal electronic medical reports. Completing this questionnaire will take from your time 10-15 minutes and you can choose between completing a paper or electronic questionnaire. The tool that is used for the electronic questionnaire is Question Pro. This tool is safe as its information center is supervised 24 hours during 7 days a week. Some only qualified personnel are allowed to access the data in case there is a need to resolve any operational work related to Question Pro. All the data are saved in accounts that require a user name and password to access them. Only researchers have an account for this questionnaire with username and password to log into the data of the participants.

Risks: It is not expected that there will be any damage caused by answering the questionnaire. You may feel uncomfortable to complete this questionnaire while you are waiting for your appointment. You may also think about your reputation and privacy when you complete the questionnaire in the waiting room as you might think that the health care provided to you will be affected negatively when your answer to the questionnaire and you may think that your medical team will see your answers. You might feel weak during answer some questions. You might think, there will be no enough time to complete the questionnaire or may be worried that this questionnaire collects private and personal information about you.

If you have chosen to complete the paper questionnaire, but you worry that time will not be sufficient to complete it, you can keep the letter of information and the paper questionnaire and complete answering the questions after finishing your appointment. If you may choose the electronic questionnaire and started before your appointment, please ask me after the appointment in order to give you the (iPad) to complete the questionnaire in the waiting room. The researcher cannot leave the (iPad) with the participants, and will not be giving any access to the electronic questionnaire except by iPad.

You will complete this questionnaire as unknown person with no personal or private medical information is collected in this research. Your identity will not be detected or known from the information you provided, because the survey does not collect any information that may show the participant's identity. The medical team that includes the doctor and the nurse will not know about the information you provided in the questionnaire. The researchers only will be able to access the collected data. All information will be analyzed as a group and not individually for each patient as a case, so your reputation will not be affected during analysis of the information. No one of the researchers will know which are your answers.

For those who choose the electronic questionnaire, the iPad screen is covered with extra protective cover which darken the screen and allows more user privacy as the participant is the only one who can look at the screen and anyone else will not be able to look from the sides. In addition and to give more privacy for any one answering the paper or electronic questionnaire, you might be asked to sit in a different isolated place in the waiting room. Also, you can leave the questions that you feel uncomfortable to answer and there will be no consequences upon that.

Benefits: This research will not give you a direct benefit but we aspire to benefit from the results of this study to understand the interest in the use of personal electronic medical reports, and find out the types of activities you want to use in these reports. You'll get a gift card as compensation for your time in answering this questionnaire.

Pivacy: You are participating in this research an unknown person. No one even the researchers can uncover the identity of the participants. The provided information will be kept in a locked desk drawer and will not be open except by the researchers, until that information in the paper-based questionnaires are transferred to a locked computer with a secret PIN number. Researchers are only those who have the PIN number. The collected data with no personal identifiers will be saved for ten years after the completion of this study. These data will be used with other studies to help us to understand the Saudi interest in the use of personal electronic medical reports. After that the data will be deleted and destroyed.

Participation and withdrawal:

Your participation in this research is optional. If you chose to participate you can stop at any time. If you have completed the questionnaire, the paper questionnaire will be destroyed by shredding paper machine when you withdraw from the study. In this case, withdrawal from participation will not enter your answers within this study data. But if you answer the electronic questionnaire, its diffucult to know which answers are yours, so we can not take them out from the collected data. This means that your answers will not be withdrawn from the study in this case. Even when you withdraw from the study prior to completion of the questionnaire, you will receive a gift card worth 20 SR which will be given to you personally by the researcher student.

Participant information will be treated confidentially. The information that will be published in scientific journals and conferences will be the data that had been analyzed as a group and not as individual cases. As expected the completion date of this study is December 2015, please send us an email if you would like to get a summary of the results of this study, and it will be sent to you as soon as the search ends.

Questions about the study: If you have a question or want to get more information about the research, please e-mail me at:

alhammos@mcmaster.ca.

The research has been reviewed and approved by the Research Ethics Committee at McMaster University. If you have questions about your rights as a participant or about the methods of making this research, please contact

Secretary of the ethics committee at the University of McMaster
Tel: +9055259140 Ext 23 142
Research Office of Administration to develop and support
Email: ethicsoffice@mcmaster.ca

Appendix 8: Oral Recruiting Script

Introduction:
Hello. I'm Ohoud Alhammad. I am conducting a survey about Outpatients Attitudes and Expectations towards electronic personal health records in Secondary and Tertiary Hospitals in Riyadh. This is an external research study, and it is not undertaken by the hospital but it had been approved by the Saudi Ministry of Health and the hospital's Institutional Review Board. I'm conducting this as part of my thesis research at McMaster University's eHealth Master Program in Hamilton, Ontario, Canada. I'm working under the direction Dr. Ann McKibbon of McMaster's faculty of Health Sciences.

Study procedures:
I'm inviting you to fill a survey that will take about 10 -15 minutes. The survey has questions about your background, health status, the use of the Internet for health purposes, and your views on electronic personal health records. You may choose to complete a paper-based or an electronic survey. The tool that is used for the electronic survey is QuestionPro. To ensure its security, the data centers of QuestionPro are monitored twenty-four hours a day, seven days a week. QuestionPro employs the concept of least privilege—qualified employees are allowed access to privileged areas of the system only when such access is necessary for the operation of QuestionPro business functions. All customer data, including the data of end users, is logically separated by account-based rules that require the entry of a unique username and password with each logon. Only the researchers will have an access to this study's username, password, and the participants' information.

Risks:
It is not likely that there will be any serious harm associated with completing this survey. However, you may feel uncomfortable filing this survey while you are waiting anxiously for your appointment. You may also be concerned about your privacy and reputation when participating in a survey in a waiting area in the hospital setting. You may feel afraid that the care you are receiving in the hospital will be affected negatively if you respond to the survey and your healthcare team knows about your answers. You may also feel demeaned or marginalized when you answer some questions in the survey. You may feel that you don't have time to fill this survey, or you may be afraid that this survey is collecting personal information about you.

If you choose to participate using the paper-based survey but you are worried about not having enough time to complete it, you can keep the Letter of Information and the paper-based survey with you, and complete the survey after you have had your appointment. If you choose to use the electronic survey and would like to start it after your appointment, please ask me after your appointment to give you the iPad to fill the electronic survey in the waiting area. The researcher can't leave the iPad with the patients and no logon information will be provided.

This is an anonymous survey, and no personal information or personal health information is being collected. Your information can't be linked to your identity since no identifiable personal information will be collected. Your healthcare team including your physician and nurse will have no access to the collected information. Only the researchers will have the access to the collected data. All the data will be analyzed collectively and not case by case, so your reputation will not be affected when the data will be analyzed since no one will know, even the researchers, which answers are yours.

The iPad that is used for the online survey is covered with a privacy screen protector that will blacken the screen to the people looking to it from the sides of the iPad. With this protector, only the holder of the iPad can see the online survey questions. However, to ensure your confidentiality with both online and paper-based surveys, you may be asked to sit in a corner that has no patients in, to ensure that your privacy is protected and that no other patient is looking to your answers.

If you feel uncomfortable with answering any of the questions, you don't have to and you will not be penalized. And you can withdraw at any time.

Benefits:
It is unlikely that there will be direct benefits to you, however, by better understanding the attitudes and the expectations of Saudi patients towards personal health records, researchers and others may be able to understand the potential use and usefulness of personal health records. This may contribute in improving the quality and the future of healthcare in Saudi Arabia.

I will keep the information that is collected confidential. Any data from this research, which will be shared or published, will be the combined data of all participants. That means it will be reported for the whole group not for individual persons.

Voluntary participation:

- Your participation in this study is voluntary.
- You can decide to stop at any time, even part-way through the survey for whatever reason.
- If you decide to stop participating, there will be no consequences to you.
- If you decide to stop the paper-based survey, the survey paper will be destroyed and not included in the study.

If you are filling the electronic survey, your answers will be put into a database and will not be identifiable. This means that once you have submitted your online survey, your responses cannot be withdrawn from the study because we will not be able to identify which responses are yours. That means that once your information is entered into the database, you will no longer be able to withdraw from the study. If you withdraw from the survey without completing it, you will still receive a gift certificate worth 20 Saudi riyals, which I will give to you in person.

- You can keep this Letter of Information that has all the information about this study. If you have any questions about this study or would like more information you can call or email Ohoud Alhammad at alhammos@mcmaster.ca

This study has been reviewed and cleared by the McMaster Research Ethics Board. If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

McMaster Research Ethics Board Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Research Office for Administration, Development & Support (ROADS)
E-mail: ethicsoffice@mcmaster.ca

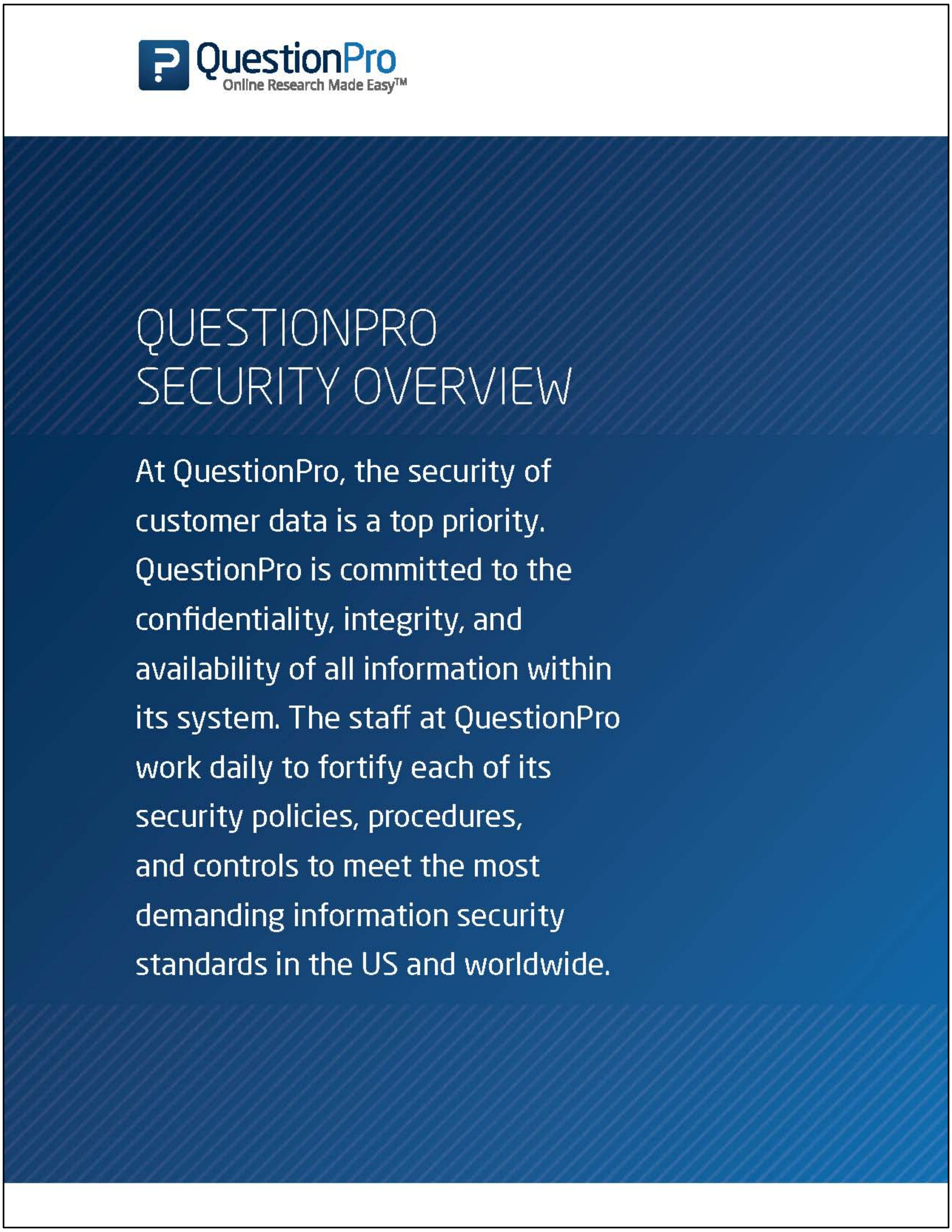
You can use this iPad to send an email to McMaster Research Ethics Board Secretariat.

I would be pleased to send you a short summary of the study results when I finish going over our results. Please let me know if you would like a summary by sending me an email about that.

Consent questions:

- Do you have any questions or would like any additional details?
- Do you agree to participate in this study knowing that you can withdraw at any point with no consequences to you?

Appendix 9: QuestionPro Security Measures



QuestionPro
Online Research Made Easy™

QUESTIONPRO SECURITY OVERVIEW

At QuestionPro, the security of customer data is a top priority. QuestionPro is committed to the confidentiality, integrity, and availability of all information within its system. The staff at QuestionPro work daily to fortify each of its security policies, procedures, and controls to meet the most demanding information security standards in the US and worldwide.

QuestionPro

SECURITY OVERVIEW

PHYSICAL SECURITY

Data Center: QuestionPro owned and managed servers are co-located in an Internap data center and are backed up in separate facility at the AdHost data center. QuestionPro restricts physical access to the data centers to senior personnel on a least privilege basis. The data centers are monitored twenty-four hours a day, seven days a week. Visitors to the center are logged and escorted throughout the facility by data center personnel. All visitors must wear ID badges. The centers utilize security guards, electronic access devices, biometric access devices, fire alarm systems, and CCTV monitoring.

Data Center Compliance: Internap, QuestionPro's primary data center, undergoes periodic SSAE 16 SOC 2 audits. Reports from these audits confirm Internap's commitment to protecting against unauthorized access and to maintaining constant data availability. QuestionPro's backup facility, AdHost undergoes periodic SSAE 16 SOC 1 audits. Reports from both these facilities are available for review upon request.

ACCESS AND AUTHENTICATION

Customer User Authentication:

Single Sign-On: Single Sign-on (SSO) allows QuestionPro users to access with the credentials of an existing company intranet. SAML, multipass/token, or cookie based SSO can be used with popular authentication systems, such as Active directory or LDAP, to determine if an end-user is authenticated.

FOR MORE INFORMATION: sales@questionpro.com • +1 (800) 531-0228

Double Opt-in Verification and reCaptcha: QuestionPro offers the ability for customers to require reCaptcha verification upon user registration. reCaptcha helps prevent automated scripts from creating fake accounts.

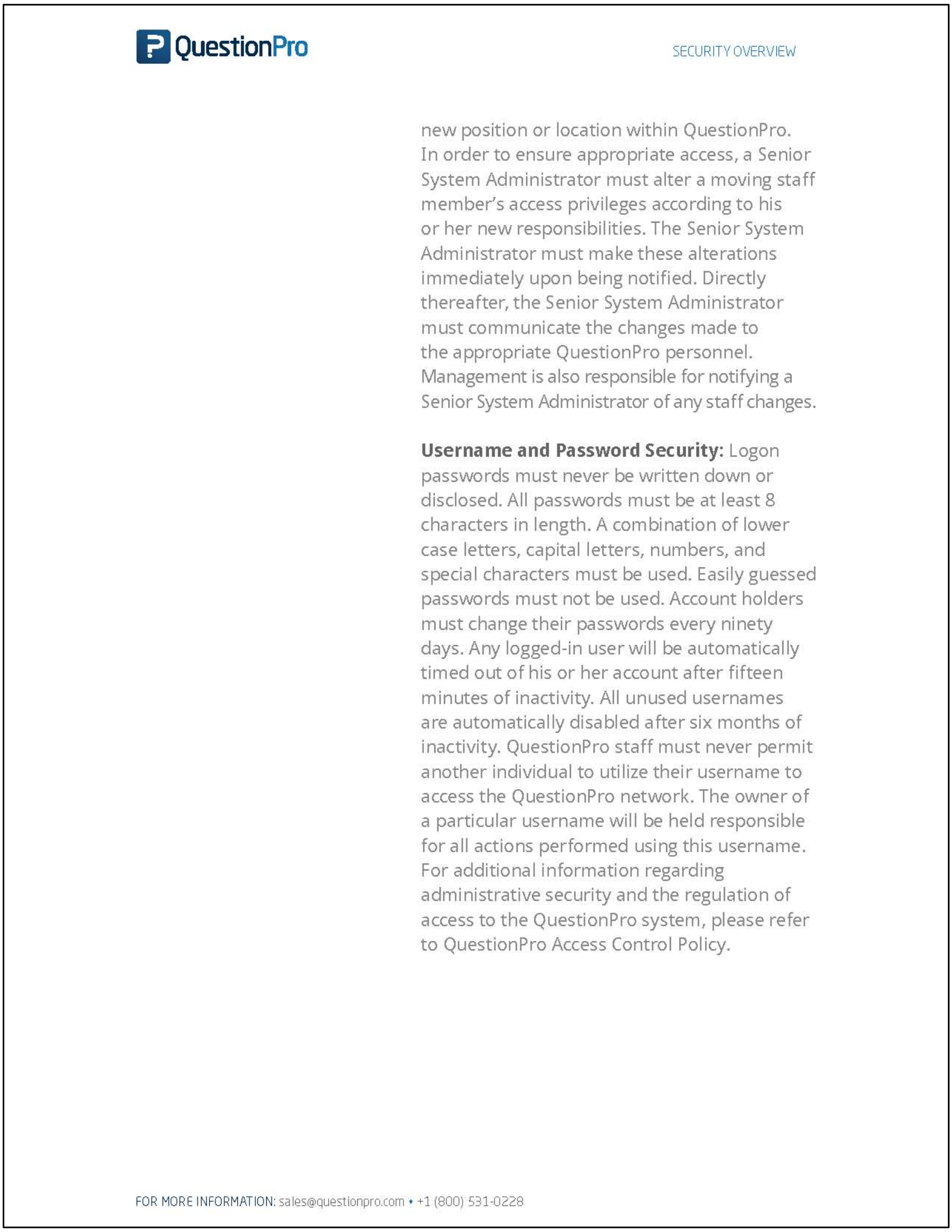
Email Based Access Restrictions: The QuestionPro Academic license allows university customers to limit registrations to individuals with email address domains of the university.

QuestionPro Personnel Authentication: Any access to QuestionPro servers (including production environment, staging environment, and databases) requires multi-factor authentication—SSH keys and passphrases. Access to the staging environment is limited to developers; access to the production environment is limited to system administrators; and access to the databases is limited to senior system administrators.

ADMINISTRATIVE SECURITY

Least Privilege: QuestionPro employs the concept of least privilege—qualified employees are allowed access to privileged areas of the system only when such access is necessary for the operation of QuestionPro business functions. Privileged accounts are only granted to appropriately qualified employees in order for them to perform essential duties.

Account Management: QuestionPro employee accounts may not be created or modified without the approval of a Senior System Administrator. Each account holder is allocated an individual username and password. Employees must notify a Senior System Administrator when moving to a



SECURITY OVERVIEW

new position or location within QuestionPro. In order to ensure appropriate access, a Senior System Administrator must alter a moving staff member's access privileges according to his or her new responsibilities. The Senior System Administrator must make these alterations immediately upon being notified. Directly thereafter, the Senior System Administrator must communicate the changes made to the appropriate QuestionPro personnel. Management is also responsible for notifying a Senior System Administrator of any staff changes.

Username and Password Security: Logon passwords must never be written down or disclosed. All passwords must be at least 8 characters in length. A combination of lower case letters, capital letters, numbers, and special characters must be used. Easily guessed passwords must not be used. Account holders must change their passwords every ninety days. Any logged-in user will be automatically timed out of his or her account after fifteen minutes of inactivity. All unused usernames are automatically disabled after six months of inactivity. QuestionPro staff must never permit another individual to utilize their username to access the QuestionPro network. The owner of a particular username will be held responsible for all actions performed using this username. For additional information regarding administrative security and the regulation of access to the QuestionPro system, please refer to QuestionPro Access Control Policy.

FOR MORE INFORMATION: sales@questionpro.com • +1 (800) 531-0228

QuestionPro

SECURITY OVERVIEW

SYSTEM MONITORING

QuestionPro utilizes monitoring tools such as Nagios, CloudFlare, and OSSEC in conjunction with the logging capabilities of Apache Logs, Linux var/log/audit/audit.log, and MySQL Statistics to generate audit records and to monitor the QuestionPro system twenty-four hours a day. With these tools, System Administrators can select specific events to audit at each layer of the system, including internal system access, failed authentication attempts, and other auditable events. Additionally, these tools allow for the time stamping of all auditable actions and enable the creation of audit trails to support after-the-fact investigations of security incidents.

BOUNDARY SECURITY

Firewall: All external connections to the QuestionPro system terminate on an iptables/ Linux firewall configured with a default "deny all" rule. Uninitiated outbound traffic is limited to external APIs (translation services, etc.) and SMTP. The firewall utilizes non-standard managed access points for HTTP traffic, SSL encrypted HTTP traffic, and SMTP outbound traffic.

Additional Boundary Protection: QuestionPro utilizes IP blacklists to lock out IP addresses that are known to be fraudulent, the integrity checker OSSEC to detect whether any unauthorized changes to the system have occurred, and the boundary protection service CloudFlare to create logical boundaries and to defend against DDoS attacks.

FOR MORE INFORMATION: sales@questionpro.com • +1 (800) 531-0228

QuestionPro

SECURITY OVERVIEW

VULNERABILITY SCANS

QuestionPro performs periodic vulnerability scans of the QuestionPro system. All discovered vulnerabilities are given an immediate security risk assessment and addressed in accordance with the assessment determination. PCI security reports are available for review upon request.

CONFIGURATION/RELEASE MANAGEMENT

QuestionPro follows a release and maintenance methodology that includes the documenting, testing, and review of proposed changes to the system. QuestionPro updates its server operating systems with the latest patches on a timely basis and issues maintenance releases at least weekly. All non-essential applications are disabled to protect the system from internet-based threats.

DEVELOPMENT PRACTICES

As part of its development process, QuestionPro maintains separate environments for development, staging, testing, and production in accordance with SDLC best practices. Access to the production environment is limited to system administrators, developers and all code is reviewed before going into production. QuestionPro protects against SQL injections through prepared statements, stored procedures, escaping user-supplied input, and enforcing least privilege.

FOR MORE INFORMATION: sales@questionpro.com • +1 (800) 531-0228

QuestionPro

SECURITY OVERVIEW

QuestionPro combats cross-site scripting by using proper escaping/encoding, blacklists, vulnerability scans, and other procedures.

ENCRYPTION

Data in Transit: QuestionPro implements SSL, TLS, SSH, and SCP encryption to securely transfer data. QuestionPro supports full SSL encryption, and all mail servers are configured with TLS. Access to system servers is only allowed via SSH on a non- standard port. Data is transferred to the backup data center via SSH using rsync.

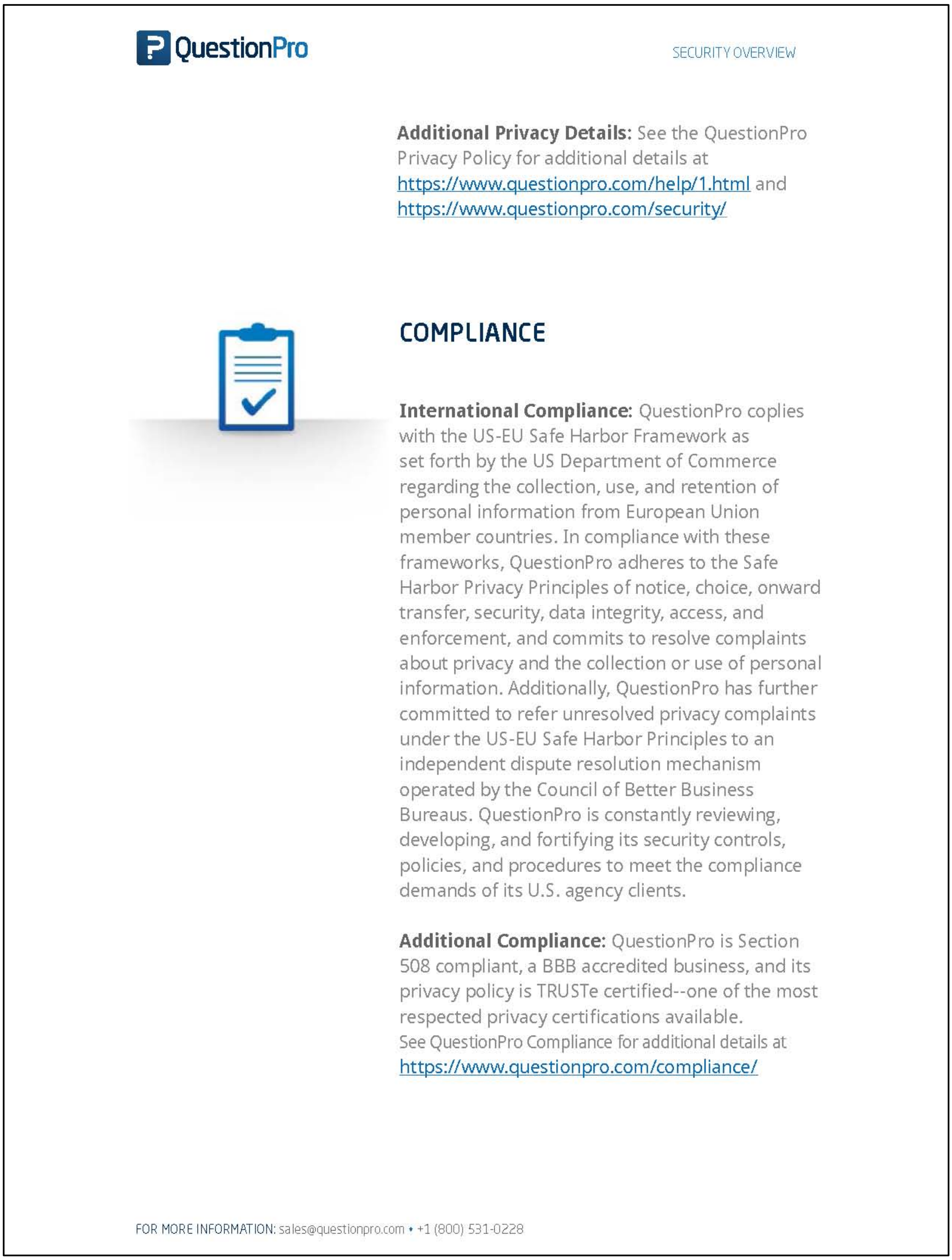
Data at Rest: QuestionPro hash encrypts all customer passwords and credit card data stored within the system databases. When customers use SSO, passwords are not stored but are authenticated with a token.

DATA PRIVACY

Separation of Data: All customer data, including the data of end users, is logically separated by account-based rules that require the entry of a unique username and password with each logon.

Employee Regulations: Prior to hiring, QuestionPro employees and contractors are subjected to criminal background screening and notified that any improper sharing of customer or Community Member data will result in the loss of employment. All employees and contractors must sign non-disclosure agreements upon joining the company.

FOR MORE INFORMATION: sales@questionpro.com • +1 (800) 531-0228



QuestionPro

SECURITY OVERVIEW

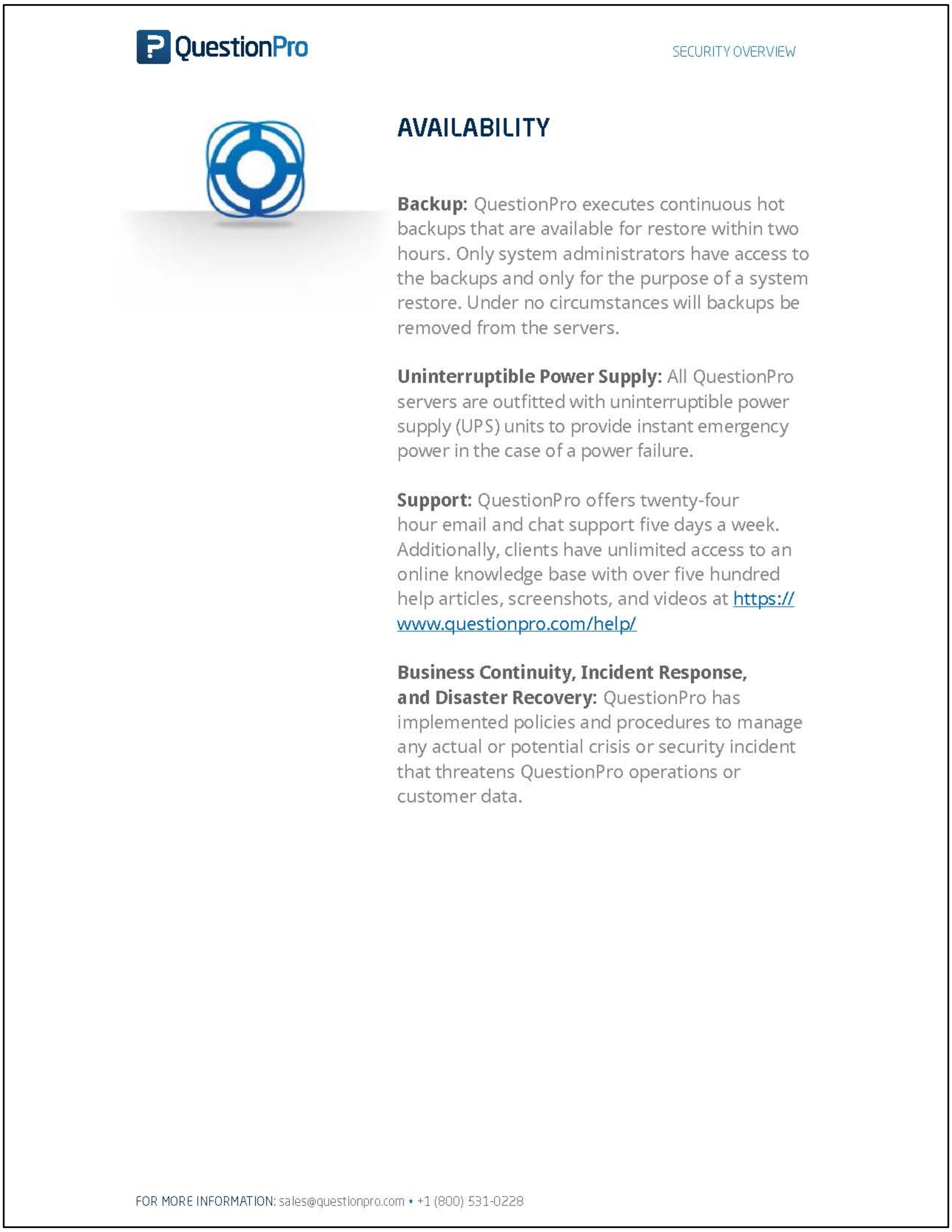
Additional Privacy Details: See the QuestionPro Privacy Policy for additional details at https://www.questionpro.com/help/1.html and https://www.questionpro.com/security/

COMPLIANCE

International Compliance: QuestionPro coplies with the US-EU Safe Harbor Framework as set forth by the US Department of Commerce regarding the collection, use, and retention of personal information from European Union member countries. In compliance with these frameworks, QuestionPro adheres to the Safe Harbor Privacy Principles of notice, choice, onward transfer, security, data integrity, access, and enforcement, and commits to resolve complaints about privacy and the collection or use of personal information. Additionally, QuestionPro has further committed to refer unresolved privacy complaints under the US-EU Safe Harbor Principles to an independent dispute resolution mechanism operated by the Council of Better Business Bureaus. QuestionPro is constantly reviewing, developing, and fortifying its security controls, policies, and procedures to meet the compliance demands of its U.S. agency clients.

Additional Compliance: QuestionPro is Section 508 compliant, a BBB accredited business, and its privacy policy is TRUSTe certified--one of the most respected privacy certifications available.
See QuestionPro Compliance for additional details at
https://www.questionpro.com/compliance/

FOR MORE INFORMATION: sales@questionpro.com • +1 (800) 531-0228



QuestionPro

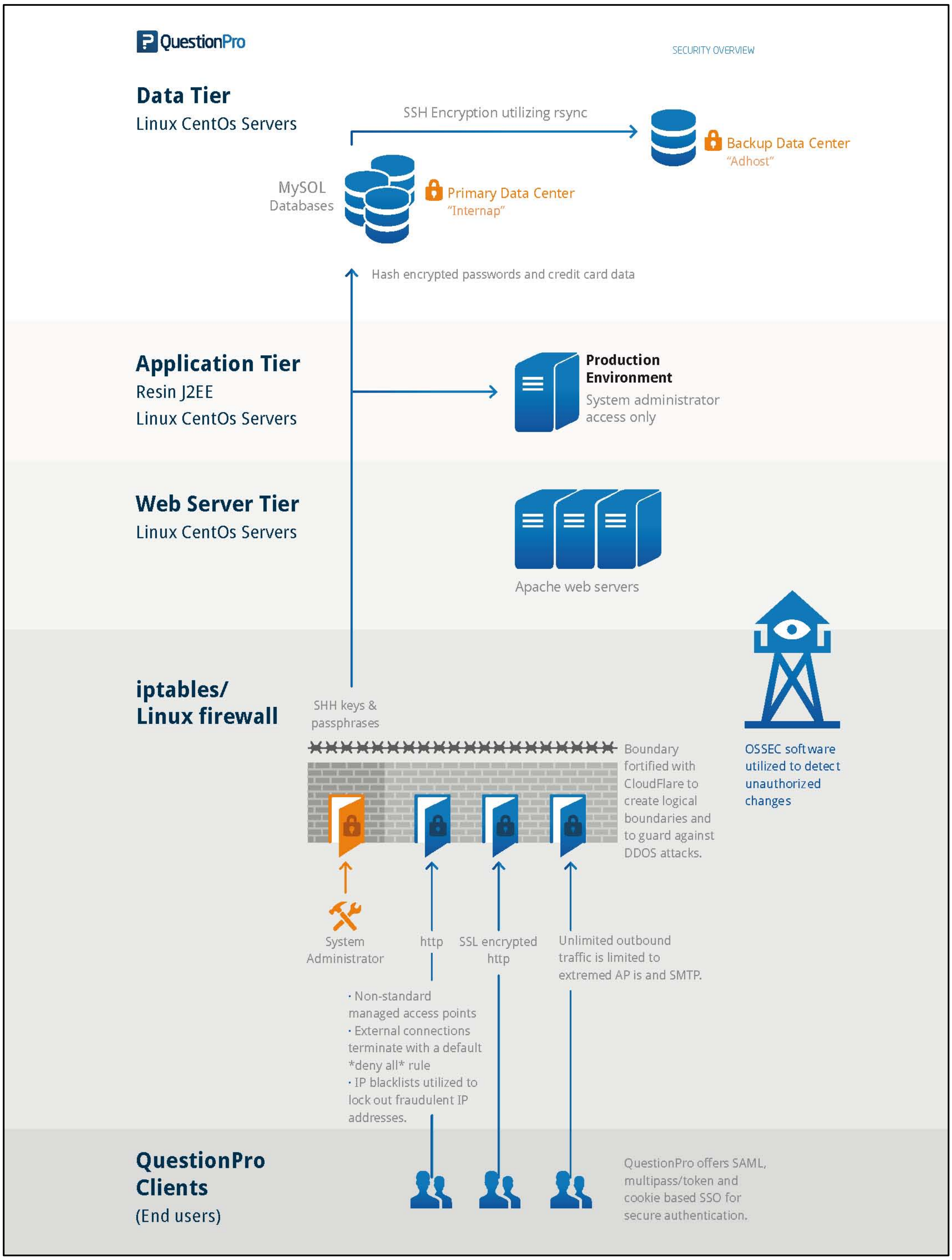
AVAILABILITY

Backup: QuestionPro executes continuous hot backups that are available for restore within two hours. Only system administrators have access to the backups and only for the purpose of a system restore. Under no circumstances will backups be removed from the servers.

Uninterruptible Power Supply: All QuestionPro servers are outfitted with uninterruptible power supply (UPS) units to provide instant emergency power in the case of a power failure.

Support: QuestionPro offers twenty-four hour email and chat support five days a week. Additionally, clients have unlimited access to an online knowledge base with over five hundred help articles, screenshots, and videos at https://www.questionpro.com/help/

Business Continuity, Incident Response, and Disaster Recovery: QuestionPro has implemented policies and procedures to manage any actual or potential crisis or security incident that threatens QuestionPro operations or customer data.


QuestionPro
SECURITY OVERVIEW
Data Tier
Linux CentOs Servers
SSH Encryption utilizing rsync
Backup Data Center
"Adhost"
MySOL
Databases
Primary Data Center
"Internap"
Hash encrypted passwords and credit card data
Application Tier
Resin J2EE
Linux CentOs Servers
Production
Environment
System administrator
access only
Web Server Tier
Linux CentOs Servers
Apache web servers
iptables/
Linux firewall
SHH keys &
passphrases
Boundary
fortified with
CloudFlare to
create logical
boundaries and
to guard against
DDOS attacks.
OSSEC software
utilized to detect
unauthorized
changes
System
Administrator
http
SSL encrypted
http
Unlimited outbound
traffic is limited to
extremed AP is and SMTP.
· Non-standard
managed access points
· External connections
terminate with a default
deny all rule
· IP blacklists utilized to
lock out fraudulent IP
addresses.
QuestionPro
Clients
(End users)
QuestionPro offers SAML,
multipass/token and
cookie based SSO for
secure authentication.

Appendix 10: Survey Questions Coding Sheet

Demographic questions: this information will be used only in summary form; it will not be used to identify you individually.

Please check the appropriate answer for your response:

1. What is the hospital you are attending today?
   ○ King Fahad Medical city (1)
   ○ King Khalid University Hospital (2)
   ○ King Abdulaziz University Hospital (3)
   ○ King Saud Medical City (4)

2. Where do you live in Saudi Arabia?
   ○ Central region (1)　○ North region (2)　○ South region (3)
   ○ East region (4)　○ West region (5)

3. How old are you?
   ○ 18 – 30 (1)　○ 51 – 60 (3)
   ○ 31 – 50 (2)　○ 61+ (4)

4. What is your highest grade or level of school you have completed?
   ○ Elementary school or less (1)　○ University graduate (4)
   ○ Intermediate school (2)　○ Graduate degree (5)
   ○ Secondary school (3)

5. What is the best estimate of your monthly household income (riyal)?
   ○ Less than 3000 (1)　○ 20,000 – 49,999 (4)
   ○ 3000 – 9999 (2)　○ 50,000 or more (5)
   ○ 10,009 – 19,999 (3)

Health related questions:

6. In general, how would you rate your overall health?
   ○ Excellent (1)　○ Good (3)　○ Poor (5)
   ○ Very good (2)　○ Fair (4)

7. Are you being treated for any chronic disease or medical problem such as high blood pressure, diabetes, heart or lung disease, or a mental health problem?
   ○ Yes (1)　○ No (2)

8. Are you taking medication(s) prescribed by a doctor?
   ○ Yes (1)　○ No (2)

9. Approximately, how many visits in the **past year** have you had with the following healthcare providers or facilities?

	Number of visits in past year
○ Primary healthcare (doctors, nurses)	
○ Specialist (e.g. heart doctor, skin doctor etc.)	
○ Emergency room	
○ Hospital (stayed at least overnight)	

10. How often do you have problems understanding your doctors when they are talking to you about your health?
   ○ Always (1) ○ Often (2) ○ Sometimes(3) ○ Occasionally(4) ○ Never(5)

11. How often do you have problems understanding written medical information (such as forms, or pamphlets) from your doctor or doctor's clinic?
   ○ Always (1) ○ Often (2) ○ Sometimes(3) ○ Occasionally(4) ○ Never(5)

12. Overall how satisfied are you with the quality of health care service you have received in the past 5 years?
   ○ Very satisfied (1) ○ Neutral (3) ○ Very dissatisfied (5)
   ○ Somewhat satisfied (2) ○ Somewhat dissatisfied (4)

Internet use questions:

13. Do you have a computer with internet access available for use, either at home or work or another location?
   ○ Yes (1) ○ No (2)

14. How often do you go on line and use the internet?
   ○ Several times a day (1) ○ Once monthly (4)
   ○ About once daily (2) ○ Rarely or not at all (5)
   ○ Once weekly (3)

15. How often do you use the Internet for health purposes?
   ○ Several times a day (1) ○ Once monthly (4)
   ○ About once daily (2) ○ Rarely or not at all (5)
   ○ Once weekly (3)

16. How concerned are you about the privacy of personal health information that is shared over the internet?
   ○ Very concerned (1) ○ Concerned (3) ○ Somewhat concerned (4)
   ○ Not very concerned (2) ○ Not concerned (5)

<u>Personal health record questions:</u> an electronic personal health record is like a paper medical record except this is created, stored, and viewed on computers. It is primarily used by you to view your health information and manage you healthcare (like make appointments and see blood test results) on the Internet.

17. Please indicate how strongly you agree or disagree with the following statement:
I am interested in using the computer to go online and use the Internet to manage my healthcare (view my health information/or do activities like making appointments)

○ Strongly agree (1) ○ Agree (2) ○ Neutral (3) ○ Disagree (4) ○ Strongly disagre (5)

18. Which of the following types of health information would you like to have as part of your personal health record? **<u>Please check all that apply:</u>**
    - ○ My allergies (Yes=1, No=2)
    - ○ Test results (e.g. blood tests, X-rays) (Yes=1, No=2)
    - ○ Immunization records (Yes=1, No=2)
    - ○ Medication I have taken or am currently taking (Yes=1, No=2)
    - ○ List of doctors and health care providers I have seen (Yes=1, No=2)
    - ○ Family history of health problems (Yes=1, No=2)
    - ○ Medical problems (Yes=1, No=2)
    - ○ Medical visits, including visits to the emergency room (Yes=1, No=2)
    - ○ Surgeries and medical procedures that I have had (Yes=1, No=2)
    - ○ Lifestyle choices (e.g., exercise, smoking history) (Yes=1, No=2)
    - ○ Information from devices that help me monitor my health (e.g., glucose from a diabetes meter) (Yes=1, No=2)
    - ○ Other health information specify ______________________

19. Which of the following activities would you like to do on the Internet? **<u>Please check all that apply:</u>**
    - ○ Receive a report from my doctor about my visit (Yes=1, No=2)
    - ○ Add my own notes or make changes to information in my patient health record (Yes=1, No=2)
    - ○ Request medical appointments (Yes=1, No=2)
    - ○ Request referrals to other doctors (Yes=1, No=2)
    - ○ Request prescription refills (Yes=1, No=2)
    - ○ Send emails to my doctor or his/her practice with my medical questions (Yes=1, No=2)
    - ○ Receive reminders for preventive health services (e.g. flu shots) (Yes=1, No=2)
    - ○ Access my child's or parent's medical record if I am their primary caretaker (Yes=1, No=2)
    - ○ Communicate with other people with similar health problems (e.g. support groups) (Yes=1, No=2)

- Receive educational materials related to my health (Yes=1, No=2)
- Record my treatment preferences (Yes=1, No=2)
- Record my selection of a family member or friend to manage my health care when I am not able to. (Yes=1, No=2)
- Other activities. Specify:_______________

20. How often do you think you would view your personal health record or do the activities listed above?
    - Once a week (1)
    - Once a month (2)
    - Once every 3 -6 months (3)
    - Once a year (4)
    - Rarely or not at all (5)

21. What effect do you think being able to view and manage (e.g. making appointments) your electronic personal health record will have on the following:

	Improve (1)	No effect (2)	Worsen (3)
s. The security and the privacy of my medical information			
t. Understanding my doctor's explanations and advice			
u. My understanding of my own health			
v. My sense of control over my own healthcare			
w. The ability of my doctor(s) and I to make decisions about my medical care together as a team			
x. My worries about my own healthcare			
y. The safety of my care (e.g. medical errors)			
z. My satisfaction with my health care			
aa. The overall quality of my healthcare			

22. Who would you give permission to view information in your electronic personal health record? **Please check all that apply:**
    - Designated family members or friends (Yes=1, No=2)
    - My primary care doctor (Yes=1, No=2)
    - Other doctors or healthcare providers who care for me (in clinic, the ER or the hospital) (Yes=1, No=2)
    - Government officials (Yes=1, No=2)
    - My employer (Yes=1, No=2)
    - I would not give anyone permission (Yes=1, No=2)

Thank you very much for completing this survey!