The Effect of Stakeholders’ Background on Perceptions of Usability and Usefulness on Personal Health Records

by

Desmond Medina Guarin
B.Sc., Andrews University, 1992
M.B.A., Dalhousie University, 1997

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

MASTER OF SCIENCE

in the School of Health Information Science

© Desmond Guarin, 2013
University of Victoria

All rights reserved. This thesis may not be reproduced in whole or in part, by photocopy or other means, without the permission of the author.
Supervisory Committee

The Effect of Stakeholders' Background on Perceptions of Usability and Usefulness on Personal Health Records

by

Desmond Medina Guarin
B.Sc., Andrews University, 1992
M.B.A., Dalhousie University, 1997

Supervisory Committee

Dr. Andre Kushniruk, School of Health Information Science
Supervisor

Dr. Elizabeth Borycki, School of Health Information Science
Departmental Member
Abstract

Supervisory Committee

Dr. Andre Kushniruk, School of Health Information Science
Supervisor

Dr. Elizabeth Borycki, School of Health Information Science
Departmental Member

Despite rapid advances in technology, there is currently a complex, and somewhat disjointed approach to the way health information is collected, stored, and organized for both healthcare consumers and professionals. Incompatible electronic medical records from various healthcare providers add to the complexity of a system tasked with delivering a patient’s relevant medical information in a timely manner to the appropriate point of care.

Personal health records (PHR) grew out of the efforts to produce an integrated electronic record to manage the multifaceted aspects of healthcare required by both healthcare consumers and professionals. PHRs are a transformative technology with the potential to alter patient-provider relationships in a way that produces a more efficient and cost effective healthcare system as a result of better patient outcomes.

PHRs can potentially include a wide variety of users ranging from the lay public to clinical professionals. As such, it is important to identify potential user groups and their corresponding health information needs in order to design PHRs that maximize accessibility, usability, and clinical relevance.
This study focused on laypeople who represented a wide age-range of individuals, evenly split in gender, with an above average level of computer literacy. Most of the participants had not used an electronic PHR prior to this study. However, after a hands-on session with PHR software, most participants found it to be easy to use, accompanied with the functionality they expected from such a system. Most participants were satisfied that an electronic PHR would meet their health information needs and would recommend the use of PHRs to family and friends.

Anyone in the general public is a potential PHR user. However, this study found that individuals with chronic conditions and those with complex health needs had the most to gain from using a PHR as an integral part of their healthcare routine. This study also demonstrated that an individual’s health condition has a stronger influence on their perceptions about the usefulness of PHRs than does their demographic background (age, education, computer literacy). Finally, this study established that PHRs are considered by participants of the study to be useful tools in meeting their health information needs.
# Table of Contents

Supervisory Committee ............................................................................................................... ii
Abstract ............................................................................................................................................ iii
Table of Contents ........................................................................................................................... v
List of Tables................................................................................................................................ viii
Acknowledgements ...................................................................................................................... ix
Dedication......................................................................................................................................... x

CHAPTER 1 : INTRODUCTION ................................................................................................. 1

CHAPTER 2 : LITERATURE REVIEW ..................................................................................... 4
   2.1 Overview.......................................................................................................................... 4
   2.2 Methodology .................................................................................................................. 6
   2.3 Defining Health Records............................................................................................ 7
      2.3.1 Impact of the Internet........................................................................................ 9
      2.3.2 Electronic Health Records............................................................................. 10
      2.3.3 EHR Standardization, Interoperability, & Connectivity .................... 11
      2.3.4 Emergence of Personal Health Records ................................................... 13
   2.4 PHR Models ................................................................................................................. 15
      2.4.1 Indivo .................................................................................................................... 17
      2.4.2 The Memory Stone ........................................................................................... 18
      2.4.3 Microsoft and Google ...................................................................................... 19
      2.4.4 Other Models ...................................................................................................... 21
   2.5 Discussion .................................................................................................................... 23
      2.5.1 The Value of PHRs ............................................................................................ 23
      2.5.2 Usability and Functionality ............................................................................. 28
      2.5.3 Pitfalls and Challenges .................................................................................... 34
      2.5.4 Identifying and Understanding PHR Users............................................. 38
6.4 Utility of PHRs (How would PHRs Be Used?) ............................................................. 102
6.5 PHR Usability and Functionality (The effect of user background on perception of PHR usefulness) ........................................................................................................ 104
6.6 Challenges .................................................................................................................. 107
  6.6.1 Why did Google Health Fail? .............................................................................. 111
6.7 Limitations of the Study ................................................................................................ 114
6.8 Implications for Future Study .................................................................................. 115
6.9 Implications for Health Informatics Education ....................................................... 117
6.10 Implications for Health Informatics Practice ......................................................... 118
References .......................................................................................................................... 120
Appendix A .......................................................................................................................... 128
Appendix B .......................................................................................................................... 129
Appendix C .......................................................................................................................... 130
Appendix D .......................................................................................................................... 131
Appendix E .......................................................................................................................... 132
Appendix F .......................................................................................................................... 133
Appendix G .......................................................................................................................... 135
Appendix H .......................................................................................................................... 140
List of Tables

Table 1 ............................................................................................................................................ 56
Table 2 ............................................................................................................................................ 56
Table 3 ............................................................................................................................................ 57
Table 4 ............................................................................................................................................ 61
Table 5 ............................................................................................................................................ 68
Table 6 ............................................................................................................................................ 71
Table 7 ............................................................................................................................................ 71
Table 8 ............................................................................................................................................ 72
Table 9 ............................................................................................................................................ 76
Table 10 .......................................................................................................................................... 79
Table 11 .......................................................................................................................................... 90
Acknowledgements

I am grateful to my supervisor, Dr. Andre Kushniruk at the University of Victoria School of Health Information Science for his guidance and mentorship in helping me choose this fascinating and worthwhile research topic. His patience and direction through each component of this project are very much appreciated.

Thanks are also expressed to Dr. Elizabeth Borycki at the University of Victoria School of Health Information Science for her active participation as a member of my thesis committee and for her insights and suggestions toward refining the “final product”.

I appreciate the participants of this study for taking the time to examine an online PHR and provide their individual opinions and observations about their experience. The findings of this study would not have been possible without their active participation and input.

Finally, I would like to recognize the encouragement and untiring support given to me by my wife, my family, and my friends. You were the coaches and cheerleaders that helped get me to the finish line.
Dedication

For my son Matthew, who has shown me the true meaning of “awesome”.
CHAPTER 1: INTRODUCTION

Currently, there is a complex, and somewhat disjointed approach to the way health information is collected and organized for healthcare consumers and health professionals. Paper-based patient records can be difficult or, at times, impossible to obtain in a timely manner by patients or healthcare professionals within the patient’s circle of care. Additionally, incompatible electronic medical records from different physician offices, laboratories, hospitals, and pharmacies further add obstacles to the complicated system of presenting a patient’s relevant medical records in a timely manner to the appropriate healthcare professional(s). An electronic personal health record (PHR) has the potential to streamline the data collection and storage of a patient’s medical records. The National Alliance for Health Information Technology (2008) defines PHR as “an electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual” (p.19). Simply put, Nelson (2009) defines PHR as “a general term for health records that are compiled and maintained by the most interested party, the healthcare consumer” (p.141).

If the public, specifically healthcare consumers, take “ownership” of their health information, this in turn will lead to a better personal understanding of their medical condition, resulting in more meaningful discussions with healthcare professionals, and leading to better compliance
with prescribed treatment and care recommendations. Furthermore, an updated and integrated record drawn from disparate and disconnected sources can be a valuable information source for physicians and other healthcare professionals as a supplement to current record keeping programs and conventional information flows.

The purpose of PHRs is to allow healthcare consumers, as “owners” of their health information, the ability to consolidate all paper and electronic medical records related to their care that reside in different locations (e.g. physician’s office, hospital, clinic, laboratory, pharmacy) into one central electronic location such as a server, hard drive, or flash memory device. A PHR on an internet-based server can be accessible through most computer platforms (e.g. PC, Apple-MacIntosh, Linux, SmartPhones). PHR software can also be installed directly on a computer’s hard drive or portable flash memory device. PHR users can give permission to allow individuals involved in their personal circle of care (e.g. medical professionals, social workers, emergency personnel) access to medical records contained in the PHR.

PHRs can potentially include a varied assortment of users ranging from the lay public to healthcare professionals. As such, it will be important to identify who these users will be in order to design PHRs that maximize accessibility and usability while keeping complexity and costs at a minimum. In order to better identify and understand who the real users of PHRs will be,
this study will examine to what extent a user’s background influences the same user’s perceptions regarding usability and usefulness of a PHR.
CHAPTER 2: LITERATURE REVIEW

2.1 Overview

Personal health records (PHR) grew out of the efforts to produce an integrated electronic record to manage the multifaceted aspects of healthcare required by healthcare consumers and healthcare professionals. Collaboration, cooperation, and interoperability are key factors that will determine this technology’s success or failure. Challenges exist that need to be addressed before PHRs can be fully accepted as a mainstream tool for participants in the healthcare system. PHRs are a transformative technology that has the potential to alter patient-provider relationships in a way that produces a more efficient and cost effective healthcare system that delivers better outcomes for healthcare consumers and healthcare professionals alike.

Information and communications technology (ICT) has been undergoing tremendous advances over the past decade. Digital technology, fibre optics, and broadband internet are transforming the way society communicates and the manner in which organizations function. The healthcare industry is an information-intensive discipline that utilizes ICT to collect, analyze, and translate massive amounts of data to improve clinical practice and patient outcomes. These are the reasons why ICT was developed into specific health information systems (HIS) tools such as electronic health records (EHR), computerized physician order entry
(CPOE), and clinical decision support systems (CDSS) are developed and deployed in most healthcare organizations. HIS not only impacts the way healthcare organizations collect, manage, and analyze data, but are also transforming the way clinicians and patients interact with each other. The internet provides access to a tremendous amount of medical and health information that patients use to become knowledgeable healthcare consumers. As a result, patients can have meaningful discussions with healthcare providers about their medical condition(s) and make educated decisions about their medical treatments and subsequent care.

Despite the rapid advances in technology, there is currently a complex, and somewhat disjointed approach to the way health information is collected, stored, and organized. Paper-based patient records can be difficult or, at times, impossible to obtain in a timely manner by patients, family members, or healthcare professionals in the patient’s circle of care. Additionally, incompatible electronic medical records from different physician offices, laboratories, hospitals, and pharmacies further add obstacles to the complicated system of presenting a patient’s relevant medical records in a timely manner.

An electronic personal health record (PHR), designed to give patients control of their medical data, will streamline the data collection, storage, and organization of the patient’s lifelong health record. This is especially useful in the case of children where parents or guardians are responsible for managing the child’s health record. It is hypothesized that if family members
take ownership of a child’s health information, this will lead to a better understanding of the child’s condition and result in better compliance with a physician’s treatment and care recommendations for the child. Furthermore, an updated and integrated record drawn from disparate and disconnected sources can be a valuable information source for physicians as a supplement to current record keeping programs and conventional information flows.

This literature review will examine both the historical development and state-of-the-art advances in PHRs. It will establish a broad definition of what a PHR is, and discuss PHR uses in general terms. The review will then focus on the role PHRs play to support patients and their families in the treatment and management of a medical condition(s). The social effects of PHRs will also be discussed, because of possible shifts in the communication and information flow dynamic that a PHR can potentially cause within healthcare. This review will examine all of these elements in the context of national and international developments pertaining to PHRs.

2.2 Methodology

Keywords used were: “PHR”, “personal health records”, “support”, “families”, “electronic records”, “EHR”, “EPR”, “EMR”. 58 articles were sourced using NCBI PubMed and Google Scholar based on title and a cursory scan of abstracts and summaries. After a more thorough assessment of each article’s abstract and summary, 12 articles were eliminated because updated information on what were essentially identical
topics was available in the more current articles. In the end, 46 primary sources were used for the literature review. One primary source cited a passage from another author that was included in this paper as a secondary source. In keeping with the international aspect of the review, articles from Denmark, Sweden, Germany, and Greece were examined in addition to those from the US, UK, and Canada.

14 articles dealt with electronic records in general with topics covering: PHRs, EHRs, EMRs, EPRs, e-health, health portals, and HIS. 6 articles discussed families and children’s health in relation to PHRs including one that focused on the electronic communication between children’s families and healthcare providers. PHR-specific tools and software were covered by 7 articles, and another 5 articles covered users’ opinions and the design of electronic records. Usability, functionality, limitations, and barriers were discussed by 6 articles and 3 articles dealt with the digital divide issue. It is important to note that there was information cross-over between the articles and that some articles discussed topics that were also touched on in others.

2.3 Defining Health Records

Health records are at the core of medical practice because they provide fundamental information about a patient such as personal identifiers, medical history, previous treatments, medications, test results, and progress notes. This information helps physicians and healthcare professionals determine the best course of action in treating a patient’s disease state or
medical condition. Records are usually kept using the preferred recording media of the time period. Ink on paper has been used for hundreds of years. However, with the arrival of computers, the medical community started to “computerize” records in various electronic forms. The terms electronic patient record (EPR), electronic medical record (EMR), and electronic health record (EHR) are often used interchangeably to describe any electronic, comprehensive, longitudinal record (Nagle, 2007) that pertains to an individual’s health or medical condition. However, there are distinct characteristics that pertain to each of these terms, and it is important to clarify these distinctions to avoid any confusion or ambiguity.

Early efforts to “computerize” medical records simply made electronic copies of existing paper records that led to the development of EMRs and EPRs. Waegermann (2003) defines an EMR as an “electronic record with full interoperability within an enterprise (hospital, clinic, practice)” (p.4), and an EPR, as a patient record that focuses on relevant information with full interoperability. Nagle (2007) limits the definition of an EMR to “electronic records maintained within a clinic, private practitioner’s office, Family Health team and so on” (p.30), but extends the definition of an EPR to “electronic records managed by healthcare organizations” (p.31). The important aspect to keep in mind regarding the EMR and EPR is that both were initially based on paper records and developed into electronic records. The EMR and EPR are controlled and maintained at the point-of-care organization with access granted to authorized users at the discretion of the organization.
Interoperability and data sharing typically function well within the organization but functionality is severely limited outside of it.

2.3.1 Impact of the Internet

Just like the arrival of the computer shifted the health record paradigm from paper to EMRs and EPRs, the emergence of the internet is again shifting that paradigm. The internet is reshaping how society communicates, collaborates, and organizes. According to Katehakis, Sfakianakis, Kavlentakis, Anthoulakis, and Tsiknakis (2007), healthcare professionals are increasingly required to share both knowledge and expertise with colleagues, while healthcare consumers demand active participation in medical decisions with increased access to healthcare services. The constant demand for access to quality healthcare services comes with exponentially increasing costs to deliver that care. Strategies such as e-health were conceptualized to utilize the internet as a way to improve the timely delivery of quality healthcare while keeping costs under control. Wickramasinghe, Fadlalla, Geisler, and Schaffer (2005) broadly define e-health as “various activities related to the use of many e-commerce technologies and infrastructures, most notably the internet for facilitating healthcare practice” (p.319). In this aspect, access to services and information must take place in a seamless environment, without visible organizational boundaries, to deliver personalized information (Katehakis et al., 2007) in a timely manner. Therefore, electronic health records (EHR)
were “proposed as a sustainable solution for improving the quality of medical care” (Linder, Ma, Bates, Middleton, & Stafford, 2007, p.1400).

2.3.2 Electronic Health Records

An EHR is defined by Nagle (2007) as a comprehensive record that incorporates select information from every healthcare encounter for a specific individual. Furthermore, Nagle (2007) explains that the EHR will consist of data taken from every EMR and EPR maintained for an individual, because there is no paper precursor to an EMR, where the health information is owned by the individual and the physical record is under the stewardship of a jurisdiction, with access granted by the individual to any authorized clinical provider within or outside of the jurisdiction. Consequently, according to Ventres et al., (2006), “Many mistakenly see the EHR as an updated version of the paper chart, but behind the superficial resemblance of tabs, notes, and flow sheets is a complicated system of functions (and, correspondingly, of human notions) that play into its application in the medical setting” (p.130). Rather, Ventres et al. (2006) describe the EHR like a third-party observer between physicians and patients who articulate their perceptions to the observer (EHR).

Goldschmidt (2005) identifies the primary benefits of EHRs as reduced cost and improved quality of care. Reduced costs are achieved through a savings in record-keeping expenses because automated sharing of information results in less duplication, reduced doctor visits, lower hospital admissions, and decreased malpractice risks as a result of improved
workflows and practice management. The streamlining of processes to improve workflow is supported by Waegermann (2003) who states that, “The most successful EHR systems improve workflow and efficiencies, enabling better management of the patient care process” (p.4).

The other primary EHR benefit identified by Goldschmidt (2005) is improved quality of care which is accomplished because of more complete and accurate documentation, and direct access with instant updates to patient records that result in fewer medical mistakes. Indeed, Waegermann (2003) points out that a major source of medical errors is illegible handwriting and personalized shorthand entries for prescriptions/documentation that may result in side effects or drug interactions. Therefore, because EHRs necessitate uniform documentation and better information management, better patient care is the result. To reinforce the improved quality of care benefit of EHRs, Goldschmidt (2005) suggests that improved clinical decisions also result because an EHR provides better decision support, is capable of data mining, and facilitates continuous improvement through easier clinical trials and better management of clinical knowledge.

2.3.3 EHR Standardization, Interoperability, & Connectivity

As a matter of necessity, the development of EHRs will induce a shift in healthcare practices with emphasis toward standardization, uniform documentation, and interoperability. Denmark is at the forefront of this philosophy such that the development of common terminologies and
classifications are emphasized to achieve seamless care and patient
involvement through shared information (Katehakis et al., 2007). However,
new technology and modern modeling techniques alone will not achieve
interoperability, according to Bernstein, Bruun-Rasmussen, Vingtoft,
Andersen, and Nohr (2005), “This (interoperability) is only achieved by
continuous standardization work with participation from healthcare
professionals and industry- and supported by validation and evaluation”
“envision an environment in which health information about an individual can
flow seamlessly among systems used by authorized health professionals,
caregivers, and the patient, when the patient authorizes such sharing”
(p.122).

Interoperability, connectivity, and seamless transactions are
characteristics common to the digital age. Internet-era consumers utilize
digital tools such as iPhones and BlackBerries to communicate, collaborate,
and organize their day-to-day lives. Automated banking
machines/automated teller machines (ABM/ATM), and point-of-sale
terminals are used to pay for purchases without paper money, resulting in
instant seamless retail transactions. On the medical front, the internet
provides access to an incredible amount of health information that is
transforming patients into knowledgeable healthcare consumers who use
this information to make informed decisions about their medical care. This
knowledge empowerment has led to an increase in patients’ desire to
become more involved and play a more active role in their medical care. As a result, Ball and Gold (2006) suggest that the PHR “will be used to build new relationships and new structures that support consumers” (p.71) in much the same way that the ATM transformed retail banking. ATM’s were originally developed as a way to give consumers access to cash. However, with the advent of the internet and e-commerce, ATM’s have become a tool for online banking and the move away from paper money and paper cheques (Ball & Gold, 2006). In the same manner, an interoperable EHR working in consort with PHRs can build on the enthusiasm for internet-enabled digital tools to transform healthcare.

### 2.3.4 Emergence of Personal Health Records

According to Nagle (2007), a PHR is used “to self-manage discrete aspects of personal health information related to specific disease entities (e.g. diabetes)” (p.32), but it can also “be used to manage comprehensive information pertaining to one’s health history” (p.32) with the information formatted to be available to share with healthcare providers in the event of a medical emergency. Ball and Gold (2006) elaborate, “For individuals working to improve their health and manage their care, PHRs will reach across time and into every setting, from their homes and offices, to their physicians’ office and the hospital” (p.71). According to Winkelman, Leonard, and Rossos (2005), a patient’s reality is not necessarily captured in a standard medical record, thus making the document less useful for the patient. However, a PHR allows the patient’s perspective to be documented
and the care decisions that the patient’s documentation influences promotes a sense of illness ownership for the patient that makes the PHR a useful and meaningful tool for them (Winkelman et al. 2005). Tang et al. (2006) underscore the importance of interoperability in describing PHRs as “more than just static repositories for patient data; they combine data, knowledge, and software tools, which help patients become active participants in their own care” (p.121). Johnston et al. (2007) list PHR tools outside of electronic records as remote monitoring, patient self-management technologies, teleconsultations, and electronic visits. Indeed, Ball and Gold (2006) point out that PHRs deliver the greatest benefits when they are interactive with the healthcare system as a whole.

Hence, an integrated and interoperable health record system incorporates the interdependent entities of EMR/EPR, EHR, and PHR (Ball & Gold, 2006). The EMR/EPR is the foundation record of patient information that feeds patient data to the EHR. The EHR is the longitudinal record that provides interoperability among different healthcare organizations, while the PHR is the personal record that is owned and managed by the patient. The PHR depends on EMR/EPR linkages to draw patient data and EHR linkages in order to accept the patient data from various provider organizations. According to Archer, Fevrier-Thomas, Lokker, McKibbon, & Straus (2011), “Linkages between PHRs and [primary care physician] EMRs thus appear to be critical to the successful use of PHRs” (p.517). In short, the PHR is the connecting hub between healthcare consumers and the healthcare system.
Dumitru, Ross, and Prokosch (2005) suggest that PHRs do bridge that gap between patients and health professionals by enabling patients to fill-in missing information into a record such as what medications they actually take or what adverse reactions they actually experienced toward medications. PHRs do not replace existing records at physicians’ offices and medical institutions, but instead complement the existing record systems with a personal, patient-controlled, comprehensive, lifelong health chronicle. However, according to Project HealthDesign (2009), as PHRs mature, they must progress from merely being personal-controlled health record repositories into vehicles that facilitate an understanding of user needs and collect, analyze, and deliver information tailored to manage those needs in a way that fits into the user’s daily routines. This can be accomplished by designing next-generation PHRs with “decision-support tools that help people take action to improve their health or manage their conditions” (Project HealthDesign, 2009, p.4).

### 2.4 PHR Models

Similar to medical records at hospitals, PHRs can be paper or electronic-based. Paper-based PHRs occur when patients keep paper copies of their medical records. Electronic PHRs can take form as a software product installed on a personal computer, an internet-based application, or a handheld device (e.g. smartphone, tablet, PDA, USB memory stick). Halamka, Mandl, and Tang (2008) present three basic electronic PHR model categories: (1) vendor created, clinic hosted; (2) self-
built, hospital hosted; (3) self-built research system, institution-neutral hosted service. An example of vendor created, clinic hosted systems is MyChart created by Epic Systems. MyChart enables a patient to review most contents of their medical record, except for progress notes, with the most popular features being access to lab test results and communication with physicians (Halamka et al., 2008). PatientSite at Beth Israel Deaconess Medical Center in New England is an example of self-built, hospital hosted PHRs. PatientSite’s most popular features include clinical messaging, prescription renewals, appointment making, and referrals (Halamka et al. 2008). Finally, Indivo at Children’s Hospital in Boston is an example of a self-built research system with institution-neutral hosted service. Indivo is an open source application that follows public and freely implementable standards.

PHRs are not limited to the three basic categories proposed by Halamka et al. (2008). Ball and Gold (2006) suggest that PHRs can be payer-based such as the case of WebMD which is available to individuals on their health plan’s Web site or for employees on their employer’s Web site. WebMD “integrates self-reported and professional data, including medical and medication claims, to create a complete profile of health history and health status” (Ball & Gold, 2006, p.80). Companies such as IBM, Verizon, Intel, Pepsi-Co., and Ford are using WebMD as the PHR for their employees.
According to Steinbrook (2008), some PHRs are accessed using secure internet connections known as patient portals. PatientSite and MyChart are examples of patient portals.

2.4.1 **Indivo**

Indivo belongs to a subset of PHRs known as personally controlled health records (PCHR). According to Mandl, Simons, Crawford, and Abbett (2007), the core functionality of the PCHR is the ability to aggregate a longitudinal health record from various data sources and share the aggregated records with third parties. The data aggregated remains the property and under the strict control of the patient. However, Mandl et al. (2007) point out that full patient control of a record implies that the accuracy and reliability of the information may be questionable. As such, healthcare professionals who rely on such information must be confident about the accuracy of a patient’s data. Therefore, Indivo will not allow a patient to modify lab test results aggregated from a hospital system.

Using simple controls designed into the software’s user interface, patients can share clinical data from Indivo with others. The user decides who to share the records with, and/or who is allowed to access those records. According to Halamka et al. (2008), the strict patient controls are “intended to promote widespread adoption by inspiring complete confidence that the system will maintain privacy and confidentiality and further that the individual will be empowered to benefit from the value of their own health care information” (p.3). Indeed, sharing of clinical data is not limited to
healthcare professionals. Indivo users have the ability to share their data with public health authorities and researchers. Mandl et al. (2007) believe that voluntarily sharing personal clinical data is preferable to involuntary sharing of data, where identities have been removed, because de-identifying data limits the types of data that can be shared and, as a result, valuable clinical and genomic data can be lost.

The open source code base of Indivo allows the customization of user interfaces toward specific user communities (e.g. diabetes). The open source approach encourages application development of both user-grown and commercial applications. Indeed, Indivo has expanded from Children’s Hospital in Boston to include the Massachusetts Institute of Technology’s PCHR for employees and students; Dossia, a non-profit PCHR consortium created by AT&T, Applied Materials, BP, Cardinal Health, Intel, Pitney-Bowes, Sanofi-Aventis, and Wal-Mart; and the MyOscar PCHR in Hamilton, Ontario.

2.4.2 The Memory Stone

Enquist and Tollmar (2008) present the concept of “palpable computing” which they describe as software technology that is “easy to grasp, modify, and understand for users” (p.104). This is especially important in a world where technology is increasingly becoming interconnected with the affairs of everyday life. The PalCom Project research was funded by the European Union (EU) and tasked with the development of prototypes that follow the principles of palpable computing.
PalCom software is released as open source and is developed through the participation of a large group of collaborating software developers from 21 EU universities and industries.

One result of the PalCom developments is a handheld PHR device called The Memory Stone which was targeted to support pregnant women and their families as well as the healthcare professionals caring for them. Enquist and Tollmar (2008) explain that the Memory Stone was to “be the means to store and communicate data between the pregnant woman and the health care system by allowing data to be transferred to the device from the electronic patient journal (EPJ) and other personal devices such as laptops or mobile phones” (p.106). Pregnant women indicated a desire to obtain more than just clinical data from the device. They requested such things as: information on what to expect during pregnancy; documentation of the changes in fetus and mother; a personal diary for the child; and support for communication with healthcare professionals. Therefore, the Memory Stone needed the ability to move data seamlessly from one device to another whether in upload or download modes (Enquist & Tollmar, 2008). Future developments using “palpable” software architecture will allow PHRs to function on almost any handheld device (e.g. smartphone, PDA, memory stick).

2.4.3 Microsoft and Google

Microsoft HealthVault and Google Health represent the efforts of technology firms who want to leverage their influence over internet-era
consumers to capture the growing desire of today’s society, who effectively use the internet for health information and advice, to control their own health records. According to Lohr (2007), “Microsoft’s software animates more than 90 percent of all personal computers, while Google is the default starting point for most health searches” (p.C1); specifically, Stoltz (2008) points out that more than 70 percent of people searching for health-care information start from Google. Furthermore, Steve Shihadeh, general manager of Microsoft’s health solution group, notes that the three most popular health record systems in place at physicians’ offices are built with Microsoft software and programming tools (Lohr, 2007).

Both HealthVault and Google Health are integrated Web-based PHRs where users are in complete control of access and determine what information is to be included in the health record. Both include search features, and both will not share personal information without the permission of the user. Users will not have to pay to use HealthVault and Google Health. Revenues are generated from advertising on health-related searches (Steinbrook, 2008).

Microsoft is collaborating with New York Presbyterian Hospital on HealthVault data extraction, while Google Health is working with Cleveland Clinic to test their platform’s data exchange abilities. Both systems are designed to automatically extract data from devices, services, and healthcare providers. According to Stoltz (2008), Microsoft has collected a list of companies with products and services that are capable of downloading
data into HealthVault. Google, on the other hand, is promoting open technology standards that will allow different information systems from around the world to communicate with each other (Stoltz, 2008). The results of these efforts, according to Steinbrook (2008), will be the ability for patients to store their personal health records in one place and facilitate communication with healthcare providers, pharmacies, and online health applications.

### 2.4.4 Other Models

The National Health Service (NHS) in the UK launched HealthSpace, a secure internet-accessible PHR organizer that was initially used to store patients’ health notes. Functionality has increased that allows patients to record health data such as blood pressure and weight readings, generate e-mail reminders, and book hospital appointments. However, according to Pagliari, Detmer, and Singleton (2007), “HealthSpace will not provide access to detailed care records, [but] clinicians can add data to the summary record with the patient’s agreement” (p.331). The challenge for HealthSpace, according to Kidd (2008), is whether UK patients will be content to participate in government funded PHR programs like HealthSpace or whether they will take a more direct approach to managing personal health data using vendor-supplied tools or even Microsoft HealthVault and Google Health.

LifeSensor is an internet-based PHR available in Germany, Switzerland, Austria, Bulgaria, and the US. It is built on the e-Health
framework of InterComponentWare AG (ICW) which allows health application developers to build interoperable applications with tools that support a complete software development lifecycle (Andry, Freeman, Gillson, Kienitz, Lee, Naval, & Nicholson, 2008). According to Charles Eaton, a Professor of Family Medicine at the Warren Alpert Medical School of Brown University, “LifeSensor, as an integrated PHR, fully supports the concept that healthcare providers and patients are equal partners in monitoring and managing patients’ health” (“ICW America and Memorial Hospital of Rhode Island Team Up to Offer an Interoperable Personal Health Record”, 2007, para. 4). Indeed LifeSensor as implemented at Barmer, Germany’s largest insurance company, is interoperable with physician practice management systems and is compatible with the German national e-health program (“Germany’s Barmer Begins PHR Trial”, 2007, para. 9). All the basic PHR elements such as the storage and management of health status and the ability to authorize caregiver access to the records are available on LifeSensor.

The National Healthcare Portal in Denmark has been in operation since year-end 2003. According to Detmer, Bloomsrosen, Raymond, and Tang (2008), with patient consent, the portal allows health professionals to access patient data in local electronic patient records and laboratory systems. Edwards (2006) lists the functions that the portal enables patients to do: (1) view their data and medicine profiles; (2) renew and purchase prescriptions; (3) view summaries of medical histories and pregnancy
records; (4) view information on medical conditions, preventative medicine, and health laws/regulations; (5) book appointments and consult electronically with general practitioners; (6) view a directory of healthcare organizations; and (7) specify organ donation preferences. The National Healthcare Portal is funded by the Danish government, and data sharing is compulsory (Moller & Vosegaard, 2008).

2.5 Discussion

2.5.1 The Value of PHRs

PHRs have the potential to transform the delivery of healthcare in a way that adds significant value for healthcare consumers, the medical community, and society at large. According to Detmer et al. (2008), significant value will be realized when PHR functionality is enhanced by incorporating “systems, tools, and other resources that leverage the data in the record and enable consumers to play a more active role in their health care” (Transformative Potential of Integrated PHRs section, para. 2). Johnston et al. (2007) hypothesize that “PHR value is determined by the number and types of functions supported by the PHR system: generally the more function, the greater the value” (p.374); and they suggest that an assessment of PHR value should include the following steps: (1) Data gathering (i.e. evidence on costs and impacts); (2) framework finalization (i.e. comprehensive PHR framework for future analysis); (3) evidence synthesis (i.e. determination of clusters of value for specific functions); (4)
model development (i.e. integration of value clusters into model); and (5) report generation (i.e. summary of findings, policy implications, and barriers). Because not all functions produce equal amounts of value for different users, determining which functions produce the greatest value for specific users will ensure that application developers can significantly mitigate the risk of failure of a given PHR application.

According to Johnston et al. (2007), existing research generally submits that PHRs benefit three major aspects of healthcare: (1) reduced medical costs, (2) improved healthcare efficiency, and (3) enhanced quality of care. Detmer et al. (2008) expand upon these benefits by listing capabilities that recognize the PHRs potential as a transformative technology: (1) quality, completeness, depth, and accessibility of health information; (2) facile communication (i.e. the ability for synchronous and asynchronous communication that permits interactive decision-making between patients and healthcare providers); (3) access to health knowledge; (4) portability; and (5) auto population (automatic insertion of reusable content from cross-site data transfers among disparate sources of content).

One facet of enhanced quality of care made possible by PHRs is the patient’s access to credible health information and medical data such that it empowers them to take a more proactive approach towards the management of their own medical condition(s) or that of family members within their circle of responsibility. According to Archer, et al. (2011), this can be achieved when information from the consumer is integrated with
information from the facilities where they received treatment (i.e. primary care provider’s EMR) using interoperable networks that gather information resulting in PHRs that are integrated with the healthcare system. Tang et al. (2006) state that patients can leverage their access of trustworthy health information to improve their health and manage their disease(s). This situation is most effective in patients with chronic conditions (e.g. diabetes, cancer, irritable bowel syndrome (IBS)), and patients with episodic care/treatments (e.g. in-vitro fertilization) (Pagliari et al., 2007). Nguyen, Carrieri-Kohlman, Rankin, Slaughter, and Stulbarg (2004) assert that the reason for this is that individuals with chronic diseases need to obtain information on self-management of the disease, along with coping strategies, such as maintaining social supports, which become more difficult to access with greater disability. Tang et al. (2006) suggest that PHRs enable patients with chronic diseases to collaboratively track their disease(s) with their caregivers, thereby “promoting earlier interventions when they encounter a deviation or problem” (p.123). Additionally, according to Pagliari et al. (2007), PHRs promote partnerships among caregivers and health professionals through the sharing of information.

However, Winkelman et al. (2005) point out that informational requirements, needs, knowledge, and understanding will fluctuate over the course of an illness, and therefore, support for patients should be adjusted accordingly. These fluctuations in information requirements can be effectively managed using PHRs because of their capacity to capture observations of daily living.
(ODL) such as information on sleep, diet, exercise, mood, and adherence to medication regimens. According to Project HealthDesign (2009), “Collecting ODL data through PHRs gives both clinicians and patients insights that are unattainable in records that capture information only from clinical encounters” (p.6). The end result is better communication between patients and health professionals that “changes encounters from episodic to continuous, thus substantially shortening the time to address problems that may arise (Tang et al., 2006, p.123). The value of PHRs in the area of chronic disease management also extends to the home care setting.

Hagglund, Scandurra, Mostrom, and Koch (2007) state that an aggregated care plan that contains information from both a home health service and a nursing plan helps foster cooperation between the two professions as they become aware of each profession’s contribution to the patient’s care and how it impacts the patient.

A benefit that touches all three of the healthcare aspects identified by Johnston et al. (2007) is patient education. According to Kupchunas (2007), the PHR gives healthcare professionals a tool for enhancing health literacy by allowing them to educate patients about their health condition(s). As a result of enhanced knowledge, patients become better able to communicate with healthcare professionals and participate in the decision-making and care management of their medical condition. However, Mitchell and Begoray (2010) “urge caution regarding the use of technology without first ensuring that patients have the basic, functional literacy skills that can be
built upon to enhance knowledge and ultimately gain the critical literacy skills needed for empowerment” (p.6). Kupchunas (2007) suggests, “Instead of regarding the PHR as a new and separate regulatory hurdle that depletes already stressed staff resources, the process of teaching patients how to maintain their own health records is an opportunity to tie together various standards and capitalize on education time spent with patients” (p.186).

A knowledgeable, self-motivated, and proactive health consumer has the potential to keep medical costs restrained by providing healthcare professionals with the appropriate information to make effective treatment decisions in an efficient manner thereby enhancing the quality of care provided. Therefore, healthcare professionals are also direct beneficiaries of PHRs. They make better decisions because they have more complete data. Additionally, proactive patients become willing participants in therapy with potentially better outcomes because of better adherence to medication protocols. Finally, Tang et al. (2006) point out that “asynchronous, PHR-mediated electronic communication between patients and members of their health care teams can free clinicians from the limitations of telephony and face-to-face communication or improve the efficiency of such personal contacts” (p.124). Less time spent on administrative tasks gives clinicians more time to focus on the clinical aspects of their practice. While this may not necessarily reduce the amount of work, it certainly facilitates a more meaningful type of work (Hagglund et al., 2007).
2.5.2 Usability and Functionality

Much has been written about the value of integrated electronic records as a tool to improve the quality and delivery of healthcare services, contain healthcare costs, improve collaboration within the healthcare community, and improve communication between patients and healthcare professionals. However, just as important as the tool itself, is how functional and usable the tool actually is for the people that use it. According to Moller and Vosegaard (2008), successful electronic records need to have an interface that is both appealing and responsive for the user. However, Zurita and Nohr (2004) state that “the impact on human issues and patient opinions remain relatively unexplored” (p.1333). Without such facts, how do you determine whether the systems were acceptable for the users? Jensen and Aanestad (2007) claim that the failure of electronic record systems typically occur because “healthcare professionals [find] that the systems [do] not meet their needs and [require] work-arounds in order to complete work procedures” (p.29).

A study by Ralston et al. (2007) found that the greatest satisfaction among users of a secure patient Web site at a large mixed-model health system came from accessing services and information about active and ongoing care (e.g. viewing medical test results, and requesting medication refills) as well as the participation in secure clinical communications between patients and healthcare providers. Conversely, according to Kim and Johnson (2002), usability and functionality problems tend to occur in the
process of data entry and validation. In fact, the Kim and Johnson (2002) study found that none of the PHR systems they examined had a method for directing patients on how to select the appropriate diagnoses to enter or how to abstract the relevant information from prescriptions and test results. In order for PHRs to be useful, Tang et al. (2006) suggest that PHR data and its accompanying tools must be presented “in ways that enable the individual to understand and to act on the information contained in the record” (p.123). The reason for the disconnect in the usability experience between data collection and application may be explained by Moller and Vosegaard (2008) who state that these two aspects are typically considered separate and may even be developed by different groups (i.e. integration architects for the data collection and application developers for the application aspect).

Additionally, Kjeldskov, Skov, and Stage (2008) show that the cause of usability problems is because of: (1) the complexity of information, (2) poor relation to work activities, and (3) a lack of support for mobility. Moller and Vosagaard (2008) suggest that the disconnect between data collection and application can be mitigated if “the overall solution [is] designed with an end-to-end perspective in mind because application functionality depends on data structure and quality” (p.20-21). Moreover, according to Kim and Johnson (2002), patients will need to be guided (i.e. orientation/training, and/or support/help-line) through the data entry process to help them determine the appropriate data elements to include in the PHR. Above all, it is relevant information coupled with effective system usability (i.e. viewing
patient data should not require too many user operations) (Moller and Vosegaard, 2008) that is needed to make a PHR credible to its intended users.

In addition to the high patient satisfaction rates in PHR applications pertaining to accessing services and information about ongoing care, Ralston et al. (2007) also found a growing demand for access to after-visit summaries which they attribute to filling patients’ unfulfilled information and care needs. Sometimes, according to Zurita and Nohr (2004), patients feel the need to audit their summary records because of past experiences where they came across errors in previous notes and summaries. More likely, however, Ralston et al. (2007) state that “summaries can provide a patient with a focused plan of care combined with personalized educational material” (p.804). The patient empowerment that follows was observed by Enquist and Tollmar (2008) where learning and information compliance were enhanced when patients were part of the information loop because “the knowledge became grounded in the lifework of the participants” (p.109). This is further strengthened in applications, such as the Memory Stone, which allow patients to add personal annotations to accompany the medical information contained in the PHR (Enquist & Tollmar, 2008).

A user’s perception of usability and functionality can fluctuate depending on the user’s occupation. For example, although physicians and nurses are a part of the PHRs primary users, each profession may employ the tool distinctly and integrate it into their work routines in different ways.
Jensen and Aanestad (2007) found that physicians perceived that electronic records did not mirror their roles nor preserve their autonomy of practice. On the other hand, they found that nurses considered electronic records as accurate indicators of their work practices that could potentially enhance their identity in practice (Jensen & Aanestad, 2007). A study by Collins, Currie, Bakken, and Cimino (2009) pointed out that although information needs varied according to clinician specialty, all clinicians, regardless of specialty, required evidence-based information in the form of institution-specific guidelines with nurses valuing patient education materials in addition to the institution-specific guidelines. Therefore, according to Jensen and Aanestad (2007), the adoption and use of electronic records is dependent on how clinicians “choose to receive and integrate the system in their work practices”, (p.41) with managers facilitating the process by clarifying the needs, values, and preferences of the users. Ultimately, Tang et al. (2006) suggest that an understanding has to be developed that identifies how the PHR fits into the activities of what individuals do on a day-to-day basis.

The perception of usability also fluctuates depending on user ability. Novices will react differently when compared to expert users of a given system. However, the distinction between novice and expert can be blurred by the simple fact that with complex systems, such as electronic records, a wide variety of features are available but are not necessarily utilized by all users. Therefore, Kjeldskov et al. (2008) suggest that “even highly experienced users of a system may still be novices in respect to some parts
of it” (Evaluating With Novice and Expert Users, para. 3). Kjeldskov et al. (2008) further suggest that during usability testing, novices may not accurately expose usability problems because they sense that they, rather than the system, is under evaluation. Conversely, Kjeldskov et al. (2008) point out that usability problems may not appear when evaluating expert users because they may have developed methods to circumvent poor design. As such, Kjeldskov et al. (2008) conclude that expertise reduces the severity of usability problems, and time allows users to develop expertise to overcome system peculiarities, but usability problems due to poor design will remain albeit concealed.

In order to lessen the likelihood of usability problems, Pagliari et al. (2007) suggest that both patients and clinicians “be involved in the design, development, implementation, and evaluation to generate a sense of ownership and ensure that systems meet users’ needs and are easy to operate” (p.332). Tang et al. (2006) propose that understanding the types of users, what functions they frequently use, and what changes in health-related behaviours result from PHR use, can be beneficial to future PHR development. User-centered design, a process pioneered by IBM and described by D’Alessandro and Dosa (2001) as development that uses “feedback from the intended users to modify and improve the product” (p.1132), can be applied to ensure that usability and functionality are suitable for the end-users.
Collaboration, cooperation, and interoperability are key factors that will determine a PHR system’s success or failure. According to Ralston et al. (2007), “success will require interoperability of information systems and shared communication functionality” (p.805) that result in effectively connecting patients and healthcare providers around test results, medication refills, and care plans. The basic foundation of trust in healthcare, according to Mandl et al. (2007), remains the patient-physician relationship. Ultimately, Ball and Gold (2006) reason that patients are more concerned about receiving the correct medical treatments for themselves and their families than about a PHRs technical features, and clinicians are more focused on providing the appropriate care for their patients than on acquiring/using an electronic record. Indeed according to Goldwater et al. (2013), health information technologies such as electronic records cannot improve care “unless it is supported by the redesign of care delivery within the healthcare setting; the incorporation of quality and process improvement of care activities across the care continuum” (p.3); and the use of decision support functionality such as reminders and alerts. Therefore, Ralston et al. (2007) conclude that valuable use and high-level satisfaction of a web-based PHR is directly related to “providing a constellation of shared medical record services that are well integrated with clinical care” (p.805). Without such integration, Tang et al. (2006) argue that PHRs will become “information islands” that are isolated from other relevant information about the patient
and will be of limited value for both patients and the healthcare professionals that support them.

### 2.5.3 Pitfalls and Challenges

A concern surrounding PHRs is the quality and accuracy of patient-entered data. Kim and Johnson (2002) found that few systems at the time could verify extracted information. Steinbrook (2008) supports this notion in citing problems with personally controlled electronic health data, “The data may be incomplete, inaccurate, or difficult to verify, resulting in liability concerns for physicians who rely on them” (p.1655). Liu, Shih, and Hayes (2011) point out that a seemingly small typographical error such as an additional zero can lead to potentially damaging or life-threatening results for a patient. There is also the risk, according to Tang et al. (2006), that patient-supplied data may not be clinically relevant and volumes of such irrelevant data may overwhelm healthcare professionals thereby encumbering the delivery of care. Kim and Johnson (2002) further point out that in the absence of signifiers indicating patient-entered data, printed summaries of PHRs can potentially be mistaken for provider-entered records (i.e. EHR/EMR/EPR).

Beyond data challenges, concerns exist at the clinical practice level about increased workload, loss of monetary compensation, and liability risks. Detmer et al. (2008) suggest that clinicians may be ill-equipped to handle the role of information broker as they assist and clarify health-data from different sources for their patients. Halamka et al. (2008) add that although patients
ultimately have the right to access their entire medical chart, the level of explanation required for items such as clinician progress notes may be disproportionate to the useful information a patient will gain. Furthermore, Detmer et al. (2008) explain that activities such as electronic communication with patients, and shared decision-making may lack the compensation or other incentive components resulting in unfunded work for clinicians. In addition to the liability risk that can result from clinicians making sub-optimal decisions based on patient-supplied data that is incomplete or inaccurate, there is a potential liability risk resulting from the documentation contained within a PHR. Prior to electronic communication, conversations between patients and physicians consisted of verbal exchanges. A consequence of electronic communication (e.g. e-mail) is documentation that can be stored and used as evidence in legal proceedings. However, Halamka et al. (2008) suggest that legal liability risk can be minimized by restricting integrated PHR access to patients and physicians that already have an established relationship, and by practicing prudent professional judgement. Tang et al. (2006) add that “[healthcare] providers must learn to encourage patients to enter the [medical] information accurately and to trust that information appropriately” (p.125).

Patient concerns focus predominantly on security, privacy, and confidentiality issues. Interestingly, however, Liu et al. (2011) found that clinicians tended to be less concerned about the security of online health records than patients. Pagliari et al. (2007) point out that patients tend to be
the most sensitive about mental and sexual health data. The reason for these concerns, according to Detmer et al. (2008), are media reports about security breaches of health information systems as well as an effective privacy advocacy community. Liu et al. (2011) observed that frequent users of several services from the same company (i.e. Google, Microsoft) tended to be more wary when the login information used for the PHR is the same as for other services provided by the same company (i.e. Google has one password for Gmail, YouTube, GoogleDocs, etc.). Steinbrook (2008) suggests that updated legislation may have to be enacted to safeguard personally controlled electronic health data because legal protections have not kept pace with technological advances. However, Pagliari et al. (2007) citing McKinstry (2007), states that “the risk of privacy invasions may be greatest at the family level, whether the intent is supportive or malign (e.g. spousal abuse), which is difficult to control for” (p.331). In the end, in addition to encryption technologies and privacy legislation, Tang et al. (2006) acknowledge that a key to resolving confidentiality issues may amount to having trust that healthcare professionals will only use the medical information for the patient’s benefit.

A health population concern is the issue of the digital divide. Kim, Mayani, Modi, Soh, & Kim (2005) define the digital divide as the gap between individuals or communities and their ability to have ICT available for their use as well as their ability to use the technologies to access and create content (i.e. medical data and information). According to Detmer et al.
(2008), “the continuing digital divide between those with and those without the ability to effectively use digital information technology is an obstacle to the promotion and use of integrated PHRs” (Equity and Usability: The Digital Divide, para. 1). This has the potential to create inequalities due to the lack of access to ICT, deficiencies in technical skills needed to operate the ICT tools, and health illiteracy. Pagliari et al. (2007) suggest that mobile phones and digital TV can help improve the situation if developers include these alternative media in designing future electronic records and HIS. Additionally, Pagliari et al. (2007) propose that a focus on usability and training can “overcome access disparities resulting from poor technical skills” (p.332).

While Katehakis et al. (2007) do not see technical issues per se as a significant barrier to integrated electronic records, Pagliari et al. (2007) note that the incompatibility between systems and databases is the barrier to integrated records. Detmer et al. (2008) states, “The immaturity and slow diffusion of standards for interoperability and data portability are key barriers to the integration and exchange of structured data among PHRs and the range of relevant entities that provide and finance health care” (Lack of Technical Standards for Interoperability, para. 1). Pagliari et al. (2007) state that the incompatibility differences between systems will diminish as consistent technology and data standards are adopted. Detmer et al. (2008) lists several standards necessary for integrated PHRs: (1) Data Integrity Standards (promote comparable and consistent information); (2) Common
Data Set/Minimum Data Set (ensure minimum amount of data available); (3) Consumer Terminologies (health care vocabularies with lay vernacular); (4) Authentication Processes (protect against unauthorized disclosure); (5) Identification Processes (positive patient identification); (6) Security Standards (technical security mechanisms); (7) Data Integrity Processes (ensure data has not been altered or corrupted); (8) Privacy Standards (rights for individuals and obligations for organizations); and (9) Certification (ensure compliance with data interchange standards).

Finally, beyond the pressing issues of technical standards, patient accessibility, privacy and security, usability, and data quality is the unknown factor of long-term PHR sustainability. According to Archer et al. (2011), sustainability involves more than just positive results from PHR adoption, use, acceptance, satisfaction, and usability. Sustainability includes favorable individual and organizational impacts. Archer et al. (2011) believe that long-term PHR sustainability “is extremely important if healthcare systems are to avoid the spectre of financing apparently successful PHR innovations that are abandoned or under-utilized by patients after an initial flurry of use” (p.520).

2.5.4 Identifying and Understanding PHR Users

Much has been written about the transformative power of PHRs in shifting the paradigm of how healthcare consumers and the medical community will interact with one another, in terms of communication and delivery of care. However, not much has been written about who the actual
PHR users are beyond the broad definition of patients and clinicians. If healthcare as a system is so complex, and PHRs are an important tool to facilitate a better flow of information and communication within that system, then it follows that understanding and classifying who the users are will greatly benefit PHR research and development in the areas of usability, functionality, and relevance.

Leonard, Casselman, and Wiljer (2008) suggest that the segment of the population most frustrated with the current healthcare system, and therefore having the most to gain from embracing change, are the ones most likely to be early adopters of PHRs. Leonard et al. (2008) identify this demographic as people with chronic illnesses because they interact frequently with the healthcare system due to their need to live with, and manage long-term medical conditions that accounts for $100 billion out of the $146 billion in Canadian healthcare spending in Fiscal 2006. If this demographic were enabled and empowered to self-manage their chronic condition(s) by adopting PHRs, it would have a dramatic effect on healthcare costs.

Marchionini, Rimer, and Wildermuth (2007) further classified the healthcare consumers most likely to be early adopters of PHRs into four categories: adults with chronic illness, parents with young children, adults caring for older parents, and older adults. This list builds upon the concept of PHRs empowering patients to self-manage their personal medical records and extends the benefits to family members by enabling those who act as
caregivers for patients that are unable to care for themselves (i.e. the very young and the very old) to assume similar health record management responsibilities and information sharing abilities as the self-managed patients themselves. Tang et al. (2006) suggest that the health care management tools contained in PHRs such as information regarding medications and appointments as well as provider communication and health care knowledge resources may be attractive to health consumers (i.e. families).

Indeed record-keeping is a tedious task that persons with chronic illnesses must undertake as part of the regimen in the management of their long-term medical conditions. This is also true for family members acting as caregivers for children or the elderly. Certainly PHRs can play a role in alleviating the difficulties and tedium of record-keeping, and Kientz et al. (2007) suggest that technology can actually be persuasive in motivating the data collection process: “Proactive technologies can prompt patients to look for specific milestones at key times or even help contact a healthcare professional if parents have any questions” (p.1352). Mann et al. (2006) emphasize that in the case of caring for children with medical condition(s), effective communication to share timely information between families and clinicians as well as between generalists and specialists “is pivotal in coordinating [the] care of children, especially those with special health care needs” (p.S316).

Older adults were identified by Marchionini et al. (2007) as early adopters of PHRs and, because of the baby boom demographic, this group could potentially be one of the most active users of PHRs. Therefore,
Marchionini et al. (2007) suggest that careful attention be directed towards age-related abilities and preferences. In the case of elderly adults not in the care of family members who needed assistance due to lack of computer literacy, or cognitive and physical impairments, Lober et al. (2006) found that health professionals such as registered nurses were able to offer limited assistance in creating and updating PHRs. Although the PHR assistance time was limited, the time spent with patients tended to improve the patient’s health literacy. Indeed, Britto et al. (2009) found that some users accessing health information over electronic portals experienced anxiety on interpreting that information because it lacked immediate contact with a clinician.

At the receiving end of PHR use are the health professionals that use the information contained in PHRs to determine an appropriate course of action in response to a given medical condition presented by a patient. Endsley, Kibbe, Linares, & Colorafi (2006) suggest that family physicians are uniquely adept at embracing PHRs as a component of their practice because of the patient-centric training and philosophy that is fundamental to family medicine. As the healthcare system continues to expand the implementation of electronic records such as EHRs, healthcare consumers and consumer advocates will respond with the expansion of corresponding electronic mechanisms such as PHRs. Primary care will potentially be the intersection of these two electronic record tools and perhaps clinicians in primary care will find themselves active users of those tools.
Indeed, according to Detmer et al. (2008), interoperable/integrated PHRs present innovative opportunities for new channels of communication and care management that allow patients to engage in the health delivery and treatment process in ways that were not possible before. However, Marchionini et al. (2007) caution that given the variance of users in terms of physical, mental, and experiential traits, the challenge for PHR systems will be to ensure universal access and usability that maximizes usefulness without adding complexity.

2.6 Summary

PHRs have grown out of the efforts to produce an integrated electronic record to manage the multifaceted aspects of healthcare for 21st century consumers. In order to succeed and gain mainstream acceptance beyond interested technophiles, PHR development must consider the needs of the intended end-users. This is best accomplished by utilizing user-centered design that includes the involvement of healthcare consumers (e.g. patients) and healthcare professionals (e.g. clinicians) alike. Collaboration, cooperation, and interoperability are the keys to ensuring the successful integration of PHRs into the practice, delivery, and access of healthcare. Steps should be taken to avoid simply making the PHR into stand-alone medical data repositories that simply reiterate medical records collected from disparate sources into one central location. While this is an important first step, development efforts should exploit the transformative potential of PHRs to facilitate the process of empowering healthcare
consumers towards a proactive approach of managing personal health and wellness. Beyond empowerment, developers should expand the capacity of PHRs to alter the relationship between patients and physicians that result in shared-decision making on issues of disease management and treatment. A functional, relevant, and interoperable PHR is purported by experts to produce efficiencies, cost savings, and improved outcomes to the healthcare system.

Efforts should also be extended beyond direct PHR technical development to address issues that can potentially impede the acceptance of PHRs by both healthcare consumers and healthcare professionals. Social, economic, and educational strategies can be used to tackle the digital divide such that PHRs can be utilized by patients regardless of socio-economic status or lack of technical know-how. On the clinician side, monetary and legal issues need to be addressed to ensure that clinicians can participate fully in activities relating to PHRs without the loss of compensation or fear of undue legal liabilities.

A proper understanding of who will actually get value from using PHRs is important because that understanding will drive the innovation to make PHRs usable, useful, and ultimately relevant for the intended users. The challenge will be in designing a system with universal appeal that ensures accessibility and usability for a variety of users without being excessively complex.
CHAPTER 3 RESEARCH QUESTIONS

3.1 Research Objective

The research study will investigate the information needs of PHR users, such as healthcare consumers. The study will also investigate how a user’s background can affect their perception of PHR usability and usefulness. Additionally, the study will probe into whether the information contained within a patient-controlled electronic record such as PHRs are viable data supplements to share with healthcare professionals using current record keeping programs with conventional information flows.

3.2 Central Questions

The central research questions are: (1) What are the public’s perceptions of PHRs? (2) What are the public’s information needs with regards to PHRs? (3) What are the types of potential PHR users? (4) How would they use a PHR? (5) What is the effect (if any) of user type on PHR usability and usefulness?

3.3 Summary

Electronic PHRs are being developed to allow for the collection, recording, and analysis of personal health information over time. This research will assess whether such an approach will provide useful information for users of the system on both sides of the circle of care (i.e.
information for personal use and information to share with healthcare professionals).
CHAPTER 4 METHODS

4.1 Subjects

15 people (i.e. healthcare consumers) were invited to participate in this study and consisted of adults recruited from the University of Victoria campus, and from the Greater Victoria professional and social communities (i.e. professional networks, as well as community and religious organizations). The initial point of contact for participants was the University of Victoria campus and the Greater Victoria professional and social communities. This was followed by snowball sampling where the initial contacts were asked to identify potential candidates who may be willing to participate in the study.

Snowball sampling is so named because, according to Bailey (1994), the individuals initially chosen for the sample are asked for referrals to other individuals who may have the appropriate characteristics to be part of the sample. According to Penrod, Preston, Cain, and Starks (2003), “the conceptual underpinning of snowball sampling is that members of a special or rare population are familiar with others in that population (p.102). Indeed, Trochim (2006) points out that snowball sampling is especially useful in locating samples that may be difficult to find or may otherwise be inaccessible.
The participants were initially recruited by letter of invitation and word-of-mouth from the University of Victoria campus and the professional and social communities of Greater Victoria. At the end of the demonstration and interview sessions, participants were informed about snowball sampling and encouraged to nominate candidates that they thought may be interested or well suited to participate in the study. Individuals nominated using snowball sampling were contacted by the nominator for permission to be approached for the study. When permission was granted, the potential participants were e-mailed a letter of invitation to participate in the study. The initial point of contact for participants was followed-up at the end of the interview session with snowball sampling to identify additional candidates who may be willing to participate in the study.

4.2 Setting

The study involved interviews that took place at an office in the McPherson Library at the University of Victoria. Some interviews took place at a participant’s office or private residence.

4.3 Materials

The PHR software used was Google Health, an online electronic PHR, which study participants accessed with a laptop connected to the internet. Audio and video recording devices were also be used, including a portable digital camcorder mounted on a tripod with a microphone attached, as well as a screen capture device known as Hypercam. See Appendix A
for a diagram of the office and desk setup using the appropriate interaction and observation equipment.

Hypercam is a screen recorder that captures the action of a PC desktop and saves the capture as an AVI (Audio-Video Interleaved) movie file. Hypercam also allows a microphone to be plugged into the PC so that the user’s voice can be recorded as part of the AVI file (Muradin, 2005). This software allows the researchers to see how a user is navigating the demo PHR on the PC desktop while also hearing the user’s thoughts as he/she thinks aloud during data entry and navigation of the demo PHR.

4.4 Procedures

The procedure involved sessions held with each participant that contained the following parts: (1) participants were first interviewed regarding their understanding of computers and PHRs, (2) participants were then shown a brief demo of the PHR and asked to respond, (3) participants were given the opportunity to interact with the system while being recorded and were asked to think-aloud, (4) participants were interviewed after their interaction with the PHR. Each session took approximately one-hour per participant. The following sections describe the methods employed for each part of the sessions with participants.

4.4.1 Interview

When participants arrived for their session, the objectives of the research study were explained to them and their role within the study was
described. They were given a consent form to examine and to sign before the session proceeded further. Once the consent was signed, a copy of the consent was given to the participants. The participants were then given a short demographic questionnaire to fill out (see Appendix B for the demographic questionnaire). The questionnaire provided a demographic, educational, and professional profile of the study participants to determine the extent to which education and professional backgrounds affect a user’s perception of PHR usability and usefulness.

With paperwork complete, the interview proceeded with the researcher conducting a semi-structured interview with the participant. The interview and interview prompts were designed to assess the participant’s access to and usage of computers, the extent of Internet use, current health information needs, and whether participants had ever used a PHR in the past. Furthermore, the interview prompts allowed the researcher to ascertain if lay-people would be willing to share medical information with health professionals within their circle of care (see Appendix C for lay-people interview prompts). The interview prompts will also established the participant’s comfort level with submitting / receiving health information over an internet-based PHR.

4.4.2 Observation

After completing the interview prompts, participants were introduced (via a brief demonstration) to Google Health (an online electronic PHR system) to give them a visual overview and high-level perspective of the
PHR they will examine and assess for the study. Additional interview prompts were directed at the participants following the demonstration to ascertain participants’ perceptions about PHRs and how they might use a PHR for their health information needs (see Appendix E for interview prompts pertaining to PHR demo).

The brief PHR demo and interview was followed by giving the participants a generous amount of time to fully interact with Google Health. Participants generally spent 20-45 minutes for this segment. During this time, participants were encouraged to enter dummy health data from fictional medical reports such as sample immunization records or laboratory reports. See Appendix G for the list of tasks participants were asked to execute in the PHR system during observation. During the dummy data entry process, participants were asked to comment aloud about their impressions of the system’s usability for what they found to be both challenging and easy. The process of having participants comment aloud while performing a task is known as think-aloud. Charters (2003) describes think-aloud as “a research method in which participants speak aloud any words in their mind as they complete a task” (p.68). Illustrating the value of using the think-aloud method in research, Charters (2003) cites Olson et al. (1984), “using think-aloud technique is one of the most effective ways to assess higher-level thinking processes (those which involve working memory) and that it could also be used to study individual differences in performing the same task” (p.71).
A combined audio / video recording system was used to chronicle the participants' think-aloud statements and reactions. Hypercam was used to capture screen views and record participants' think-aloud comments. The screen views provided context for the think-aloud comments. Kushniruk and Patel (2004) characterize think-aloud as “one of the most useful techniques emerging from cognitive science” (p.63) and contextualize this during human-computer interaction studies by using screen capture software such as Hypercam to enable detailed analysis of participants’ on-screen actions such as mouse clicks and menu selections. A video camera was set up on a tripod to record the participants’ view of the screen, the participants’ think-aloud comments, and the environment where the interview was conducted. The video recording also served as a back-up record in the event of Hypercam software failure.

The observations were primarily a usability test of an online electronic PHR- Google Health. Unlike traditional user acceptance software testing, usability testing (observations) in this study was designed to ascertain a PHR’s usefulness to meet participants’ health information needs rather than an assessment of how well Google Health can perform certain required tasks in accordance to a business specification. Techniques used during usability testing were adapted from the work of Kushniruk, Patel, and Cimino (1997) on the integration of usability engineering and cognitive research in medicine.
4.4.3 Post-Task Interview

Following the observation segment, participants were interviewed about their user experience and impressions of the PHR system. Post-task interview prompts were structured into the themes of Usefulness, Ease-of-Use, and Satisfaction which were derived from the Usefulness, Satisfaction, and Ease of Use (USE) questionnaire, and the Computer System Usability Questionnaire (CSUQ). According to Lund (2001), usability metrics seem to be neglected in favour of performance measures, yet it is user experience that is most closely tied to user behaviours and purchase decisions. Therefore, the post-task interview prompts probed into the participants’ perceptions about the usability and usefulness of the PHR system as well as how the system might be incorporated into their medical / health & wellness lifestyle and / or work routines (see Appendix H for complete post-task interview prompts). All interviews were recorded using audio and video.

4.5 Data Analysis

The data collected was coded, transcribed, and analyzed for themes using a qualitative content analysis approach. Hsieh and Shannon (2005) define qualitative content analysis “as a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns” (p.1278). According to Stemler (2001), the strength of the qualitative content analysis technique comes from its ability to allow for the coding and categorizing of research data in a rich and meaningful way.
Audio data was transcribed using transcription software. Themes and unique participant comments were identified, extracted from the transcripts and organized in a spreadsheet. Video data was viewed and analyzed to confirm themes identified from the transcripts. The video data was also used to verify statements that may have been unclear from the audio. Data from the transcripts were coded into themes based on the research questions: (1) Perceptions of PHRs; (2) health information needs of users; (3) potential PHR users; (4) the utility of PHRs; and (5) PHR usability and usefulness. The data was then organized in the spreadsheet into columns by numbered participant (i.e. LP1, LP2, LP3, etc.) and into rows by interview questions and think-aloud comments. Think-aloud comments were colour coded in the spreadsheet to the following themes: (1) Red- criticisms (negative comments); (2) Green- commendations (positive comments); (3) Blue-recommendations; and (4) Yellow- unique comments. The coding convention used for this study was based on a coding scheme developed by Kushniruk and Patel (2004) for analyzing human-computer interactions.

Descriptive statistics were employed to summarize the frequency of the appearance of themes outlined by the research questions, interview prompts, and think-aloud comments. Trochim (2006) defines descriptive statistics as a simple summation of the data sample and its measurements. Unlike inferential statistics which make inferences from the data in an attempt to reach conclusions beyond the data, descriptive statistics simply
elucidate what is shown in the data, thereby making it simple to explain what is going on in the data (Trochim, 2006).

Using the practices for data analysis put forward by Kushniruk and Patel (2004), this study looked to provide a better understanding of the interaction between electronic PHRs and the end users rather than the conventional completion of user tasks to validate technical design aspects of PHR software.
CHAPTER 5 Results

Participants in this study were laypeople who represented a wide age-range of individuals, evenly split in gender, with an above average level of computer literacy. Most of the participants had not used an electronic PHR prior to this study. However, after a hands-on session with PHR software, most participants found it to be easy to use with the functionality they expected from such a system. Most participants were satisfied that an electronic PHR would meet their health information needs and would recommend PHR applications to family and friends.

5.1 Demographics

The 15 people who participated in the study averaged 37.5 years of age and ranged from 19 to 73 years old. Three participants were over 50 years old and two were under 25 years old. The participants' gender was practically evenly split between 7 males and 8 females.

All participants completed at least a high school education. At the time of the study, two participants were completing programs at the undergraduate level, and another two were completing graduate-level programs. Six participants completed at least a bachelor’s degree (including the two in graduate-level programs), another six completed a master’s degree, and one completed a doctoral degree. The academic disciplines represented by the participants are shown in Table 1:
Table 1

<table>
<thead>
<tr>
<th>Academic Discipline</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicine &amp; Health Sciences</td>
<td>5</td>
</tr>
<tr>
<td>Social &amp; Behavioral Sciences</td>
<td>4</td>
</tr>
<tr>
<td>Arts &amp; Humanities</td>
<td>4</td>
</tr>
<tr>
<td>Life Sciences</td>
<td>2</td>
</tr>
<tr>
<td>Business</td>
<td>2</td>
</tr>
<tr>
<td>Education</td>
<td>1</td>
</tr>
<tr>
<td>Arts &amp; Humanities (Religion)</td>
<td>1</td>
</tr>
</tbody>
</table>

Note: Several participants had studies in multiple disciplines.

At the time of this study, all participants were either employed or enrolled in post-secondary studies. On a computer literacy scale of 1 to 5 (1=illiterate, 5=expert), participants had a self-disclosed average of 3.6 with the lowest score at 3 and the highest at 5. The literacy scale scores were distributed as shown in Table 2:

Table 2

<table>
<thead>
<tr>
<th>Age Category</th>
<th>Literacy Score 1</th>
<th>Literacy Score 2</th>
<th>Literacy Score 3</th>
<th>Literacy Score 3.5</th>
<th>Literacy Score 4</th>
<th>Literacy Score 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 25</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Ages 26-49</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Over 50</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

It is interesting to note that the participants generally rated themselves at least average on the computer literacy scale. As a group, the oldest participants rated themselves lower on the literacy scale compared with the
other participants, while the youngest participants generally rated themselves near the top of the scale. The middle-aged group also tended to rate themselves near the top with one participant in the grouping self-identifying with the highest rating (expert) on the scale. All participants used computers on a daily basis.

5.2 Pre-Interview

Participants identified multiple uses and roles that computers play in their day-to-day routines. Some participants distinguished between work and personal uses. All the activities fit into the following categories as shown in Table 3:

<table>
<thead>
<tr>
<th>Computer Usage</th>
<th>Frequency</th>
<th>Computer Usage</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research &amp; Information</td>
<td>8</td>
<td>Music</td>
<td>2</td>
</tr>
<tr>
<td>News / Newspapers &amp; Magazines</td>
<td>8</td>
<td>Banking</td>
<td>2</td>
</tr>
<tr>
<td>E-Mail</td>
<td>7</td>
<td>Photos</td>
<td>2</td>
</tr>
<tr>
<td>Social Media</td>
<td>5</td>
<td>Web Content Development</td>
<td>2</td>
</tr>
<tr>
<td>Word Processing</td>
<td>5</td>
<td>Documents / Documentation</td>
<td>2</td>
</tr>
<tr>
<td>Communications</td>
<td>5</td>
<td>Games</td>
<td>1</td>
</tr>
<tr>
<td>Online Shopping</td>
<td>4</td>
<td>Medical Records</td>
<td>1</td>
</tr>
<tr>
<td>Web Browsing / Internet</td>
<td>3</td>
<td>Medical Topics Research</td>
<td>1</td>
</tr>
<tr>
<td>Work</td>
<td>3</td>
<td>Videoconferencing</td>
<td>1</td>
</tr>
<tr>
<td>Spreadsheets</td>
<td>3</td>
<td>Programming</td>
<td>1</td>
</tr>
<tr>
<td>Videos / Movies</td>
<td>3</td>
<td>General Computing</td>
<td>1</td>
</tr>
</tbody>
</table>
The top activities clustered around the need for information such as research and news. This was followed closely by communication functions such as e-mail and social media. Interestingly, medical-related activities were ranked near the bottom of the list; easily out ranked by online shopping and banking activities.

The distribution of computing devices was practically equal among desktops (33%), laptops (33%), and smartphones (27%). On the other hand, tablets (7%) were still not a device of choice for the participants of this study. The average time spent connected to the internet was 62% of total time on a computing device. The time spent on the internet as a percentage of total time on a computing device ranged from a low of 15% to a high of 100%. Some participants who indicated that time spent on the internet was greater than 90% of total time on a computing device, pointed out that some of the internet time was used for passive activities such as downloading content.

When asked about preferences regarding desktop (standalone) applications versus online (web-based) applications, nearly half (47%) of participants preferred online applications. One-third (33%) of participants had no preference, provided no comment, or claimed their choice was dependent on the task at hand. Only 20% of participants preferred desktop applications. A major reason cited for choosing desktop applications was the familiarity brought about as a result of using software with a longer product life cycle.
Concern about online security and identity theft were also cited as reasons for those preferring desktop applications. On the other hand, versatility, mobility, and faster performance were cited by those who preferred online applications. Participants with no particular preferences could not distinguish any variance in performance between desktop or online applications. It is interesting to note that those preferring online applications still favoured the use of desktop applications for word processing and spreadsheets. Conversely, those who preferred desktop applications, chose online applications for data storage, web browsing, and e-mail.

Although all participants used computing devices in their day-to-day lives, it was apparent in their responses regarding computer use that managing personal health records and information were low on the task list. This was validated because filing paper copies of documents provided by health professionals was identified as the most common method (47%) of documenting and storing personal health records and information. One-third (33%) of participants did not store any form of personal health records. The reasons for not keeping personal records ranged from reliance on primary care physicians to keep records; not visiting a physician often enough to warrant keep records; to simply lacking any motivation to keep health records. A minority (20%) of participants stored their personal health records on a computer. A computer was used for a variety of reasons: some were documenting chronic health conditions for payment reimbursements or because they were participating in health research studies; others stored
simple electronic notes that can be accessed on the internet for instances when they were travelling.

The majority of participants (60%) had never used an electronic personal health record application. One participant was not aware of electronic personal health record applications. A few participants (20%) had observed electronic personal health record demonstrations as a part of education programs. One participant was actively using a government health record application to document a chronic condition for payment reimbursements. Another participant claimed to use Nintendo’s Wii Fit exercise game to store personal health information.

When describing their health information needs, participants identified record-keeping, documentation, and scheduling at the top of the list. Participants indicated that record-keeping was needed to track health issues, chart wellness (i.e. weight loss), and store immunization records. This was followed by a need for reminders to medical appointments, the ability to search for medical information such as a symptom look-up, and access to their medical records. Generally, access to medical records meant that participants wanted physician-agnostic electronic access with one participant indicating a need to link a patient’s medical records across different countries. Web-portals and websites such as HealthLinkBC were identified as examples of preferred methods for conducting a search for medical information. Participants needed a search function to get information about
diseases and to understand test results. The complete list of health information needs is shown in Table 4:

Table 4

<table>
<thead>
<tr>
<th>Health Information Need</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Record-keeping / documentation</td>
<td>8</td>
</tr>
<tr>
<td>Scheduling</td>
<td>8</td>
</tr>
<tr>
<td>Reminders</td>
<td>4</td>
</tr>
<tr>
<td>Search for medical information</td>
<td>4</td>
</tr>
<tr>
<td>Access to records</td>
<td>4</td>
</tr>
<tr>
<td>Medication tracking</td>
<td>2</td>
</tr>
<tr>
<td>Physician search &amp; contact</td>
<td>2</td>
</tr>
<tr>
<td>Receive test results</td>
<td>1</td>
</tr>
<tr>
<td>Disease surveillance</td>
<td>1</td>
</tr>
<tr>
<td>Medication refill history</td>
<td>1</td>
</tr>
<tr>
<td>Medical procedure checklist</td>
<td>1</td>
</tr>
<tr>
<td>Procedure wait-time information</td>
<td>1</td>
</tr>
</tbody>
</table>

*Note: Several participants indicated multiple health information needs.*

Interestingly, willingness to share personal health information with health professionals was not unanimous among the study participants. Most participants (67%) were willing to share their health information with a health professional. However, the willingness to share was not open to all health professionals at all times. Participants indicated that permission to share would only be granted to those involved with their care. One participant stated:

“I think [granting permissions] is on a need basis…if I had a family physician, I would grant them access… then if I go see a specialist…I would grant them access before they could see it, instead of just granting access to all physicians and specialists…maybe [they] have no need to see my information.” (Participant 14, Transcript Line 84-88)
One-third of participants (33%) indicated that they would be willing to share personal information at their discretion with family members and/or friends. The reasons to share information with family members was varied among the participants. One participant indicated a willingness to share information for the sake of a family member who is on a transplant list, stating:

“My son, in the future may need a kidney transplant. So I have been identified as the most likely donor. I would be more than happy to have all my blood work...all those test results and everything shared back and forth between [my son’s doctors] that are caring for him...that would be a good use of technology.” (Participant 10, Transcript Line 82-86)

Another participant indicated that sharing health information with a family member who is a health professional (i.e. physician) could generate a meaningful opinion or helpful information about their condition.

Participants were generally wary about sharing their personal health information with employers, insurance companies, or the government. However, in the case of insurance companies, participants were willing to share personal information if a direct benefit could be gained such as for reimbursement purposes or to ensure better rates of pricing. Furthermore, some participants were willing to share information to become a part of de-identified aggregate data for research and statistical purposes.

When specifically prompted to identify the types of health professionals with whom they would be willing to share personal information with, the participants described a traditional healthcare team: physician, medical specialist, registered nurse, nurse practitioner, pharmacist, and
dentist. Several participants were open to sharing with all healthcare professionals who could help their condition, all medical personnel involved in a treatment plan, or with the complete healthcare team. One participant described their idea of a team approach to sharing information in healthcare:

“…it is important for any health care profession that I am working with to work as...part of a team in terms of knowing what the other health care worker has diagnosed or perceived, and how they are tracking my health. I think it would be better [if they] were working...with each other rather than guessing...[for example] whether my [family physician] has done a certain test. I would prefer that my massage therapist...can enquire and work with my health care providers.” (Participant 4, Transcript Line 86-89)

Several participants did indicate a willingness to share personal health information with alternative health care providers such as massage therapists, chiropractors, and naturopaths. For one participant, verbally sharing information with alternative care providers was sufficient.

The gravity of a patient’s condition appeared to be a factor in determining one participant’s willingness to share health information with nurses and allied health personnel:

“If I was quite ill and I had...allied health [professionals] and nurses that needed access to my information, then I would have to open it up...if I was just routinely going to a doctor for checkups, then I wouldn’t see the need for an occupational therapist or nurse to have access to my information.” (Participant 14, Transcript Line 100-103)

One participant seemed to be sensitive about sharing health information with privately funded health facilities:

“[Sharing personal health information with] G.P.’s, Emergency [Department] like a hospital in general would be no issue. When you start talking about private clinics and that kind of thing, I might be more selective with my information. Anything that isn’t publicly funded by the Province, I think I would be selective with the amount of
information that I would share. [Sharing] with...pharmacies wouldn’t be an issue, any publicly funded facility for the most part I would have no issue in sharing the information...” (Participant 4, Transcript Line 115-116, 121-124)

All participants were willing to share their personal health information over a secure internet connection. However, one participant expressed a preference for granting access to their physician-controlled medical record rather than having to share their personally-controlled health record over a secure network. Several participants who regularly used online banking were comfortable with sharing personal health information using secure online methods.

Sharing information online was recognized as the fastest and most efficient method of communicating in our world today. Efficiency, timeliness of information (especially if the process occurs in real time), and accessibility to records were the most commonly cited reasons for allowing one’s personal health information to be shared using secure internet protocols.

One participant stated:

“...a physician or nurse practitioner is only as good as the information provided to them, so there is no point in keeping [health] information back because it is not very useful in the end.” (Participant 8, Transcript Line 90-91)

Another participant thought that one’s health information was not sensitive enough to have reservations about sharing it online. As in the case of sharing health information with health professionals, the gravity of a patient’s condition was also a factor in determining one participant’s willingness to share health information online:
“If [medical professionals] have trouble accessing my medical records thereby delaying [the necessary care for] my…survival, then [having my medical information available]...is more important than risks of having that information [shared online].” 

(Participant 15, Transcript Line 198-199)

Although all participants were willing to share their personal health information over a secure internet connection, some expressed concerns about network security and improper access to their personal records. A wide range of opinions were raised regarding what were perceived to be the results of someone gaining improper access to personal records:

- People may take advantage of someone’s vulnerabilities (i.e. mental conditions or diseases with social stigma)
- Confidentiality will not be maintained
- Changes to a health record without patient consent
- Tampering of records for the sale of prescription medications on the black market

The participants with no concerns about sharing personal health information electronically were very comfortable using the internet and trusted the security processes in place for online financial information:

“I am more concerned about my banking information which is readily available on-line. So…I wouldn’t be that concerned about [personal health information online]…obviously I wouldn’t want people going in and finding out information and using it for another purpose; but yeah, not really concerned about it… if we have a system to keep our financial information safe then surely we have a good enough system to keep our medical information safe.” 

(Participant 10, Transcript Line 111-114, 119-120)
A large majority of participants (73%) were willing to maintain their own personal health records. Some participants indicated that their willingness to maintain their own records was dependent on whether the files were easy to access. Multi-step processes were regarded as barriers to easy access. The ability to maintain one’s own health records was regarded as being valuable because:

- It provides a patient chronicle / diary of day-to-day health information that a physician may not be aware of
- It allows the patient to be better engaged in their own health and wellness
- Allows a patient to read and absorb information at a reasonable pace rather than receiving it verbally during a compressed period of time at the physician’s office

A few participants (20%) wanted their health records to remain under the control or supervision of a healthcare provider such as a physician or nurse. They were concerned about misinterpreting the data provided to them, potentially affecting the accuracy of the information entered into their personal health record. Only one participant refused to maintain a personal health record outright.

5.3 Introductory Demonstration

Each participant was shown a brief introductory demonstration of the personal health record (PHR) software to give them a visual overview and
high-level perspective of the system they will be interacting with for the study. The participants responded positively to the possibility of using the PHR software for themselves as part of their health care routine. The positive responses ranged from a decisive absolutely / definitely to a more timid probably / maybe. The most common reasons given by participants for indicating yes to the idea of using the PHR software for themselves was that the software in the demonstration appeared to be:

- Easy to navigate and learn
- Simple, user-friendly, and well laid-out
- Straightforward to use
- Familiar in look and feel to other products from the software vendor

One participant who responded with a maybe said, “I don’t know what I would need it for at the moment, but I could certainly see how it could be useful for a lot of people” (Participant 10, Transcript Line 160-161). Nobody out-rightly rejected the idea of using PHR software.

When asked to describe how they would use PHR software, participants’ responses were closely aligned to their health information needs. Participants ranked record-keeping as the most identified use of PHR software. Record-keeping was also the most identified health information need by the participants. Each function identified by participants as a way to use PHR software can be paired with a health information need.
Health information needs that did not have a corresponding use in PHR software was:

- the need to search electronically for a physician, and
- the need for procedure wait time information.

A ranking of the uses of PHR software and health information needs are shown in Table 5:

### Table 5

<table>
<thead>
<tr>
<th>Use of PHR Software</th>
<th>Frequency</th>
<th>Health Information Need</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Record-keeping</td>
<td>7</td>
<td>Record-keeping / documentation</td>
<td>8</td>
</tr>
<tr>
<td>Monitoring &amp; Tracking</td>
<td>6</td>
<td>Scheduling</td>
<td>8</td>
</tr>
<tr>
<td>Access and control of records</td>
<td>5</td>
<td>Reminders</td>
<td>4</td>
</tr>
<tr>
<td>Alerts and reminders</td>
<td>4</td>
<td>Search for medical information</td>
<td>4</td>
</tr>
<tr>
<td>Research and information</td>
<td>2</td>
<td>Access to records</td>
<td>4</td>
</tr>
<tr>
<td>Receive test results</td>
<td>1</td>
<td>Medication tracking</td>
<td>2</td>
</tr>
<tr>
<td>Statistics</td>
<td>1</td>
<td>Physician search &amp; contact</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Receive test results</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Disease surveillance</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Medication refill history</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Medical procedure checklist</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Procedure wait-time information</td>
<td>1</td>
</tr>
</tbody>
</table>

*Note: Several participants indicated multiple uses of PHR software and multiple health information needs.*

The top 85% of identified uses of PHR software were closely aligned to the top 85% of health information needs. This illustrates that the participants were able to translate their health information needs into what they considered useful functions in PHR software.
As a result, participants generally had positive responses when asked whether the PHR software in the demonstration will meet their health information needs with 87% of participants indicating yes or probably. Two participants indicated that the PHR software will meet their needs if their physicians were also linked to their personal records. The reason for keeping a connection to their physicians was to avoid patient-entered errors and to provide meaningful data that the physicians will find informative. One participant explained:

“I don’t want to [use personal health records] just [for] the sake of doing it if [healthcare professionals] are not linked into the system. Otherwise, it is a waste of my time…if it is just stored somewhere out there…but nobody has access to it.” (Participant 15, Transcript Line 276-278)

When asked to identify any perceived challenges to using PHR software, 53% of participants did not list any challenges. Those listing concerns included:

- Data quality / accuracy
  “…the biggest part to be perfectly honest is the reliance on the user to track [their own health] information and how accurate it is going to be when the person actually brings it to the Physician.” (Participant 4, Transcript Line 244-245)
  “I think it is like a lot of things, it is only as good as the person using it.” (Participant 8, Transcript Line 180)

- Reliability of source information
  “My only concern would be if like I was searching for a condition or things like that, I would not be sure how reliable the sources are.” (Participant 14, Transcript Line 199-200)

- Security
“…the risk of people who are not supposed to be looking at it, looking at it and the risk of needing information but having no internet access.” (Participant 15, Transcript Line 295-296)

- Aesthetics

“Just in my initial look at it, it doesn’t look all that user friendly, to be honest. It is set up…like a list …I always compare things to Facebook and how well Facebook has things laid out and people are so [accustomed] to using social media now they get used to it looking a little bit fancier.” (Participant 10, Transcript Line 193-196)

- User motivation (or lack thereof) to maintain record

“…the only limitation is the desire to keep a thorough record yourself.” (Participant 7, Transcript Line 203)

5.4 Usability Testing (Think-Aloud)

During usability testing, participants were asked to follow a Think-Aloud protocol whereby they were encouraged to verbalize their thoughts and reactions as a result of interacting with the PHR software. They were encouraged to voice out comments such as criticisms, commendations, recommendations, and any unique out-of-the-box thoughts that come to mind. There were 29 instances of comments that appeared to be criticism, 45 instances that appeared to be commendations, and 18 instances that appeared to be recommendations. As such, based on their Think-Aloud comments, it appears that participants had more instances of positive interactions (commendations) with the PHR software during usability testing than negative (criticisms) ones.

A confusing screen layout was the most commonly cited criticism during usability testing. This was followed by difficulty and confusion navigating to and from the screen, along with confusion about the functions
available within the screen. A ranking of usability criticisms are shown in Table 6:

Table 6

<table>
<thead>
<tr>
<th>Think-Aloud Criticism (Negative Comments)</th>
<th>Number of instances cited</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confusing screen layout</td>
<td>6</td>
</tr>
<tr>
<td>Confusing screen navigation and/or difficulty with screen navigation</td>
<td>4</td>
</tr>
<tr>
<td>Confusing functions (i.e. calendar)</td>
<td>4</td>
</tr>
<tr>
<td>Difficulty with correct medical terminology to use</td>
<td>3</td>
</tr>
<tr>
<td>System is slow</td>
<td>3</td>
</tr>
<tr>
<td>Data movement and synchronization</td>
<td>2</td>
</tr>
<tr>
<td>Data storage concerns</td>
<td>1</td>
</tr>
<tr>
<td>Security concern</td>
<td>1</td>
</tr>
<tr>
<td>Confusing system warnings</td>
<td>1</td>
</tr>
<tr>
<td>System confusing overall</td>
<td>1</td>
</tr>
<tr>
<td>Information overload</td>
<td>1</td>
</tr>
<tr>
<td>Internet connectivity</td>
<td>1</td>
</tr>
<tr>
<td>Not meeting expectations</td>
<td>1</td>
</tr>
</tbody>
</table>

*Note: Several participants indicated multiple usability comments.*

The most commonly cited commendations (positive comments) during usability testing were directed towards how the system was intuitive, uncomplicated, simple, consistent, and straight-forward. Study participants also liked the display of visuals on the screen such as graphs, charts, and calendars. A ranking of positive usability comments (commendations) are shown in Table 7:

Table 7

<table>
<thead>
<tr>
<th>Think-Aloud Commendations (Positive Comments)</th>
<th>Number of instances cited</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intuitive / uncomplicated / simple / consistent / straight-forward system</td>
<td>8</td>
</tr>
<tr>
<td>Likes display visuals (i.e. graphs, charts, calendars)</td>
<td>6</td>
</tr>
</tbody>
</table>
Although participants had more positive comments than negative ones, they also did not hesitate to provide recommendations during the Think-Aloud process. The most common recommendation was to safeguard against accidental deletions and a process for restoring information that was accidentally deleted. This was followed by a need to validate the data entered into the PHR with their physician and to link the PHR with their physician’s electronic medical records. The recommendations from the Think-Aloud process are shown in Table 8:

Table 8

<table>
<thead>
<tr>
<th>Think-Aloud Recommendations</th>
<th>Number of instances cited</th>
</tr>
</thead>
<tbody>
<tr>
<td>Safeguard against accidental deletions with data recovery</td>
<td>3</td>
</tr>
<tr>
<td>Validate personally-entered data with physician</td>
<td>2</td>
</tr>
<tr>
<td>Connection between PHR and physician’s EMR</td>
<td>2</td>
</tr>
</tbody>
</table>

Note: Several participants indicated multiple usability comments.
<table>
<thead>
<tr>
<th>Think-Aloud Recommendations</th>
<th>Number of instances cited</th>
</tr>
</thead>
<tbody>
<tr>
<td>E-mail reminders (for immunizations)</td>
<td>2</td>
</tr>
<tr>
<td>Sharing of test results with physicians</td>
<td>1</td>
</tr>
<tr>
<td>Definition of medical terms</td>
<td>1</td>
</tr>
<tr>
<td>Identification of congenital conditions</td>
<td>1</td>
</tr>
<tr>
<td>Use date-of-birth rather than age</td>
<td>1</td>
</tr>
<tr>
<td>Data should be pre-filled from official medical record</td>
<td>1</td>
</tr>
<tr>
<td>On-page back button rather than using browser back button</td>
<td>1</td>
</tr>
<tr>
<td>Search box or dropdown menu</td>
<td>1</td>
</tr>
<tr>
<td>Different format</td>
<td>1</td>
</tr>
<tr>
<td>Software to take into account user's level of computer literacy</td>
<td>1</td>
</tr>
</tbody>
</table>

*Note: Several participants indicated multiple usability recommendations.*

Several participants also generated unique comments not mentioned by others during the Think-Aloud process. On the theme of simplicity and convenience for the user, the following unique comments were captured during Think-Aloud:

- **Using language people understand**
  “...all the names of the conditions and medications, they don’t mean a lot to me. To find them, though, I need something that is definitely lay-language and this [software] seems to be.”
  (Participant 1, Hypercam Time 06:18 – 06:31)

- **Alphabetical scrolling for people unfamiliar with medical nomenclature**
  “So, if you are unsure about what is going on you can actually scroll through these alphabetically. That’s very handy actually for someone who may not be super familiar with terms or may want to be sure that they’re clear on what they’re actually adding to their record so that when they provide it to someone that it is clear.”
  (Participant 4, Hypercam Time 10:10 – 10:32)

- **Multiple export options available**
  “I can also download an event to a PDF or a CCR, or a CSV, HTML, or XML. I can send it to another service and I would send a copy of my profile to other personal health record systems that
Some participants had unique comments concerning the quality of information / data for the PHR system:

- **Effects of wrong information**
  "So if a health care professional is accessing this and I didn’t put in the right information- that could be really deadly. Like, for example, I could say that I was immunized with chicken pox, but then there could be a chicken pox outbreak in the emergency room and I could catch it even though they thought I was immunized.” (Participant 5, Hypercam Time 30:28 – 30:53)

- **Regularly updating data could be an issue**
  "Overall I think the problem or the issue would be weekly updating of data and if Google, or whatever it was, could have a reminder to say ‘remember to update your health report’; that would be a good thing to do.” (Participant 8, Hypercam Time 18:05 – 18:25)

- **Meaningful, contextualized information**
  "So I just entered my blood pressure, but again coming back to the concept that you don’t have any clue whether those numbers are correct, or it doesn’t give you any information about whether that is a good set of numbers or not, so that’s always the kind of information that I am looking for…” (Participant 10, Hypercam Time 00:27 – 00:45)

- **Physicians sharing records and manual upkeep of records**
  “I wonder, why would I use this one because doctors don’t usually give you your file unless you ask for it, I guess. Procedures…this is a neat one, to add all the Procedures so you have it updated…never forget the dates…immunizations, that’s a very good one…drop down menu…keeping your records…test results…that would be a problem because doctors don’t usually give that to you, you just have to remember it when they vocalize it to you. It would take a lot of time, though, on a daily basis to fill this out considering I have hardly anytime on my hands, this is quite detailed.” (Participant 12, Hypercam Time 14:30 – 15:14)

- **Advertising and data mining for services (note that what the participant perceived to be advertising were actually tips for the user; the participant misunderstood the tips to be advertising)
“Oh, there are Google Ads in here, how fabulous! I’m annoyed by that, I’d just like to put in on record.” (Participant 7, Hypercam Time 16:00 – 16:07)

“…again with the Google ads. First thing I am going to look at and I am annoyed.” (Participant 7, Hypercam Time 17:48 – 17:51)

“That’s sort of interesting, that you can choose services based on your information, I guess. Interesting that there’s a lot of sort of pharmaceutical stuff.” (Participant 7, Hypercam Time 20:41 – 20:55)

5.5 Post-Observation Interview

Immediately following the observation segment, participants were interviewed about their user experience and impressions of the PHR system. Post-observation interview prompts were structured into the themes of Usefulness, Ease-of-Use, and Satisfaction.

5.5.1 Usefulness

All the participants indicated that the PHR software demonstrated in usability testing features, at a minimum, the functions and capabilities they would expect from a PHR system. The software’s functions and capabilities were sufficient for some user’s needs while others indicated that those same functions and capabilities exceeded their needs. While commenting on PHR functions and capabilities, one participant emphasized a caveat:

“...I haven’t seen any of the other [PHR systems] so can’t say if this would be the ultimate tool or not...I think it has obviously spotted the main points of one’s personal health.” (Participant 8, Transcript Line 254-257)

The most “liked” feature of the PHR, cited by participants, was that the software is easy, simple, and intuitive to use. They also liked its clear and
organized layout. Some participants liked how the PHR software’s look and feel appeared consistent and standardized to other products from the vendor. The software’s organized layout and its ease-of-use may have contributed to participants liking the ability to add more information such as notes and access that information easily when required. The list of what participants liked about the PHR system is shown in Table 9:

Table 9

<table>
<thead>
<tr>
<th>What was liked about the PHR software</th>
<th>Number of instances cited</th>
</tr>
</thead>
<tbody>
<tr>
<td>Easy / simple / intuitive</td>
<td>6</td>
</tr>
<tr>
<td>Organized / clear layout</td>
<td>4</td>
</tr>
<tr>
<td>Consistent and standardized appearance with other products from the vendor</td>
<td>4</td>
</tr>
<tr>
<td>Add more information as needed (i.e. ability to post notes) and access the information easily</td>
<td>4</td>
</tr>
<tr>
<td>Learning and engagement is useful to user’s personal health (i.e. ability for users to track their health regularly instead of only in preparation for visiting a physician)</td>
<td>3</td>
</tr>
<tr>
<td>Ability to produce graphs</td>
<td>3</td>
</tr>
<tr>
<td>Help features</td>
<td>2</td>
</tr>
<tr>
<td>Pre-filled information boxes and dropdown options</td>
<td>2</td>
</tr>
<tr>
<td>Medication warnings</td>
<td>1</td>
</tr>
<tr>
<td>Calendar functions</td>
<td>1</td>
</tr>
<tr>
<td>Wellness tracker</td>
<td>1</td>
</tr>
<tr>
<td>Audit function (i.e. ability to track who)</td>
<td>1</td>
</tr>
<tr>
<td>What was liked about the PHR software</td>
<td>Number of instances cited</td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>has accessed the records)</td>
<td></td>
</tr>
<tr>
<td>Import function</td>
<td>1</td>
</tr>
</tbody>
</table>

*Note: Several participants indicated multiple “likes”.*

When participants were asked to suggest improvements to the PHR, the most common cited improvements were to usability / navigation (20%) and aesthetics (20%). Flexibility and customization were important components identified towards improving usability and navigation. One participant suggested the ability “to move around pieces so that the pieces I use the most I could put at the beginning [of a page]” (Participant 9, Transcript Line 378-380). Another participant suggested utilizing touchscreen technology to improve usability and accessibility. The remaining comments regarding improvements to usability focused on clarifying functions, wording and designing page layouts to appear user friendly and intuitive, which overlaps with comments made for improving aesthetics. Suggestions for improving aesthetics included improving the look of the interface to be clean yet visually interesting and appealing.

Other improvements cited were for better linkages between the PHR and physicians’ medical records (16%), better help / examples (12%), and scheduling / alerts / reminders (12%). The suggestions of participants who wanted better links between the PHR and physicians’ medical records ranged from one participant wanting to defer all opinions regarding PHR system improvements to their physician contrasted with other participants
who considered the linking to physicians’ records as a means to synchronize information between the patient and their healthcare provider. Regarding synchronization, one participant explained:

“It would be good if medical practitioners…also used the [PHR] system that they could enter [records into]. [I had] a problem [where] I could not remember the immunization I had about 2 to 3 years ago, which my doctor could enter. [A PHR is] good as a record if everyone is using [it] together.” (Participant 15, Transcript Line 391 - 394)

Another participant implied synchronization by wanting a two-way communication function with their physician where the participant enters wellness information and the physician enters medical records into the PHR. However, this participant also expressed the need to clarify the responsibilities for data input into the PHR:

“It’s not an outstanding way of presenting the information. I think it could be done in another way.” (Participant 8, Transcript Line 363 – 366)

This participant’s comments are also related to the suggestions for improving the PHR’s help and examples. Some participants suggested providing examples of the information required for entry into the data fields. One participant stated, “It would be nice if you picked a Test and it would show you how to enter in the format” (Participant 14, Transcript Line 279 – 280). Another participant suggested having dummy data available as a live example to practice becoming proficient in using the PHR.
To improve PHR functionality, participants wanted reminders of scheduled appointments with their physicians and for medical procedures such as laboratory tests. Improvements to the communication function between PHR users and physicians were also identified as a means of alert about a user’s medical condition(s). One participant stated:

“If I was on the verge of developing diabetes, and they were doing blood tests, there should be a way to put this result in [the PHR] and I can look and see that’s something I am going to have to do something about…” (Participant 8, Transcript Line 280 – 282)

Regarding providing their physician with more information on their medical condition, another participant stated:

“I am wondering if [the PHR has] a button where you can actually access information and pull out information and say this is the research I found and talk to [the] Doctor about [it] and [the PHR sends] little alerts so it comes up…when you are talking to your Doctor [and] you can [recall] it on a future date.” (Participant 12, Transcript Line 285 – 288)

The complete list of suggested improvements is shown in Table 10:

<table>
<thead>
<tr>
<th>Suggested improvements to PHR</th>
<th>Number of instances cited</th>
</tr>
</thead>
<tbody>
<tr>
<td>Usability / Navigation</td>
<td>5</td>
</tr>
<tr>
<td>Aesthetics</td>
<td>5</td>
</tr>
<tr>
<td>Link to physician medical records</td>
<td>4</td>
</tr>
<tr>
<td>Help / Examples</td>
<td>3</td>
</tr>
<tr>
<td>Scheduling / Reminders / Alerts</td>
<td>3</td>
</tr>
<tr>
<td>None</td>
<td>2</td>
</tr>
<tr>
<td>Security</td>
<td>1</td>
</tr>
<tr>
<td>Usefulness</td>
<td>1</td>
</tr>
<tr>
<td>Removal of advertisements</td>
<td>1</td>
</tr>
</tbody>
</table>

*Note: Several participants made multiple suggested improvements*

When participants were asked whether the PHR software would meet their health information needs, all but one agreed that their health
information needs would be met using the software. Positive responses included:

“Well there is something about putting things all in one place and that’s helpful to me, it’s kind of how I think. I have lots of ideas, but [this helps you] to see the big picture.” (Participant 1, Transcript Line 372 – 373)

“I think this would…definitely [meet] my basic needs for entering any problems, medications, allergies and things. This is what I would expect from a system.” (Participant 6, Transcript Line 295 – 296)

One participant who responded positively qualified the response by stating,

“I don’t think it is too complex…if it is going to be too complex, I am not going to be willing to spend the time [using the PHR]” (Participant 8, Transcript Line 289 – 290). This same participant went on to suggest that the tracking of health records would be useful for both themselves and their physician. However, not every participant shared the view that the information would be useful for physicians:

“It would be easy for me to find information that I would want to find. [However] I don’t know if it would be useful for a physician, I don’t know how helpful the information would be for them.” (Participant 7, Transcript Line 322 – 324)

The one participant who thought that the PHR would not meet their health needs explained:

“…it is great having this activity. What you need is the connectivity with the other users, like…your doctor, and being able to have your lab results, and being able to have your pharmacist telling you when your prescriptions are ready, and things like that. I don’t know that what we have here I couldn’t just do on a piece of paper.” (Participant 10, Transcript Line 297 – 300)

When asked whether the PHR software will give better control of a user’s health information needs, 11 (73%) of participants said yes. This was
attributed by most to the capacity of the PHR to centralize records and communication in an organized manner that results in information that is accessible, searchable, and verifiable (easily checked). A participant cautioned that better control of one’s health records only comes when there is a willingness to actively engage in the process of maintaining those records:

“If I took the initiative to proactively fill in the data, absolutely it would give me more control knowing my health history and paying attention as to what is going on in the health care system in relation to myself.” (Participant 7, Transcript Line 332 – 334)

Although the PHR provides users with quick and easy access to their health information, one participant noted that, “…whether I do anything with that [information] is up to me, but it wouldn’t hinder anything, at least” (Participant 13, Transcript Line 310). Indeed, another participant stated that control of one’s health information needs is strengthened when that information is shared with physicians and health professionals in their circle of care:

“I believe people have to take ownership of their own health and this [PHR software] is one way of doing it; and also if it is shared with the family health team or G.P. then I think people would, or I would be more inclined to do it [maintain health records] if I know my [physician] was going to find this [information] useful, rather [than] just [being] a health diary which otherwise that’s all it would be.” (Participant 8, Transcript Line 296 – 299)

Two participants did not think that the PHR software would provide better control of a user’s health information needs. One argued that the system provides information but does not explain what the meaning of the information or provide any context about it, for example:
“...you put in the information but it doesn’t explain what that information tells you; like is that blood pressure rate a good rate or a bad rate...I need a bit more information to talk to my doctor about it.” (Participant 10, Transcript Line 306 – 309)

The other dissenting participant simply did not see the PHR software as being any different than one’s ability to control health information on a paper-based file.

Finally, one participant questioned the control of health information needs with shared access, expressing concern about the possibility of health professionals entering the wrong information into one’s health record. The participant explains:

“...what is preventing...a nurse from going in and entering wrong information [about] me because they think I am someone else....one of the risks is that my records could be mixed with someone else’s.” (Participant 15, Transcript Line 430, 431, 434)

Participants were asked to describe how they would use the PHR to meet their health information needs. Most participants indicated that they would use it to chronologically document their own personal and family health histories, such as immunizations, in one centrally accessible location. The purpose for documenting health histories were mainly for monitoring one’s health or the health of family members in their care. One participant wanted to keep health documentation for their personal health diary to monitor their weight management by tracking their diet and exercise.

Some participants indicated that they would be more likely to use a PHR for more of their health requirements if the software was better linked to their health care providers. Participants’ definition of what they considered a
“link” ranged from having physicians e-mail results for PHR input to having PHRs automatically linked to physician systems for seamless downloads of information. One participant wanted to give their physician complete access to their PHR at the point of care:

“Every time I had a test result, blood pressure or whatever, every time I have a problem, I would ask my physician to [enter] data…I would just give access to my family doctor; that is the only [person] I would give access [to the PHR].” (Participant 3, Transcript Line 376 – 378, 392)

Another participant pointed out that having an automatic link between PHR and physician system would mitigate any security concerns around sharing direct access (such as providing passwords) with anyone other than the user:

“I would like [data sent directly to PHR]. I would rather that than have someone have my username and [pass]code. I would like [the link] to be automatic, that would be good, that would be my first choice.” (Participant 9, Transcript Line 454 – 456)

When participants were asked to consider whether a PHR would simplify or complicate their health care routine, 27% indicated that it would simply their routines. No participants indicated that a PHR would exclusively complicate their health care routines. One participant stated that they were neutral on the issue. The majority of participants (67%) anticipated that a PHR could both simplify and complicate their routines depending on the situation with most stating that their routines would be complicated in the short term because of the learning curve involved with familiarizing themselves with PHR software. However, the long term payoff for the time invested in learning the PHR will be a simpler, more efficient, and
standardized health care routine. This dichotomy was summarized by one participant:

“A PHR will simplify [my health care routine] in the sense that it is more accessible to me and other people, but more complicated because it will take some time to update [records]” (Participant 15, Transcript Line 458 – 459).

When commenting about the long term payoff, one participant emphasized the need to maintain data inputs, “…later on down the road it could be useful, but again, I would have to be very diligent about entering my information on a regular basis” (Participant 10, Transcript Line 339 – 340).

Other participants indicated that a PHR may be valuable for people with chronic health conditions that require frequent monitoring and tracking. Conversely, a PHR may unnecessarily complicate routines for otherwise healthy people. One participant explained:

Currently it would probably complicate [my routine] a little bit [because] it is just one more [thing] that I would need to [do]. But, if I was going to a lot of different doctors and nurses and had a [condition] that was complex, then [a PHR] would simplify things. I would not have to keep track of all these different papers and test results…or [have to] call the doctor to find out when I had my next [appointment]. I would just have all the information [in the PHR]. (Participant 14, Transcript Line 325-329)

5.5.2 Ease of Use

When asked whether the PHR software was comfortable to use, 87% of participants answered positively. Two participants indicated that they were not entirely comfortable when first interacting with the software because of unfamiliarity and the learning curve. One participant explained:
"I am never comfortable in a new situation and there is a bit of pressure in what we are doing right now. It is kind of like you said, it would take an hour of your time and my time and the fact that I could just sit by myself and play with it might have been easier. So, this is an artificial setting, but I think it is somewhat intuitive and I didn’t have any major problems.” (Participant 1, Transcript Line 407 – 410)

Of the participants that were comfortable using the system, they described it as easy to navigate, basic, straightforward, and not complex. Although they were generally comfortable with the system, one participant indicated that they were apprehensive about the medical terms and felt that having a physician provide baseline information would be helpful.

When participants were asked whether they were able to accomplish what they had set out to do during their interaction with the PHR software, 73% responded positively. One participant indicated that they were not able to accomplish their goals because of the time constraints of a 2-hour room booking and their desire to register complete and detailed information into the system. Two participants indicated that they did not reach their goals because they lacked understanding of medical terminology and felt the need to verify their entries with a medical professional.

When asked about the ability to make corrections and recover from errors to data entries, 53% of participants indicated that they were easily able to make the necessary corrections. Two participants did not observe that any errors were made on their part that necessitated any corrections. They considered the software to be intuitive such that errors would be limited to accidental entries. However, they felt that if an error was made, it would be easy to make corrections. One participant explained:
“[The software] is really clean and [dropdowns] collapse and…expand in [such] a way that [it] is easy to see what is happening. The buttons… are very self-explanatory…I think it would be difficult to make an error unless your dexterity was an issue and you accidently hit [the wrong function button].” (Participant 7, Transcript Line 398 – 402)

Three participants indicated that they found it difficult to recover from errors they made. One participant was unable to erase an unwanted entry. Another participant suggested that there should be a way to recover information that was accidentally removed. Lastly, one participant was concerned about errors that may go unnoticed, such as misspellings, and wondered whether the system has the ability to identify and bring such errors to the attention of the user.

Participants were asked to rate the organization and layout of the software. The most common observation about organization and layout was that 53% of participants commented that it was easy to find information / components / features of the PHR software. One-third (33%) of participants commented that the software was clear and simple. The suggested improvements to organization and layout included:

- Reducing some detail to simplify
- Information on the right side of screen perceived as advertisements
- Ability to tailor screens to fit personal preferences
- Information pop-up windows that were perceived as advertisements

When asked whether they would be able to quickly learn to be proficient using the PHR software, 87% of participants responded positively. One participant who did not think they could learn the system quickly stated,
“I am not sure that I could do that quickly, but that’s a reflection on me, not the system. It is how I relate to new things…” (Participant 1, Transcript Line 449 – 450). Another participant noted that computer proficiency may ease the learning curve; stating, “I think if someone is proficient in using a computer then they would be proficient in using [this PHR software]” (Participant 14, Transcript Line 365 – 366). Another barrier to learning the system quickly as noted by one participant is the ability to learn medical terminology. The participant stated:

“I have spent a limited time with [this software] and already feel like if I had something I needed to enter I don’t imagine it would be difficult. The only tricky point would be when you got into the medical jargon. I think that is where it would get a little tougher, but with the drop down menus I think it is very straightforward [when] entering [data]. I think it would get harder if [the user] did not have [a medical report] in front of them, [it] might be hard for them to remember [a medical term] because it is unfamiliar [to them].” (Participant 4, Transcript Line 525 – 531)

Participants were asked whether the PHR software was intuitive enough to learn or whether a written user manual was needed to facilitate learning. Two-thirds (67%) of participants considered the software intuitive or stated that they did not require a written user manual. This group considered the software self-explanatory for those familiar with navigating the internet. As such, in their opinion, users could quickly learn to become proficient simply by using the software. Only one participant explicitly indicated that they needed a written manual for learning. This participant explained:

“…I am one of those people that a written manual always helps and [if] I have to look online for information, I often get frustrated, but that’s
me personally not a reflection on this [software]. [Having a written manual], for whatever reason, I can look up a problem and have [a solution] in my hand, it’s helpful.” (Participant 1, Transcript Line 458 – 461)

Other participants needing support to facilitate learning, preferred to have online resources available at the point-of-need, a tutorial, or a user video. While the majority of participants did not want a written manual, they did admit that it may be useful for users who are not computer literate.

5.5.3 Satisfaction

When participants were asked whether they would use the PHR software for their health information needs, 87% answered positively. Responses ranged from emphatic “Yes, I definitely would” (Participant 5, Transcript Line 423) to a more tepid “I would consider it, certainly” (Participant 7, Transcript Line 428). Other participants specified conditions for their use of a PHR, such as:

- Information in the PHR is shared with their physician
- The PHR would only be used for what is considered to be important information
- Speed and privacy assured, “…I would definitely have no problem using the system, providing…it was up to speed and the privacy aspect [secure]” (Participant 6, Transcript Line 373 – 375).

Only two participants indicated that they would not use the PHR software mainly because they did not consider it useful for their current health information needs. One participant explained, “…I don’t see the need right now for something that is this detailed” (Participant 10, Transcript Line 407). For the other participant, while the PHR was not useful in their current
situation, a change in their health care routine may induce them to use a PHR:

“Currently… I guess I don’t have much use for [a PHR], but once I started going to a doctor regularly, even if just for checkups, I probably would [use a PHR].” (Participant 14, Transcript Line 381-382)

When asked whether they would recommend the PHR software to others, 93% of participants indicated that they would recommend the software. One participant declined to answer. The top demographics that participants would recommend the software to were family, friends, and the elderly. One participant wanted the option to share their PHR information with family. The top reasons for recommending the software was for chronic conditions and multiple health problems. Some participants felt that the PHR software was simple enough to recommend for individuals with basic computer and internet-navigation skills. The software was also recommended for those who wanted to take ownership of their health management. Although one participant indicated that they would recommend the software for those who wanted to maintain their own health records, they were hesitant to advocate the use of the PHR software for individuals with a health issue that they wanted to keep private. The participant explained:

“I certainly don’t know enough about the privacy of [this PHR software] and I noticed there was a lot of [what appeared to be advertisements] on it, which makes me question the integrity of their data and what they do with their data. So I don’t know that I would like be a huge advocate and say [people] use it when I know someone [has] a health issue that they wouldn’t want [to be] shared publicly.” (Participant 7, Transcript Line 438 - 442).
Privacy and security topped the list of concerns about using the PHR software and was cited by 37% of participants. The significance of concerns regarding privacy and security ranged from those who believed that nothing on the internet is truly secure, to those whose security concerns were mitigated knowing that banking-type encryption was applied to electronic health records. Knowing who had access to their records and having control over who could access records gave some participants an assurance of security/privacy. Others expressed privacy and confidentiality concerns around data mining for advertising purposes. Participants' comments regarding privacy and security concerns were as follows:

“I would want the level [of security to be] at least of the 128-bit encryption [grade] that the banking system seems to have as a standard...that right there would ease my concerns quite a bit...but, I would also want to know exactly who can access the [personal health] records and who has the right to look at [my health] record…”

(Participant 6, Transcript Line 405 – 408)

“My only concern would be, like I said, the integrity of the security and what they do with my data...whether somebody is actually going in, extracting, and paying any attention to what I do, likely not, but...they [may] have the capability... advertising could persuade [people] and especially at a time when you are very vulnerable if you are having health issues. That poses an ethical problem for me.”

(Participant 7, Transcript Line 465 – 466, 468 – 470, 475 – 476)

Participants who had no concerns about using the PHR software comprised 16% of responses. Another 16% of participants were concerned about data entry errors and incorrect records. The complete list of concerns about using the PHR software is shown in Table 11:
Concerns about using PHR software | Number of instances cited
---|---
Privacy / Security | 7
None | 3
Data entry errors and incorrect records | 3
System reliability | 2
Data control and use | 1
Advertisements (perceived) | 1
System maintenance | 1
System interface | 1

*Note: Several participants listed multiple concerns about using PHR software*

### CHAPTER 6 Discussion

This study was designed to identify and understand who the viable users of PHRs are, and to examine the extent to which a user’s background may influence their perceptions regarding the usability and usefulness of a PHR.

#### 6.1 The Public’s Perception of PHRs

Most people have not used an electronic PHR. However, most have kept some form of paper record containing health information about their encounters with the health care system. People with young children and those with frequent medical appointments tended to keep the most comprehensive personal records in the form of paper copies of medical reports. People who had infrequent encounters with the health care system simply received information verbally from their clinician without any electronic or paper copies of the report for personal records. Because of their infrequent encounters, they trusted that their medical records would be
retained and archived by the health care facility; therefore they did not feel a need to have copies of medical reports for their personal records. Conversely, people with frequent medical appointments find it difficult to keep track of all the information they receive and need a system to organize information essential for the management of their medical conditions. Typically, a paper-based PHR system entails a simple method of keeping paper reports in organized folders. Therefore, while the general public may be unaware or unfamiliar with electronic PHRs, they may be using a record-keeping and filing system that is in fact a paper-based PHR.

### 6.2 The Public’s Health Information Needs

The top health information needs identified by participants of the study were record-keeping / documentation, scheduling, reminders, medical information, and access to health records. Frequent users of the health care system such as parents of young children and people with chronic conditions need a way to organize the volume of medical information they receive in a manner that will help them efficiently manage their situation. This requires a system that addresses each of the top health information needs identified in the study.

Parents with young children understand the importance of keeping a record of their child’s immunizations, growth development, allergies, and medications. These records contain critical details about the child’s health profile that can inform future treatment decisions or the management of the child’s condition. A basic PHR allows vital health information to be stored in
an organized manner such that it can be easily accessed for future needs. More elaborate examples such as electronic PHRs online (i.e. Google Health and Microsoft HealthVault) allow health information to be accessed anywhere in the world and may be useful in emergency situations away from home. According to careforkids.com.au Australia’s online childcare resource, “With busy lives and hectic schedules, parents can rest easy, knowing that they have complete control over the location and accessibility of their children’s medical records” (“Online health”, n.d., para.7).

Having the capacity for self-management is an important function for people with chronic diseases. Self-management incorporates all of the top health information needs identified by participants in this study: record-keeping / documentation, scheduling, reminders, medical information, and access to health records. EHRs are used in clinical settings for chronic care management. According to Goldwater et al. (2013), “The features of an EHR to coordinate care effectively between team members, provide evidence-based clinical management, support comprehensive self-management and extend the amount of time clinical team members spend with patients underscore the importance of this technology to manage chronic care” (p.1). Electronic PHRs can play a similar role in supporting self-management at the individual patient level. PHRs can facilitate and coordinate the scheduling of appointments and reminders between patients and the various clinicians providing chronic care management.
The ability to search for medical information relevant to their health condition is an important need for any health care consumer. This is more apparent for parents with small children and people with chronic diseases. Generally, young children cannot accurately describe the symptoms they are feeling. Online PHRs can provide parents with quick and easy access to medical information that can clarify and better describe their child’s situation. Likewise, electronic PHRs can function as portals to online medical information that can provide timely information to support self-management for people with chronic diseases.

The ability for patients to access their medical records is especially valuable for chronic disease self-management. People with chronic conditions tend to have an array of clinician specialists providing care. As such, their medical records can be scattered across the healthcare system making it difficult for an individual to access those medical records. PHRs can provide a central location in which to bring together these scattered medical records. For example, Coverly (2012) describes a platform called Health Space that allows patients to securely upload their own health history and records, with patient control over who can access their personal health information.

Conversely it is also valuable for clinicians managing patients with chronic diseases to have access to patient telemetry (i.e. blood glucose levels of diabetics). According to Coverly (2012), the need for daily routine follow-up appointments can be significantly reduced because Health Space
has the ability to share real-time monitoring (i.e. glucometer readings) information between clinicians and patients with chronic diseases. In this case, Health Space functions like a PHR portal that centralizes disparate patient records, coordinates the sharing of real-time monitoring data resulting in a more proactive approach to chronic disease management. Because of shared telemetry data, clinicians can intervene in a timely manner when a critical situation is encountered. Patients also benefit beyond timely care because the ability to access their own records keeps them actively engaged in their own care. James (2013) states that “a growing body of evidence demonstrates that patients who are more actively involved in their health care experience better health outcomes and incur lower costs [to the health care system]” (p.1).

6.3 Potential PHR Users

Anyone in the general public is a potential PHR user. Almost everyone in an industrialized country has interacted with the health care system at one point in their lives. Generally, one’s first encounter with the health care system is at birth. For the most part, children are born into the industrialized world under the care of a physician, nurse, or midwife. Even in emergency circumstances where a physician, nurse, or midwife is not present (i.e. on the way to the hospital), an emergency line (i.e. 9-1-1) operator can provide over-the-phone instructions on the process of delivering a baby to an attendant helping the mother in labour. During an
emergency situation, first responders are immediately dispatched and can be at hand within minutes to stabilize the situation.

Encounters with the health care system happen both directly and indirectly. Each encounter is a data point in time that generates an account of a medical / therapeutic service provided by a health care professional or facility. These data points constitute an individual’s medical / health record. According to the College of Physician and Surgeons of Ontario (2012), medical records are living documents that tell the medical story of a patient and facilitates encounters with health professionals by enabling them to identify problems and patterns that may help determine the management of a patient’s health.

Anyone in the general population who has received a service from the health care system will benefit from properly maintained medical records. However, there are specific segments of the population that will benefit from a user maintained PHR that centralizes an individual’s health records from the wide assortment of medical record systems utilized by various health care professionals.

The potential PHR users who participated in this study averaged 37.5 years of age and ranged from 19 to 73 years old. All the participants completed at least a high school education. At the time of this study, all participants were either employed or enrolled in post-secondary studies. Participants rated themselves slightly above average in computer literacy and mainly used computers for information gathering such as research and
news followed closely by communication functions such as e-mail and social media. Interestingly, participants ranked online shopping and banking activities ahead of medical-related activities.

The majority of participants had never used an electronic PHR application. Archiving paper copies of documents provided by health professionals was identified as the most common method of documenting and storing personal health records. A minority of participants stored digitized copies of their medical documents on computer, albeit not using a PHR application.

Demographically, potential PHR users identified in this study covered a wide age range from students to recent retirees. They tended to be educated, employed, or retired from career employment. Perhaps these attributes contributed to their above average level of computer literacy and the information-gathering activities on which their computing activities were concentrated upon. This made them comfortable with the concept of a user-controlled health record. However, while the concept of an electronic PHR was appealing, those who had minimal encounters with the health care system anticipated that this may be useful for them only in the future with the onset of deteriorating health. They felt that their current generally healthy conditions with minimal health information needs did not motivate them enough to invest the effort required to maintain a PHR. Those who were motivated to invest the effort into managing a PHR tended to be individuals who needed to document chronic health conditions to facilitate care planning
with their clinicians or to coordinate payment reimbursements for treatments received. Additionally, caregivers of those with chronic conditions, such as parents of small children with complex health issues, also showed a favourable response to electronic PHRs to support the management of their current circumstances.

Project HealthDesign (2009), a national program in the United States that supports innovative ideas that may lead to significant breakthroughs in the future of health care, identified the chronic disease populations with diabetes and those with breast cancer as potential beneficiaries of PHR software. People with diabetes greatly benefit from timely advice provided about immediate actions that can be taken to avoid spikes or dips in blood glucose levels. The PHR application for diabetics was designed to capture information about daily living that is important for diabetes management, analyze the data, and provide timely advice. These actions help a diabetic function proactively in self-managing their condition. For breast cancer patients, a calendar was designed to integrate a patient’s treatment schedule with their personal schedule to coordinate their care.

According to Goldwater (2013), systems such as open source EHRs can be adapted and modified to incorporate elements of chronic care management such that changes in care delivery can be made to manage chronic disease more effectively. By extension, an electronic PHR’s components can also be adapted and modified to support the needs of different chronic disease populations to encourage proactive self-
management as seen in the examples provided by Project HealthDesign (2009).

As both caregivers and guardians, parents have a high potential for PHR use. Most parents already employ a paper-based PHR system of filing documents such as immunization records and pediatrician reports. A child’s health record is important for many reasons such as health surveillance, tracking immunizations, and pediatric development. Additionally, a child’s health records are important for clinicians (primary care and specialists), schools, and public health. Similar to chronic disease patients, children sometimes receive care from several clinicians at different facilities. Therefore, it is valuable for parents to channel medical records from disparate systems into one PHR. This is supported by a Kaiser Permanente (2013) study showing that parents of young children who used an integrated PHR were more likely by 15 months of age to have attended more of the nationally recommended well-child care visits. Additionally, the American Academy of Pediatrics (2009) supports the adoption of electronic PHR use in pediatric care as a way to improve pediatric health and empower the children’s families resulting in “care that is safer, timelier, and more effective, efficient, equitable, and patient centered” (p.406), especially for children with special needs.

At the other end of the age spectrum are the elderly who can benefit from the advantages of PHRs. This demographic is more likely than others to have multiple chronic conditions (i.e. diabetes). They also tend to take a
multitude of medications for those chronic conditions. Henceforth, a team at the University of Colorado at Denver and Health Sciences Center has used the medication function of PHRs to develop a touch screen tablet designed for older patients and their caregivers to help them manage complex medication regimens by using barcodes to generate medication lists and linking the medication list to authoritative sources of pharmaceutical information (Project HealthDesign, 2009).

Parents of children who have undergone organ transplant surgery fit into the special needs category. Therefore, they are potentially good beneficiaries for PHR use. Popkin et al. (2009) piloted eFOSTr an online specialized PHR designed to provide support to families of children with organ transplants and their healthcare providers. This specialized PHR has all the basic functions expected from a PHR such as secure data entry, data storage, and data access under the control of a child’s parent / guardian. However, this specialized PHR may be more than the sum of its parts because the ultimate objective is to provide continuity of information and education to highly motivated parents of children under life-threatening circumstances with healthcare providers from different specialized organizations that may be separated by considerable geography.

By extension, PHRs are potentially useful for adults who have undergone organ transplants. The same benefits that apply for managing the care of children can also apply for adults. Additionally, because transplant patients must also adhere to a rigorous schedule of treatments
and medications, they would benefit in the same way patients with chronic conditions benefit: proactive self-management that leads to better health outcomes.

Other potential users who may benefit from PHRs are people who want to improve health and wellness without having a specific acute or chronic health condition. This can range to from individuals who have a keen interest on healthy living to others who may be athletically training for an event (i.e. triathlon). According to Kahn, Aulakh, and Bosworth (2009), relatively simple behaviour changes such as eliminating tobacco use, regular exercise, and dietary improvements can have a crucial impact on health but these behaviours may be difficult to achieve individually. A PHR can facilitate these healthy behaviour changes by tracking the user’s progress resulting from incremental improvements in behaviour. PHRs can also link a user to others seeking similar health improvements or to supervising clinicians, thereby creating a social network to support the change in behaviour.

Participants in this study also suggested that a PHR may be useful to those who travel extensively out-of-country. Web-based PHRs, such as Google Health which was used in this study, would give travelers an easy point of access to their health records especially in emergency situations overseas.
6.4 Utility of PHRs (How would PHRs Be Used?)

After a brief introductory demonstration of an online PHR (Google Health), study participants were asked to describe how they intended to use PHR software, their responses appeared to align closely with their health information needs. For example, most participants indicated that they would use PHRs for record-keeping. This aligned precisely with most participants ranking of record-keeping as their top health information need. Analysis showed that the top 85% of expected functions for PHR software identified by participants aligned with their top 85% of health information needs. This demonstrates the participants’ capability to relate their health information needs into what they considered to be useful functions in PHR software.

After full usability testing of Google Health, participants were asked to describe how they would use PHRs to meet their health information needs; most indicated that they would use it to chronologically document their personal and family health histories (i.e. immunizations) in one centrally accessible location for the purpose of monitoring their health or the health of a family member in their care (i.e. parents for children or caregivers for the elderly).

Clearly, participants were looking for ways to organize their health information in a way that will help them meet their health information needs. The foundation in this process is to assemble the components of fragmented health records into one centralized and easily accessible place. Other PHR functions identified by participants that follow from having centralized records
include: surveillance of health condition(s), access and control of records, scheduling alerts and reminders, repository for test results, and statistics.

The starting point for any PHR is to have the data (i.e. health records) to drive the decision-support functions (i.e. alerts and reminders) that allow people to take actions that promote self-management for improved health outcomes. In order to be effective at promoting self-management, Bates and Bitton (2010) suggest that PHRs “should include tools that enable patients to communicate with [health professionals] and to track specific [health] parameters” (p.618). According to Project HealthDesign (2009), “Effective PHRs are not about the record, they’re about the actions they enable” (p.10).

Some participants indicated that they would be more likely to use a PHR if the software was linked to their health care provider(s). However, the participants’ definition of what they considered a “link” varied considerably from simply having physicians e-mail results for PHR input to having PHRs automatically tethered to physician systems for seamless downloads of information. Indeed, when PHRs facilitate the sharing of information between patient and provider, they become “dynamic resources for action” (Project HealthDesign, 2009, p.4). Without linkages, PHRs are simply static data repositories. A critical benefit of PHRs identified by Tang et al. (2006) “is that they provide an ongoing connection between patient and physician, which changes encounters from episodic to continuous, thus substantially shortening the time to address problems that may arise” (p.123). It is the consistent continuity of information facilitated by a PHR in the form of alerts,
facts, advice, and instruction that promotes active participation of individuals in their health and encourages effective self-management for those with chronic conditions. According to James (2013), better health outcomes and lower health care costs occur when patients have the skills, ability, and willingness to manage their own health.

6.5 **PHR Usability and Functionality (The effect of user background on perception of PHR usefulness)**

This study demonstrated that an individual’s health condition has a stronger influence on their perceptions about the usefulness of PHRs than does their background. None of the study participants indicated that a PHR would exclusively complicate their health care routines. However, the majority of participants admitted that learning how to use a PHR would initially complicate their health care routines in the short term. In turn, the expected long term payoff would be a simpler, more efficient, and standardized health care routine. The perceived payoff may be well in the future for healthy individuals because their simple health information needs may be unnecessarily complicated by a PHR’s learning curve. Therefore, healthy individuals will perceive that a PHR will only become useful for them in the future as they potentially develop more complex health conditions. Conversely, individuals with complex health care needs may perceive a more immediate payoff because of the PHR’s ability to centralize records and communication in an organized manner that produces health information that is accessible and searchable. Indeed, all the benefits identified that
PHRs can provide to facilitate self-management of chronic conditions will have an impact on how individuals with chronic conditions perceive PHR usefulness. They will perceive the PHR learning curve to be an investment with immediate gains rather than an appliance that will become useful sometime in the future.

The majority of participants indicated that a PHR would give them better control over their health information needs. Indeed, the precise characteristics of control are noted in an electronic PHR’s ability to centralize disparate records, coordinate communication, and facilitate scheduling with alerts and reminders, thereby advancing two-way information sharing between patients and health care providers. The importance of two-way information sharing was recognized by some participants because they indicated that the value of participating in the management of one’s health is strengthened when the health information is shared with those in their circle of care. Archer, et al. (2011) support this view because they describe the ideal PHR as one that is “integrated with the healthcare system” (p.519).

Most participants indicated that they found the electronic PHR used in this study (Google Health) to be comfortable to use. They described Google Health as easy to navigate, basic, straightforward, and not complex. They explained that the layout of the Google Health screens were well organized, making it easy to find information, components, and features of the software. Clearly, with a self-disclosed computer literacy of slightly above average, Google Health was an adequate fit for most participants’ computing abilities.
It is possible that participants were competent at browsing the internet and were accustomed to using Google products (i.e. Gmail, Google Calendar, Google Chrome browser) such that navigating Google Health conveyed a sense of familiarity with Google’s other internet-based applications. The familiarity with a vendor’s family of products may be an intentional design approach to emphasize the brand (i.e. Google). For example, Liu et al. (2011) relate how users in their PHR investigation describe Microsoft’s PHR (HealthVault) as having a Windows-like feel to the application.

Consequently, the majority of participants felt that they could quickly become proficient in using Google Health. They indicated that the software was intuitive enough that a written manual would not be necessary in order to become a proficient user. Therefore, this study shows that users with at least an average level of computer literacy, using intuitive software with good usability, can quickly learn to be proficient at using an electronic PHR. Certainly, several participants indicated that, in their opinion, Google Health was simple enough to recommend for individuals with basic computer and internet-navigation skills. Acquiring the proficiency to use web-based applications is important because sources of health information are increasingly being made available through the internet, prompting Kahn et al. (2009) to identify computer literacy and internet access as policy priorities that are essential to promote the wider adoption of PHRs by the general public. Additionally, Mitchell and Begoray (2010) emphasize that a person’s health literacy and computer skills must be matched to PHR software if that
person is to benefit from a PHRs ability to promote self-management and better control (autonomy) of one’s health information needs.

The majority of participants believed that Google Health was a useful PHR for their health information needs. However, the point at which participants would integrate an electronic PHR into their health care routine may be influenced by their current health conditions and needs. Those with chronic conditions requiring a complex circle of care will tend to adopt the use of an electronic PHR sooner than healthy individuals with simple health needs. This viewpoint is highlighted in the participants’ recommendations regarding PHRs to other people. Participants indicated that they would recommend Google Health to family, friends, and the elderly, particularly those with chronic health conditions and multiple health problems.

6.6 Challenges

During the introductory demonstration of Google Health, participants were asked to identify any perceived challenges to using an electronic PHR. The perceived challenges identified were: data quality, reliability of data sources, security, software aesthetics, and user motivation (or lack thereof). After they had spent some observation time using Google Health and exploring its features, participants still had the same concerns as what they had originally perceived during the introductory demonstration. Interestingly, after the observation session, privacy and security became the top concern while data quality and reliability became secondary and equal (in the number of instances cited) to having no concerns.
Data security and identity protection are critical issues put forward by Kahn et al. (2009) as central to the promotion of PHRs for widespread acceptance and adoption. Potential PHR users may be hesitant to adopt an electronic PHR for their health information needs if they are not convinced that their personal data is secure and that their personal identity is protected. Additionally, participants in this study noted that, as PHR users, they would like to control who will have sharing/viewing access to the data contained in their PHRs. In the opinion of Kahn et al. (2009), “Consumers who adopt PHRs will require that the information be protected and private; that ownership lie solely with the consumer; that storage and use of the data be approved by the patients; and that the data be easily portable and in a format that is understandable” (p.375).

Data quality and reliability are directly related to health literacy and the complexity of information systems. Liu et al. (2011) found that patients and clinicians alike expressed concerns about the potential for patient-created mistakes in managing medical data. Family practice physicians are cautious “about the quality of the information contained on PHRs and indicated that this would limit their use clinically” (Yau, Williams, & Brown, 2011, e181). Additionally, the needs of patients and clinicians are often diametrically opposed, with patients complaining that PHRs are too complex and physicians deploring overly simplistic applications (Liu et al., 2011).

Participants in this study also expressed concerns about their lack of health literacy and medical terminology potentially resulting in incorrect data
entry and transposition errors. Other participants felt that adding their lay-person perspective may dilute the validity of their medical record. Physicians are especially concerned about patients experiencing unnecessary anxiety as a result of being unable to interpret medical information yet are responsible for data entry and management of their PHRs (Yau et al., 2011). To mitigate concerns about data quality and health literacy, Liu et al. (2011) suggest that PHRs, which are typically designed for the general public, keep specific medical jargon as simple and basic as possible. In addition to avoiding difficult medical jargon, Mitchell and Begoray (2010) suggest making use of relevant examples to improve reading comprehension by lay-persons. One participant in this study noted that while Google Health provides a wealth of information, it does not provide any explanation or context about it.

PHRs are viewed by some physicians as a potentially disruptive technology to their clinical workflow. Yau et al. (2011), note physician concerns about increases in workload and uncertainties about physician obligations to their patients with respect to PHR use. For example, a person’s ability to control who they share their PHR’s information with, could potentially have them exclude a certain physician within their circle of care resulting in that physician making clinical judgments with incomplete information thereby leading to unintended negative consequences for the patient (Do, Barnhill, Heermann-Do, Salzman, & Gimbel, 2011). As such, the clinical relevance of PHRs is at issue. To illustrate, Liu et al. (2011)
suggest that PHRs have the potential to provide large amounts of unprocessed patient-controlled health data that must be analyzed and verified by the physician to ensure that the data does not increase the risk for medical errors, and to determine which components of the data that a patient has given them is clinically reliable.

Beyond the challenges of privacy and security, data quality and reliability as well as health and computer literacy, is the issue of a user’s personal motivation to effectively manage a PHR with clinically relevant information. Despite the accolades about PHRs empowering health consumers, facilitating self-management of chronic conditions, and linking patients to clinicians in their circle of care, a PHR is only as effective as its user. The level of motivation to manage a personally controlled health record was noted by several participants in this study. They recognized that a PHR, like any tool, is only as good as the person using it. Based on this, a lay-person is potentially the weak link in the chain of PHR users because it is at the personal level that the access and sharing functions for PHR data is controlled.

In the scenario of this study, where Google Health was not linked to the medical record system of a health provider, it will typically be necessary for the user to transfer digital files or manually enter paper data received from the health provider’s system. A user’s motivation to engage in this manual process directly determines the quality of data in the PHR. Data accuracy notwithstanding, any gaps in the record due to a user’s lack of
motivation to keep pace with incoming data may deem that user’s PHR to be clinically irrelevant. In healthy patients, the motivation may be low due to the disproportionate amount of manual-entry effort required in relation to the potential benefits in the future. However, the level of motivation may be high in patients with chronic and complex health conditions due to the more immediate benefits realized.

6.6.1 Why did Google Health Fail?

Google Health was used in this study because, as an internet-based electronic PHR, it was available anywhere with an active internet connection and it was accessible using any of the major computer operating systems (Windows, Mac, Linux). At the time of this study, Google Health was the only major online PHR available free-of-charge to Canadian users (all the participants in this study were based in Canada). Google decided to permanently discontinue Google Health on January 1, 2012. Users had until January 1, 2013 to transfer the data from their Google Health accounts to other systems or to extract as a comma-separated values (CSV) file. According to Google, as of January 2, 2013, all Google Health accounts have been systematically destroyed and Google is unable to recover Google Health data for any user.

The majority (87%) of participants in this study indicated that they would be willing to use Google Health for their health information needs. A greater majority (93%) indicated that they would recommend Google Health to other people. However, the willingness of participants in this study to use
and recommend Google Health did not extend to the general public. In the end, according to Google, they were unable to create the impact they wanted with Google Health but continue to support the role information plays in healthcare and in improving how people manage their health (Brown & Weihl, 2011).

McGee (2011) suggests 5 reasons why Google Health failed: (1) Consumers were not interested or did not know what a PHR is; (2) Consumers who are aware of PHRs tend to use physician, hospital, and even health-plan portals to keep track of their records; (3) Lack of provider relationships and other data sources; (4) Google lacked other communication and convenience features that patients look for when dealing with their health information electronically; and (5) Privacy and security concerns by consumers, whether warranted or not.

The results of this study somewhat support McGee’s (2011) first point suggesting lack of consumer awareness of PHRs. The majority of participants in this study indicated that they had not used an electronic PHR. McGee’s (2011) second point about consumers relying on existing health provider systems, is supported by the discussions in this study that people without chronic diseases or multiple health conditions see limited present value in using a PHR because their low and sporadic utilization of the health care system. McGee’s (2011) third point notes a lack of provider relationships. This is further exacerbated in Canada, where the study was conducted, because there are no known provider linkages to Google Health.
However, participants in the study emphasized that in order to be relevant for their health information requirements, PHRs need to have good linkages with their health care provider’s systems. On McGee’s (2011) fourth point about the lack of communication and convenience features, the study participants put scheduling and reminder functions high on their priority list of health information needs. McGee’s (2011) final point about privacy and security are also supported by this study in that most participants listed privacy and security the top concern about using Google Health. This view is also supported by Dolan (2011) who states that consumers are generally wary about trusting large corporations like Google or Microsoft with their personal health information.

Dolan (2011) introduces the argument that Google Health’s consumer-centric bottom-up approach kept clinicians out of the design loop. However, Chase (2011) additionally suggests that physician compensation models also played a part in Google Health’s demise because fee-for-service typically requires that physicians see patients face-to-face. This face-to-face requirement does not take advantage of a PHR’s ability to coordinate care and channel some basic patient health telemetry and data. According to Chase (2011) doctors consistently indicate that up to two-thirds of their patient interaction time does not need to be face-to-face and that they can deliver high quality care without necessarily being in the same room as the patient. PHRs can support such practice, but physician compensation models must be revised to enable this shift in practice.
6.7 Limitations of the Study

This study was limited by several factors worth noting. First, the participants in this study generally had a high level of academic education. All participants completed at least a secondary level education. At the time of the study, those who did not complete a post-secondary academic education were enrolled in post-secondary studies at the college or university level. However, those with a vocational education did not participate in this study. This was because responses to the study invitation were only received from university students, white-collar professionals, and retired white-collar workers. If PHRs are to be adopted by health consumers, all educational categories of the population should be included as participants in future usability and usefulness studies.

Second, the participants in this study, as an aggregate, had an above-average level of computer literacy. According to Barrett (2013), a recent study by the Organization for Economic Co-operation and Development (OECD) showed that 15 percent of adult Canadians were unable to perform basic computer tasks and 20 percent of Canadian respondents to the OECD survey could not complete the assessment using computers. Therefore, the results from this study only account for users with at least an average level of computer literacy. As such, the opinions expressed are not an accurate representation from all potential PHR users. This gap could potentially exclude those with lower computer literacy levels from gaining the benefits of PHR use. The Canadian Institutes of Health
Research (2004) linked literacy with health and stated that with the increased use of computers to learn about health, those who find it difficult to use computers may have more health problems than those who are computer literate. Therefore, by omitting those with lower literacy levels from participating in usability studies pertaining to PHRs, we miss the opportunity to design systems that would also benefit them.

Third, clinicians were not participants in this study. PHRs are a conduit for the exchange of information between the health consumer and their health care provider(s). The implications of not having clinician input into PHR usability put the clinical relevance of the PHR data into question. Patients cannot benefit from PHR data and health outcomes cannot be improved if physicians will not / cannot utilize PHR data for clinical management decisions because PHR data is not clinically relevant or PHR usability impedes physician clinical workflows.

6.8 Implications for Future Study

In the future, greater effort should be made to recruit participants with vocational education in usability studies involving PHRs. Advertising should be concentrated where tradespeople are more likely to be receptive to a study invitation. Additionally, a study invitation especially geared toward tradespeople should mitigate any hesitancy toward participating in an academic study.

The same suggestions listed for those with a vocational education should also apply to the recruitment of those with low-to-limited computer
literacy levels. A study invitation should be geared toward those who have difficulty using computers and a more thorough sample demonstration should be considered. The end result should be the inclusion of those with low computer literacy levels in PHR studies to capture their opinions about usability such that PHR systems can be designed to provide a health benefit to them as well.

Future studies on the usability and usefulness of PHRs should take a focused look at the specific needs of those with chronic conditions, the elderly, parents of young children, and transplant patients. These are the populations identified in this study as having the most benefit to gain by adopting PHRs into their health care routines. Understanding their specific needs could lead to specialized PHRs that are tailored to those specific needs.

Clinicians, specifically physicians, should be included in future PHR usability and usefulness studies. If PHR data is not clinically relevant, physicians will not use it as part of their clinical management decision-making process. If the PHR application is difficult to navigate and impedes physician workflow, the software will not be used. If PHRs are not used by physicians, the full benefits discussed in this study will not be realized by their patients. Therefore, future studies should consider the potential effects on physician workflow as a result of including PHRs as part of the clinical decision-making process. Furthermore, the effect of current compensation
models such as fee-for-service on physician behavior toward incorporating PHRs into their workflow should be contemplated.

Automation of data exchange and PHR linkage to clinician medical record systems were important characteristics identified by participants of this study regarding PHR improvements. Therefore, future usability studies should consider linked or tethered PHRs as a next step to the stand-alone system used in this study. Finally, the recent proliferation of mobile telecommunication devices (i.e. smartphones and tablets) should lead future studies to consider the use of mobile technologies as vehicles for PHRs with the accompanying usability implications of using smaller transportable devices.

6.9 Implications for Health Informatics Education

The major health informatics curriculum knowledge domains identified by COACH: Canada’s Health Informatics Association (2013) were Health Systems, Health Information Processes, Information and Communications Technologies (ICT), Research, and Pedagogy. Electronic health records such as PHRs encompass the areas of Health Systems, Health Information Processes, as well as ICT. One of the findings of this study is the need to connect and centralize disparate health records located in various providers’ systems into one patient-controlled record in the form of a PHR. To enable this, new health informatics professionals must accept PHRs as part of a longitudinal patient health record ecosystem. Additionally, because electronic health records encompass three out of five health informatics
knowledge domains, electronic health records should not be discussed in a disconnected context such as EMRs only for primary care providers, EHRs only for health systems, and PHRs only for personal use. Rather, these systems should be taught in the context of a longitudinal health record with each application comprising unique functions under one ecosystem. This will cultivate interconnectivity between record systems and encourage shared standards that facilitate timely communication and expeditious transfer of electronic health information throughout an individual’s circle of care.

**6.10 Implications for Health Informatics Practice**

Health literacy of PHR users was identified in the study as a challenge to the meaningful use of PHRs. A lack of understanding of medical terminology could potentially result in incorrect data entry and transposition errors thus directly impacting PHR data quality. Therefore, an opportunity exists for health informatics professionals to design PHR systems that contain less clinical jargon and utilize more commonly understood medical terms in order to improve data quality. However, this is a paradox of needs because if a PHR system becomes too simplistic in its attempt to appeal to consumers, the accompanying clinical relevance for clinicians may become diluted. The challenge for health informatics professionals will be to find the ideal intersection where PHRs are user friendly to consumers yet remain clinically relevant for clinicians managing their care.
Finally, the study established that PHRs are considered by the study participants to be useful tools in meeting their health information needs. The challenge is maintaining the motivation of PHR users to incorporate the management of health data into their healthcare routines. It is often easy for consumers to become excited about a new software application. The consumer electronics life cycle appears to become shorter with each new hardware and software release. However, an electronic PHR should be more than the newest healthcare fad. As such, it is incumbent on health informatics professionals to design systems that will continue to appeal to healthcare consumers. Incorporating new vehicles for PHRs such as mobile devices is one way to shift the paradigm. More importantly, however, PHRs should become easier to use, automatically tethered to feeder systems, and available in real-time all within a secure environment. Fast-paced consumers accustomed to instant communications, real-time data access, and secure information sharing will demand that healthcare information tools such as PHRs keep up with these demands if they are to be relevant to modern-day living.
References


Appendix A

Office and desk setup for observation and interview
Appendix B

Demographic Survey Questions

The questionnaire could include, but would not be limited to the following questions for all study participants:

(1) What is your age?

(2) What is your sex? (i.e. male or female)

(3) What is your occupation? (i.e. physician, accountant, engineer, student)

(4) How long have you been working at your occupation?

(5) What is the highest level of education attained? (i.e. primary, secondary, post-secondary, graduate, post-graduate)

(6) In what discipline are / were your educational studies concentrated? (i.e. medicine, allied health, computer science, business, social sciences, arts, etc.)

(7) On a scale of 1 to 5, what is your level of computer literacy? (1=illiterate; 5=expert)

(8) How often do you use computers? (i.e. daily, weekly, monthly, never).
Appendix C

Interview prompts could include, but would not be limited to:

(1) What role do computers play in your day-to-day routine? (i.e. news information, online shopping, social networking, research, work, etc.)

(2) What type of computer devices do you use? (desktop, laptop, netbook, smartphone, tablet, etc.)

(3) What percentage of your computer time do you spend on the internet?

(4) Do you prefer to use online applications on the internet or stand-alone software on your computer? Explain / justify your choice?

(5) How do you currently document / maintain / store your personal health records?

(6) Have you ever used an electronic personal health record? If yes, explain what you used it for?

(7) What are your current health information needs? (i.e. need to store records, need access to disease & medication information; need scheduling / reminder for medical appointments, etc.)

(8) Who would you be willing to share your personal health information with? (i.e. healthcare professional(s), employer, government, insurance company, etc.)

(9) Which healthcare professionals (if any) would you be willing to share your personal health information with? (i.e. physicians, nurses, allied health professionals [imaging technologists, physiotherapists, lab technicians], alternative health professionals [chiropractor, naturopath, midwife], etc.)

(10) Would you be willing to share your personal health information electronically with healthcare professionals? Why, or why not?

(11) What concerns (if any) would you have about sharing your personal health information electronically with a healthcare professional?

(12) Would you be willing to maintain and update your own personal health records electronically? Why, or why not?
Appendix D

Interview prompts following a demo of the PHR software:

(1) Do you think you could use this PHR software?

(2) If willing to use this PHR software, describe how you would use it and for what purpose would you use it?

(3) Will using this software meet your health information needs?

(4) Do you perceive any challenges / difficulties / issues in using this software to meet your health information needs?
Appendix E

During observation, tasks the participants will be asked to execute within the electronic PHR system could include (but are not limited to) the following (User Centric, Inc., 2009):

1) Create an account and enter medical data
2) Customize how information is viewed (i.e. by date, by condition, etc.)
3) Upload a medical document
4) Update personal profile with new medical conditions
5) Upload information from medical devices
6) Learn about side effects to medications being taken
7) Learn about symptoms one may be experiencing
8) Locate a physician or specialist
9) Share medical information with a physician
10) Share medical information with healthcare providers (non-physician)
11) Create an account for a spouse or dependent
Appendix F

Post-Interview prompts could include, but would not be limited to the following:

Usefulness

(1) Do you think the system has all the functions and capabilities you expect a PHR to have? (i.e. Does it do everything you expect a PHR to do?)

(2) What did you like about using the system?

(3) What do you think needs improvement?

(4) Do you think this system will meet your health information needs / requirements?

(4) Do you think this system will give you better control of your health information needs / requirements?

(5) How would you use this system for your health information needs / requirements?

(6) Do you think this system will simplify or complicate your healthcare routine?

Ease of Use

(1) Did you feel comfortable using the system?

(2) Were you able to complete the assigned tasks easily, using the system?

(3) When a mistake was made, was it easy to recover from the mistake and make a correction?

(4) Was the organization / layout of information on the system screen clear and easy to find?

(5) Do you think you could quickly learn to become proficient in using the system on your own?

(6) Was navigation within the system intuitive or would you need a written instruction manual?
Satisfaction

(1) Would you use this system for your health information needs / requirements?

(2) Would you recommend this system to others for their health information needs / requirements?

(3) Would you have any concerns about using this system? If so, what would be those concerns?
Appendix G

Participant Consent Form

The Effect of Stakeholders’ Background on Perceptions of Usability and Usefulness on Personal Health Records

You are invited to participate in a study entitled “The Effect of Stakeholders’ Background on Perceptions of Usability and Usefulness on Personal Health Records” conducted by Desmond Guarin, a graduate student (MSc candidate) at the School of Health Information Science, University of Victoria. If you are interested in participating in the study, or if you have any further questions, you may contact Mr. Guarin by telephone at (416) 779-3675 or by email at dguarin@uvic.ca. This research is in partial fulfillment of the degree requirements for the Master of Science in Health Informatics at the School of Health Information Science, University of Victoria.

Purpose and Objectives
The research study will investigate the information needs of personal health record (PHR) users, such as healthcare consumers and healthcare professionals. The study will also investigate how user backgrounds affect a user’s perception of PHR usability and usefulness. Additionally, the study will probe into whether the information contained within a patient-controlled electronic record such as PHRs are viable data supplements for healthcare professionals using current conventional record keeping programs.

Importance of this Research
Electronic PHRs are being developed to allow for the collection, recording, and analysis of personal health information over time. This research will assess whether such an approach will provide useful information for users of the system on both sides of the circle of care (i.e. lay-public and healthcare professionals).

A proper understanding of who will actually get value from using PHRs is important because that understanding will drive the innovation to make PHRs usable, useful, and ultimately relevant for the intended users. The challenge will be in designing a system with universal appeal that ensures accessibility and usability for a variety of users without being excessively complex.

Participants Selection
You are being asked to participate in this study because you:

a) are a lay-person, such as a healthcare consumer or patient
b) are a healthcare professional such as a physician, registered nurse, or allied health professional
Participant Consent Form

What is involved
If you agree to voluntarily participate in this research, your participation will include the following 3-step process:

(1) INTERVIEW: When YOU ARRIVE FOR THE STUDY, the objectives of the research will be explained AND YOU will be given a consent form to READ and sign before the session can continue. YOU will then be given a short demographic questionnaire to fill out. With paperwork complete, YOU WILL BE INTERVIEWED ABOUT YOUR HEALTH INFORMATION NEEDS AND ANY PREVIOUS EXPERIENCES (IF ANY) WITH PERSONAL HEALTH RECORDS (PHRs). THE INTERVIEW WILL BE VIDEO AND AUDIO RECORDED.

(2) OBSERVATION: After completing the interview, YOU will be introduced (via a brief demonstration) to an electronic PHR system AND ASKED A FEW QUESTIONS ABOUT YOUR IMPRESSIONS OF THE SYSTEM. YOU WILL ALSO BE ASKED to enter dummy (i.e. fictitious/hypothetical patient data) health data from medical reports such as sample immunization records or laboratory reports into the PHR system. During the dummy data entry process, YOU will be asked to comment aloud about YOUR impressions of the system’s usability for what they find both challenging as well as effortless. THE COMPUTER SCREENS WILL BE VIDEO-RECORDED AND YOUR VERBAL COMMENTS WILL BE AUDIO-RECORDED. THE VIDEO AND AUDIO DATA WILL BE USED BY THE RESEARCHER TO ASSESS THE USABILITY OF THE PHR SYSTEM (I.E. THE RESEARCHER WILL REVIEW THE INFORMATION CONTAINED IN THE VIDEO AND AUDIO DATA TO DO THE USABILITY ASSESSMENT).

(3) POST-TASK INTERVIEW: Following the observation segment, YOU will be interviewed about YOUR experience and impressions of the PHR system. THE INTERVIEW WILL BE VIDEO AND AUDIO RECORDED.

Inconvenience
Participation in this study may cause some time and travel inconvenience to the participant. However, the study is not required to take place during normal business hours, and may be scheduled at a time mutually convenient for the participant and the researcher. Participation in the study will take approximately 60 - 90 minutes of the participant’s time.

Further inconveniences would include traveling to the office where the interviews will take place at the University of Victoria. A minimal monetary inconvenience to pay for parking at the rate of $1.00 per hour or to take public transit to the University of Victoria may also occur.
Health Information Science
University of Victoria

Participant Consent Form

Risks
There are no known or anticipated risks to the participant for taking part in this research study. Participants will access the personal health record (PHR) to be used for the study by using ordinary personal computers that are common in everyday personal and professional life. Interaction with the PHR using a personal computer will involve the normal keystrokes and pointer movements used with other commonplace software (i.e. word-processing, spreadsheets, databases) and internet browsing. Therefore the "probability and magnitude of possible harms" to accessing a PHR for the purpose of this study is considered to be within the "aspects" of participants' daily life.

Benefits
A proper understanding of who will actually get value from using PHRs is important because that understanding will drive the innovation to make PHRs usable, useful, and ultimately relevant for the intended users.

Participation in this study may help software developers (i.e. healthcare informaticians & computer scientists) design electronic tools that exploit the transformative potential of PHRs to facilitate the process of empowering healthcare consumers towards a proactive approach of managing personal health and wellness. Beyond empowerment, software developers could expand the capacity of PHRs to enhance the relationship between patients and physicians that result in shared decision making on issues of disease management and treatment. A functional, relevant, and interoperable PHR is purported by experts to produce efficiencies, cost savings, and improved outcomes to the healthcare system.

Compensation
Participation in this study is completely voluntary. However, subjects will be compensated $20 for the time they spend in participating in this study. IF A SUBJECT WITHDRAWS FROM THE STUDY DURING DATA COLLECTION, COMPENSATION WILL BE PRO-RATED (i.e., $5 FOR EVERY 15 MINUTES UP TO THE FULL AMOUNT AT 60 MINUTES). IF A SUBJECT WITHDRAWS FROM THE STUDY AFTER DATA COLLECTION, FULL COMPENSATION WILL BE GIVEN.

Voluntary Participation
Participation in this research study is completely voluntary. Should you decide to participate in the study, you may withdraw from participation at any time during the study without consequence. If you withdraw from the study your data will not be used and all your data (electronic, digital, and paper-based) will be destroyed.

On-going Consent
To ensure the participant’s on-going consent for participation in the study, the researcher will remind the participant throughout the study that participation is voluntary and that the participant is free to stop, withdraw, or refuse to participate in the study at any point in time, and that there will be no repercussions whatsoever associated with a participant’s withdrawal from this study.
Anonymity
Study participants' names will not be used in relation to the information gathered for the research study or any reports and publications derived from the study. All personal & background information, paper-based questionnaire responses, and interview data contained in digital audio/video recordings will be stored in a secure room at the School of Health Information Science on the University of Victoria campus. Electronic data stored on computers will be password-protected. Paper-based data and other data not contained on a computer will be stored in a locked cabinet at the secure location on the University of Victoria campus. All paper-based questionnaires, and digital audio/video recordings will be assigned an alpha-numeric code number. As such, a participant's name and any unique identifying information will not be used in conjunction with the paper-based questionnaire, or with the digital audio/video recordings for the study.

Confidentiality
Confidentiality of the participant and confidentiality of the data will be protected by the researcher. All information provided by the participant for the purposes of this study will be kept confidential. Only the researcher (Desmond Guarin) and thesis supervisor (Dr. Andre Kushniruk) will have access to a participant's name and/or any other information that might identify the study participant.

Dissemination of Results
It is anticipated that the results of this study will be shared with others in the form of presentations, conference papers and journal publications. Participants may request a summary of the study findings once the study is completed.

Disposal of Data
Data from this study will be disposed of in an appropriate manner. During the research study, all the data will be stored in a secure location at the School of Health Information Science on the University of Victoria campus. Electronic data stored on computers will be password-protected. Paper-based data and other data not contained on a computer will be stored in a locked cabinet at the secure location on the University of Victoria campus. Data will only be stored for the duration of the study period to complete this research. All reasonable security measures will be taken until the completion of the research study, at which time all paper-based data will be shredded and all digital data (including video & audio recordings) will be electronically deleted.

Contacts
The contact individual regarding this study is the researcher, Desmond Guarin. He may be contacted by phone at (415) 779-3675 and by e-mail at dguarin@uvic.ca. Additionally, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria by phone at (250) 472-4645 or by e-mail at ethics@uvic.ca.
Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

Name of Participant ____________________________ Signature ____________________________ Date _____________

A copy of this consent will be left with you, and a copy will be taken by the researcher.
Appendix H

Ethics Certificate of Approval

Certificate of Renewed Approval

<table>
<thead>
<tr>
<th>PRINCIPAL INVESTIGATOR: Desmond Guarin</th>
<th>ETHICS PROTOCOL NUMBER: 10.262</th>
</tr>
</thead>
<tbody>
<tr>
<td>UVic STATUS: Master's Student</td>
<td>Minimal Risk - Delegated</td>
</tr>
<tr>
<td>UVic DEPARTMENT: HEIS</td>
<td>ORIGINAL APPROVAL DATE: 06-Jul-10</td>
</tr>
<tr>
<td>SUPERVISOR: Dr. Andre Kushniruk</td>
<td>RENEWED ON: 02-Jul-13</td>
</tr>
<tr>
<td></td>
<td>APPROVAL EXPIRY DATE: 05-Jul-14</td>
</tr>
<tr>
<td>PROJECT TITLE: The Effect of Stakeholders' Background on Perceptions of Usability and Usefulness on Personal Health Records</td>
<td></td>
</tr>
<tr>
<td>RESEARCH TEAM MEMBERS: None</td>
<td></td>
</tr>
<tr>
<td>DECLARED PROJECT FUNDING: None</td>
<td></td>
</tr>
</tbody>
</table>

CONDITIONS OF APPROVAL

This Certificate of Approval is valid for the above term provided there is no change in the protocol.

Modifications
To make any changes to the approved research procedures in your study, please submit a "Request for Modification" form. You must receive ethics approval before proceeding with your modified protocol.

Renewals
Your ethics approval must be current for the period during which you are recruiting participants or collecting data. To renew your protocol, please submit a "Request for Renewal" form before the expiry date on your certificate. You will be sent an emailed reminder prompting you to renew your protocol about six weeks before your expiry date.

Project Closures
When you have completed all data collection activities and will have no further contact with participants, please notify the Human Research Ethics Board by submitting a "Notice of Project Completion" form.

Certification

This certifies that the UVic Human Research Ethics Board has examined this research protocol and concluded that, in all respects, the proposed research meets the appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Participants.

Certificate Issued On: 02-Jul-13