ELECTRONIC PERSONAL HEALTH RECORDS:
A MATTER OF TRUST

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By

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ABSTRACT

Early trials of Electronic Personal Health Records (ePHRs) show they provide two strong benefits: better healthcare outcomes and lower taxpayer costs. However, consumers are concerned about the possible loss or misuse of personal health data. For people to adopt ePHRs, they must trust both the system and the operating organization. Trust has been assessed in many ways, in combination with risk, motivation, and other technology adoption issues, but not in a comprehensive model incorporating all of these factors focusing on ePHRs. The model presented here studies consumers' likelihood of adopting ePHRs, combining trust, distrust, risk, motivation, and ease of use; as well as their perceptions of government, software vendors, and physicians as providers of ePHRs. Based on the Technology Acceptance Model, and incorporating elements of trust-distrust dualism and perceived risk, the model was tested empirically using survey data from 366 Canadian adults; a group of 58 responses was extracted to validate the survey scales, while the remaining 308 responses were used for analysis. The model explains 52 percent of the variance in the intention ⁇⁇⁇⁇⁇⁇⁇⁇⁇⁇ÿ⁇⁇⁇⁇⁇⁇Ĉ⁇⁇⁇⁇⁇⁇⁇⁇⁇⁇⁇Ĉ⁇⁇⁇⁇⁇⁇⁇⁇⁇Ĉ⁇⁇⁇⁇⁇⁇⁇⁇⁇⁇Ĉ⁇⁇⁇⁇⁇and distrust, and strong positive effects from trust and perceived usefulness. The combination of conventional structural assurances and the source of the example ePHRs presented to participants either engendered trust and an intention to use an ePHR , or heightened distrust and perceived risk, discouraging an intention to use. Other findings include further evidence that trust and distrust are different constructs, not ends of a spectrum; that Canadians' relationship with their healthcare system is complex; and that the risks in using an online system can be overcome by the perceived benefits. Open-ended responses show that people generally trust their doctors, but are sceptical that a doctor could provide a secure ePHR. Responses indicated that participants liked the consolidation of data and ease of access, but feared loss of privacy.

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LIST OF ABBREVIATIONS USED

AVE	The Average Variance Extracted, a measure of the variance in a latent variable construct captured from its inputs compared to measurement error; a measure of discriminant validity
CHI	Canadian Health Infoway; a not-for-profit organization, created to accelerate the development and adoption of electronic health record projects in Canada
CR	Composite Reliability, a statistical measure of internal consistency in a survey construct
ePHR	Electronic Personal Health Record, a patient-centred, longitudinal collection of heath information stored in a central repository and available to authorized individuals
IS	Information Systems, the study of the hardware and software systems used to collect, store, organize, and analyze information
MOHLTC	(Ontario) Ministry of Health and Long Term Care, the administrator and payer for health care in the province of Ontario
PEOU	Perceived Ease of Use, a construct from the Technology Acceptance Model that captures the user's perception of the complexity and level of effort involved in using a technology
PHR	Patient Held Record, a collection of health information in the control of a patient; the format is usually paper, but portable electronic storage (e.g., memory card) may be used
PLS	Partial Least Squares, a variance based method of Structural Equation Modeling
PU	Perceived Usefulness, a construct from the Technology Acceptance Model that captures the user's perception that using the technology would contribute to the performance of their activities
SA	Structural Assurances, the markers that make the appearance of something "look right", such as a lock symbol on a secure website
SEM	Structural Equation Modeling, a statistical method of determining relationships between constructs
TAM	Technology Acceptance Model, a theory of how users perceive a technology, and come to adopt it
TPB	Theory of Planned Behaviour, a psychological model of the relationship between beliefs and behaviours, used to predict or interpret actions
VA	The United States Department of Veterans Affairs, the provider of, among other services, healthcare to American armed service personnel, and operator of a large health information system

DECLARATION OF ACADEMIC ACHIEVEMENT

The following is a declaration that the content of the research in this document has been completed by E. David Daglish and recognizes the contributions of Dr. Norm Archer, Dr. Khaled Hassanein, and Dr. Ann McKibbon in both the research process and the completion of the thesis.

1   Introduction

Electronic Personal Health Records (ePHRs)—complete records of the health, diagnostic tests, treatments, and prescriptions that pertain to individuals, available, as required and authorized, to healthcare deliverers (CHI, 2007; Tang et al., 2006)—have been suggested as a part of the solution to the rising costs of healthcare delivery in developed nations. Healthcare costs have been increasing at greater than the rate of inflation while the expected rise in costs as the baby boom generation ages is beginning to be felt as a significant part of that increase. It is still early days for the introduction of ePHRs in Canada, following a few experimental studies (Chan, 2008; Urowitz et al., 2008; Walberg et al., 2008), publicly available ePHRs are nearing completion and slowly being rolled out (CHI, 2012). ePHRs are expected to contribute ultimately in two ways: cost savings and better health outcomes (MOHLTC, 2012; Morgan, 2004). For the consumer, the collection of all personal data in one place offers the ability to detect and track health trends, and to ensure that all relevant personal health data are available to a provider of healthcare services. Costs may be contained by preventing duplication, among other effects, and better outcomes may be achieved by better coordination between providers. For these benefits to materialize, ePHRs need to be widely used by both the patient population and the medical community (DesRoches et al., 2010; Flynn et al., 2009) but what usage there may be is seen to drop off over time (Moss, 2005). Recent studies have shown an adoption rate that is below expectation (Agarwal et al., 2013; Greenhalgh et al., 2010), and one large online free-to-use ePHR has suspended operations (Google, 2013). This lack of use necessitates building a strong initial base of usage by motivating consumers beyond those seriously committed to ePHRs because of perceived direct benefits (e.g. consumers with serious chronic illnesses) so that, when the expected leveling off in usage occurs as the novelty effect is reduced, the residual user population will still be significant. A number of issues can be seen to impact the expected adoption of ePHRs, but a critical one is trust.

Trust plays a role in many consumer behaviours (Cunningham et al., 2004; McEvily et al., 2012; McKnight et al., 2002a; Singh & Sirdeshmukh, 2000) but unique factors are involved in health information systems such as ePHRs. While a

bank can provide financial restitution, reissue credit and debit cards, and create new accounts in the case of a privacy or security breach, health information cannot be recovered or replaced in a similar manner; thus the banking system's "good enough" security is inadequate for ePHRs where the possibility of accidental disclosure of potentially sensitive information exists, as has happened in the past (Kable, 2009; Lau, 2010).   In online electronic commerce (eCommerce), privacy and security breaches have had a high profile. However, while people are generally wary of disclosing private information where a risk of data release or misuse can occur, the increasing rate of current online commercial transactions, doubling to $122 billion between 2007 and 2012 in Canada, indicates circumstances where people feel that it is worthwhile to do business in this manner. They appear to believe that the data they provide will be safe; specifically, the heaviest users of eCommerce express the lowest levels of concern for security of transactions (StatsCan, 2008, 2011, 2013). Clearly, there are mitigating factors that consumers using online commerce sites recognize as signals that the site can be trusted with the data. Research has shown that many visible factors on the site (Kim et al., 2008; Metzger, 2006; Nicolaou & McKnight, 2006), as well as the basic nature of consumer personalities, are key forces in consumer decisions to provide the personal data necessary to enter an online transactional relationship.

Health data, and online systems to manage that data such as ePHRs, are somewhat different. First, the nature of an ePHR is intangible to many, as little to no physical manifestation of the system is apparent where the ePHR is implemented as an online portal, for example. When the system is based on some portable storage media such as a smart card, there is a physical tangibility, but a mental intangibility (Featherman & Wells, 2004) would likely still exist. Mental intangibility in online transactions has been shown through research (Featherman & Wells, 2004; Laroche et al., 2004) to adversely affect the assessment of risk, and thus raise the level of trust necessary to overcome the reluctance to initiate a transaction online; physical intangibility on its own (e.g., software and music downloads) was found to not be a contributing factor to risk (Laroche et al., 2004). Secondly, the provider is different from the accepted norm in eCommerce. In eCommerce, the site is run by a retailer, and consumers must place their trust in the retailer's filling the supplier side of the transaction before undertaking a transaction. In the Canadian healthcare system on the other hand,

an obvious provider of the ePHR, such as a governmental agency, a visible system vendor such as Microsoft or Telus, or medical practitioners may provide and use some of the data (Archer & Cocosila, 2008). Finally, consumers will likely provide, manage, and use much of the healthcare data stored on the ePHR themselves.   Each of the possible ePHR providers, whether government department, system vendor, or physician, will engender or diminish consumer trust in the ePHR. Therefore the influence of each should be considered in studies of trust in ePHRs. There has also been much coverage in the news of data losses and poor data management in the government agencies that will potentially acquire, manage, and contribute data to ePHRs (Fowlie, 2010; Kable, 2009; Lau, 2010); these reports do little to build trust in the systems that these agencies are developing or sponsoring.

That these privacy failures have caused concern is not unexpected. In several studies, one of the most often cited concerns is that of privacy of the data—specifically, preventing access and misuse of the information (Bloomrosen & Detmer, 2008; CHI, 2007; King et al., 2012; Simon et al., 2007; Tang et al., 2006; Willison et al., 2007). Privacy breaches are not unusual either; in 2010 data, a Statistics Canada survey of identity fraud in Canada found that 7 percent of consumer responses indicated someone had misused their personal data online, 37 percent reported attempts to fraudulently acquire their personal information, and 65 percent reported having had a computer virus or infiltration (StatsCan, 2011). The concern over privacy has caused laws to be enacted in many countries protecting personal data, in particular health data (Agrawal & Johnson, 2007). Not all uses of health information are discouraged by the public, however. There has been a growing realization that large collections of health information, such as medical records or ePHRs, are valuable in the pursuit of better understanding of medicine and the practice of healthcare through research and data analysis (King et al., 2012; Perera et al., 2011; Willison et al., 2007). To prevent the possible disclosure of personal information during such research, several schemes to support access to health data, but block access to identifying information have been proposed (Agrawal & Johnson, 2007; Szarvas et al., 2007) but they still have some potential for data loss (King et al., 2012).

Cost savings through ePHRs have been seen as coming from several areas, but all in the general area of efficient utilization of resources. Cost savings are particularly important in a tax funded healthcare system such as in the Canadian

model. The primary areas mentioned (Mukherjee & McGinnis, 2007) are reducing the number of treatment errors and subsequent extra care in the system; supporting record portability, thus preventing the need for retesting as people move through the healthcare system; and providing efficient use of time in appointments. Medical errors, due to prescription interactions or incompatible treatments for example, cost the health system both in the initial expense and in the subsequent treatments to remedy the problem, or through liability settlements to address the legal issues involved (Mendonça et al., 2004; Morgan, 2004). As a result of programs such as Ontario's Aging at Home initiative that aims to keep patients at home and out of acute care as much as possible, patients are expected to move between home care, primary care clinics, hospitals, and other places of care more frequently than otherwise, creating the need for a comprehensive, transportable set of medical records to accompany the patient (MOHLTC, 2007, 2013). Finally, ePHRs have been shown to help doctors prepare for appointments by reviewing patient data ahead of time and pre-screening referral data, noticeably improving the physicians' productivity and satisfaction in delivering care (Liederman & Morefield, 2003; Wang et al., 2004).

More clinically important results have yet to be decisively shown in terms of assisting in the impending healthcare spending crisis, but the concept of better results with more efficient delivery of care makes for more treatment at the same price (Dorr et al., 2007). Patients become an integral part of their healthcare team by continuous monitoring and entry of data in the ePHR, rather than a passive attender of appointments (Forsyth et al., 2010); the benefit is awareness of changes and early detection of trends. ePHRs have been shown to provide better tracking of patient needs and treatment progress, as well as monitoring compliance with doctor's orders; with regular recording of data, compliance with treatment can be measured more regularly and dosage or other interventions altered. In addition, when a patient is entering information regularly, small items that might go unmentioned in a regular checkup are more likely to be recorded, possibly preventing adverse side-effects to the treatment (Staroselsky et al., 2006). Both better compliance and recording of details will improve care. Coupled with this increase in doctor-patient communication, in the cases where statistics on patient status are available, (for example blood sugar levels for those with diabetes, and blood pressure for those with

hypertension), regular electronic tracking and analysis of the data has the potential to allow for early detection of adverse trends, permitting earlier treatment adjustment and less costly self management where possible (Morgan, 2004). Improved patient safety has also been raised as an outcome from ePHRs in the form of fewer errors through electronic prescriptions, and computer-based physician order entry and decision support systems (McGrail et al., 2010; Morgan, 2004).

Therefore, clear societal benefits will likely accrue with the use ePHRs, for both providing care more efficiently, and in better patient results. For these benefits to be realized, a critical mass of patients (in either numbers, or in terms of usage of healthcare services) needs to be using ePHRs. Finding the barriers to acceptance and perceptions of value to patients is therefore an important contribution to reaching the critical usage mark. This study was initiated with that goal. The research questions to be addressed by this study are as follows:

1. What are the trust and distrust related factors involved in a consumer's decision to use or not use an ePHR and how do they influence the consumer's intention to use an ePHR?
2. What is the consumer's perception of risk in sharing personal health information online and how does this influence the intention to use an ePHR?
3. Is there a difference in the intention to use an ePHR if the ePHR is provided by a doctor's clinic, the provincial health authority, or a system vendor?
4. How does the presence or absence of traditional structural assurances influence the consumer's intention to use an ePHR?

The next chapter summarizes the state of research into the relevant topics for this research. The third chapter establishes the research model that was used in the study, and the hypotheses generated. The fourth chapter discusses the design of the survey and the initial data screening process. The fifth chapter details the analysis of the data including validity and findings. The thesis concludes with key findings, implications for research and practice, as well as limitations and further research directions.

2   Literature Survey and Theoretical Background

This chapter reviews the current research on ePHRs and studies into adoption of ePHRs by users. It also reviews the concepts of self-efficacy, trust and distrust, and the perception of risk in online transactions.

While some ePHRs are implemented as data stored on some form of portable media, or an institution-based database, the most popular and promising form is an integrated, multiple data-source collection of data, accessed through an online Web portal site offering additional services such as context-specific health information (Halamka et al., 2008). This online format is similar to many Web business sites where user authentication and other security and privacy issues are concerns. Several terms have been used to refer to these patient-centered medical record collections, such as personal health records, electronic health records, or patient-held health records; there can be some differences in intent, but the term that will be used throughout this thesis is electronic personal health record, or ePHR.

2.1   Electronic Personal Health Records

An ePHR is a patient-centred, longitudinal collection of health records in electronic form, often encapsulating the complete history of the patient within the healthcare system. One well respected definition is from the American Health Information Management Association (AHIMA), which defined such a record as

> *an electronic, universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from health care providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR is separate from and does not replace the legal record of any provider.(AHIMA, 2005)*

In the first stages of use or adoption, the data will not be complete as different healthcare providers will join the process at different times, and historical data are likely to be incomplete owing to the costs of transferring records previously kept on paper. Providers in the healthcare system are healthcare professionals or associated staff working on the behalf of consumers to provide data, some of which may be made accessible through an ePHR. Providers may also be

institutions such as hospitals or laboratories that provide supplemental care or data. Any of these entities are considered information providers within the context of this study. Consumers will also contribute to the content of their own ePHRs. Consumers using an ePHR are, at some time, patients within the healthcare system; therefore patients and consumers will be used interchangeably in this document when referring to ePHR owners.

Many forms of ePHRs are currently being studied and implemented as shown in Table 2.1 (Daglish & Archer, 2009). Some are tethered—that is, specific to one health provider such as a hospital network or health organization—whereas others are standalone and have no link to any health provider (the latter are entirely dependent on consumer provided data). Both of these systems have inherent weaknesses, such as loss of data if the user changes provider or location in the former case, or if the system fails in one of many possible ways in the latter case. For that reason, an integrated system covering many providers and many sites may become the most useful type of ePHR, since it incorporates access points and central coordination, and secure data storage and retrieval; usually this type of system, such as the U.S. Department of Veterans Affairs system (Tobacman et al., 2004) provides user data access through online portal sites. This consolidated provision of data, however, requires the widespread adoption and use of standards, a slow and often political process. Despite the interoperability issues of competing data systems, Canada Health Infoway has settled on an Internet portal-based architecture, providing the service of centralized access to personal health information (CHI, 2007, 2012). This is a commonly described architecture in studies of ePHRs (Goel et al., 2011; Nazi, 2009; North et al., 2011).

The need to centralize health data has been a concern, with several alternatives proposed (Gunter & Terry, 2005). System analysis and modelling has determined that the data can become fractured without a central repository, driving the error rate up as usage increases (Lapsia et al., 2012). Also of concern in the design of an ePHR is its content and the patient's accessibility and access points (Hirdes et al., 1999; Oberleitner et al., 2007; Shachak & Jadad, 2010). Specifically, what data are collected and stored, and in what format, is an important factor in assessing treatments for physicians; a concept of a minimum data set, detailing the least amount of data required to assess and treat a patient in cases of a transfer of a patient to another provider, gives guidance on the data to include.

The access to and functionality of an ePHR from the patient's perspective provides more requirements for the design.

Table 2.1 ePHR Architectures

Attribute	Tethered	Integrated	Standalone
Complexity	Relatively simple (conceptually)	High. Need to establish and maintain data source standards	**Smartcard:** Simple, but backup complex **Web-based Consolidator:** Moderate. Network links to consumers, practitioners, etc.
Access	Portal or client server	Internet portal	**Smartcard:** Card or memory stick readers **Consolidator:** Internet portal
Data Sources	Primary care server, pulling data from other sources (testing laboratories, etc.)	**Pull Model:** Central source, pulling from multiple primary sources **Push Model:** Central source, receiving data pushed from multiple primary sources	**Smartcard:** Direct from all sources **Consolidator:** Network connections to consumers, practitioners, institutions.
Example Installations or Trials	MyOscar (Chan, 2008)	U.S. Department of Veterans Affairs (InterSystems, 2008)	**Smartcard:** Germany (Gesundheitskarte, 2008) **Consolidator:** HealthVault (Anonymous, 2008)
Comments	Appropriate only for multiple physician clinics with staff support available	Multiple copies of data result if stored in central repository. If not stored, access delays likely to be unacceptable	**Smartcard:** May be costly to evolve system and standards **Consolidator:** Requires access permission and ability to adapt to multiple data sources

2.2 Technology Adoption Models

Consumer and technology adoption models have been studied in the information systems literature for some time (Davis, 1989; Venkatesh et al., 2003; Wilson & Lankton, 2004). These models are founded in the social sciences, in an attempt to understand the motivations of consumers in the marketplace and users of technology in business, and to better position services or products to earn more business. These models have helped to understand how consumers see eCommerce services. These models may be validated by actual usage behaviours—where that is possible to capture—or more usually with behavioural intention of consumers to adopt. Studies that are able to capture actual behaviour have shown a very strong correlation between behavioural intention and actual behaviour (Venkatesh et al., 2003), so most empirical studies rely on expressed intention only.

The Technology Acceptance Model (TAM) (Davis, 1989) has been used as the foundation of much research in user acceptance and adoption—see Figure 2.1. This model has been modified in many ways to fit specific needs of the relevant study (Gefen et al., 2003; Klein, 2007; Wilson & Lankton, 2004), through the addition of theorized antecedents, moderators, and mediators. The principal components are perceived usefulness (PU), perceived ease of use (PEOU), and the behavioural intention to use (BI). The original model also included attitude between both PU and PEOU, and BI, as well as actual use following BI. A more parsimonious model has been adopted (Davis, 1993), where BI has been removed, and actual use is often omitted as well.

In TAM, PU is defined as "the prospective user's subjective probability that using a specific application system will increase his or her job performance" (Davis et al., 1989). The same source defines PEOU as "the degree to which the prospective user expects the target system to be free of effort". As the use of TAM has broadened, the interpretation has expanded from job performance to desired task completion (Wilson & Lankton, 2004). It is in that sense that it is used in this dissertation. TAM has demonstrated robust reliability and validity in capturing predictors of consumer behaviour.
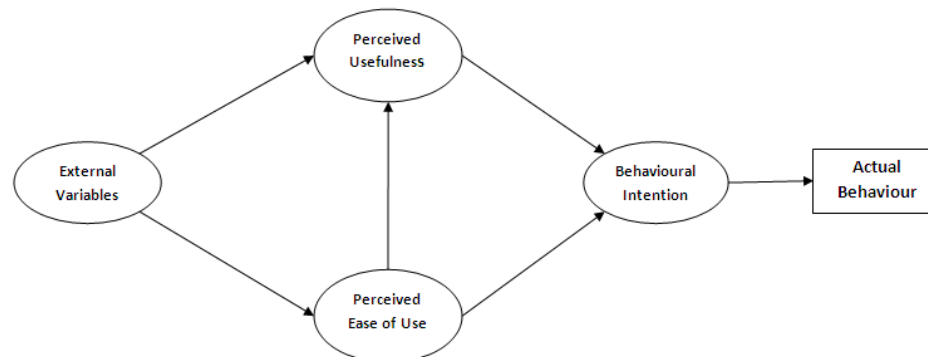
Figure 2.1 Technology Acceptance Model from Davis (1993)

In cases where actual use of a real or a demonstration system is not available for the participants, it is hard for a user to determine the possible ease of use of the system; the usefulness has to be reasonably assessed from images and functionality statements in past studies (Whetstone & Goldsmith, 2009). In these cases, an alternative measure, such as computer self-efficacy may be used. The usefulness of computer self-efficacy in adoption studies is that it is seen to allow measurement of adoption usability where full control is not possible for the user; self-efficacy measures user judgement of skills that can be applied to a new situation (Hsu & Chiu, 2004).

Computer self-efficacy is the perception by individuals of their ability to use a computer. The individual's experience, and the context of the computer usage, is considered relevant to the assessment, so that the needs and anxieties related to the task can be bundled into the one element of self-efficacy (Bandura, 1977; Compeau & Higgins, 1995). Self-efficacy derives from Social Learning Theory (Bandura, 1977) and Social Cognitive Theory (Hsu & Chiu, 2004). In these theories the person, his or her behaviour, and the environment all interact over time, so that behaviour is modified by the activity context, and the experience gained changes behaviour for the future (Bandura, 1977). In most studies of self-efficacy in information systems (IS), the specific nature of computer self-efficacy is measured. In many cases (Hasan, 2007; Igbaria & Iivari, 1995; Yi & Hwang, 2003) self-efficacy is tied to measuring user perceptions in the course of adopting or planning on adopting technology, with the dependent variable being either intention to use, or usage behaviour. Unlike other measures, where validity is enhanced by using or adapting an existing measure, computer self-efficacy is tied to very specific circumstances, which often change with a new

study, rendering the old measure inaccurate (Marakas et al., 2007). If the measure is not constructed for the specific task, taking into account established rules for the creation, it risks losing significance (Marakas et al., 2007).

2.3   Adoption of ePHR Systems

A person using an ePHR is required to place sensitive information into an online system, and that requires that the person trust the supplier of the system, and the users with access to that data; as a result, most research in ePHR adoption has incorporated trust. Many studies have built on earlier studies of eCommerce web sites, since there are some strong parallels between an eCommerce site and a portal ePHR. Both require the user to provide sensitive information—financial or health—and for a delayed provision of a service—delivery of a product or information, or healthcare. This dissertation takes advantage of those earlier studies and the conceptual parallels.

Adoption rates of existing systems have been as low as 5 percent (Hart, 2009), and many are in early stages of roll-out. Thus, many studies have been focus groups eliciting opinions or intention surveys based on demonstration systems or images in order to find information to use to increase adoption. There have been a few prototype systems, or fixed use systems—such as one satisfying specific HIV-AIDS patients' requirements (Smith et al., 2012)—that have formed the bases for other studies. And finally, some systems with active users have been studied for ePHR adoption research. This section will review the findings from some representative research in each of these study categories.

2.3.1   Focus Group Studies

An early study of the ePHR environment (Tang et al., 2006) established definitions and requirements, but also looked at the barriers the gathered experts felt were likely to impede the creation and adoption of ePHRs. The expected barriers of interoperability, funding, and regulation were discussed. The gathered experts also discussed the concern that the users needed education to be able to contribute sensibly to an ePHR and participate in managing their health status.

Many studies gathered groups of potential ePHR users together, some the general public, some the segments of the population expected to benefit more from using ePHRs, to determine the users' opinions on ePHRs and the expected benefits and risks. The most common barrier to adoption raised was the linked

concepts of privacy of the data and the security of the ePHR (Hart, 2009; Kahn et al., 2009; Patel et al., 2011; Patel et al., 2010; Pirtle & Chandra, 2011). Associated with loss of privacy is the potential for misuse of the data, either to access care in a user-pay environment, or disclosure of information to others, such as employer or insurer (Dhopeshwarkar et al., 2012; Nguyen, 2011). Several user groups also discussed ePHR features that would be designed to reassure those concerned with security and privacy, rendering a sense of confidence and trust.

The primary confidence aid for users concerned with access issues was providing audit trails in the ePHR, so that the user was able to review who accessed his or her data, when, and with what authorization (Detmer et al., 2008; Dhopeshwarkar et al., 2012). Also discussed by the user groups was to allow the user to control the access to the data, setting out which physician, administrator, or clinic is allowed to access the data and make changes (Dhopeshwarkar et al., 2012; Hart, 2009). Finally, being able to review the data and ensure accuracy and completeness ensures confidence in the ePHR and its value to personal health (Hart, 2009; Kahn et al., 2009). This ability to access the data and make changes can also be a negative, with the possibility that the user is insufficiently knowledgeable to correctly supply the required information, or to make sense of the data stored in the ePHR.

An ePHR must be available to the users, both patient and healthcare practitioner. The accessibility of the ePHR to the patients, with aspects of methods of access, loss of password, and ability to use the ePHR were also issues discussed in focus groups researching consumer attitudes to ePHRs (Kahn et al., 2009; Pirtle & Chandra, 2011; Smith et al., 2012). The interoperability of other data systems (Kahn et al., 2009; Pirtle & Chandra, 2011), and thus the presence of data from other healthcare practitioners in the ePHR is another aspect of accessibility: do the patients' providers of healthcare use the same ePHR?

The perceived complexity of an ePHR, and the costs to create it were concerns for some consumers in, or practitioners speaking for, the lower socio-economic levels. The concern that the system would be too hard to use, or be inaccessible without personal computer skills were limiting factors seen by some (Kahn et al., 2009; Smith et al., 2012), as well as the worry that the costs of providing an ePHR

would be passed on to the users in access fees (Kahn et al., 2009; Pirtle & Chandra, 2011).

A few studies determined that, while privacy was a concern, this concern would not deter those who were interested, either through need to manage health information to support better health (Forsyth et al., 2010; Lafky & Horan, 2011), or through education on the positive aspects of an ePHR (Angst & Agarwal, 2009). When questioned about privacy specifically, those participating in one study had no concern for their own data, based on what they knew, but could see that others might have a concern (Forsyth et al., 2010). Certain features of an ePHR, such as the ability to consolidate and record data, have been found to have positive effects on the participants willingness to relax their concern over privacy to achieve the benefits promised (Angst & Agarwal, 2006; Nguyen, 2011).

2.3.2 Demonstration System Studies

The studies described above, and others like them, have formed the basis of the next level of investigation into adoption of ePHRs. In the demonstration system form of research into consumer attitudes, an ePHR is presented, either through description, images, pamphlet, lecture, or video; the ePHR is not an active system that can be tried by the user during the study, it is just presented. Following the presentation, participants are asked to complete a survey, measuring their perceptions of aspects of the ePHR presented, usually including some measure of intention to adopt the ePHR or something like it. In these surveys, adoption models such as TAM were not usually used, as either the number of responses were low or the information more qualitative than quantitative; demonstration ePHR studies are usually established to answer specific questions.

In one study, the participants were studied to see if they would change their expectation of privacy in exchange for the benefits expected from the description of the ePHR (Li et al., 2012). The trust belief of the respondents was found to have a significant effect upon the intention to use the ePHR, and the perception of privacy control—that is, the ability to determine how the data are released to others—reduces the perception of risk, and thus also increases the intention to use the ePHR. Several demographic variables, such as age, gender, and current health status, were collected and investigated for possible impact on

the ePHR adoption decisions. Only age was found to be a factor, with older respondents more likely to intend to use the ePHR.

In a second study, trust was investigated as a mediator between quality of information provided by an ePHR and the respondent's intention to use the ePHR (Lim & Kim, 2012). The respondents were provided with material, either in a low trust or high trust scenario, and queried regarding their perception of the quality of the material in several categories, such as reliability, relevance, and adequacy, the trustworthiness of the ePHR, and their resulting intention to use the ePHR. When the information provided was high trust, only the quality measures of relevance and reliability had an impact on the intention to use the ePHR; when the information was low trust, the reliability and adequacy were the only quality criteria impacting the intention to use the ePHR.

Richards (2012), in her Ph.D. thesis, investigated the impacts of perceived privacy and trust in the intention to use an ePHR. Privacy was not found to have much effect on the respondents' intentions to use the ePHR, but the trust factors had an impact, moderated by the TAM constructs of PEOU and PU. The measure of computer self-efficacy was treated as a control variable, and it had impact on most of the trust and intention measures, except for the intention to share data with a third party payer or public health organizations. The control variable of healthcare need was significant in all constructs, indicating that the perception of value or usefulness will overcome perceptions of risk. Her findings also indicated that trust in the supplier of the ePHR was the leading factor in intention to use the ePHR. Similarly, another Ph.D. thesis found the same link between a higher need for healthcare services and a higher intention to use the ePHR (Logue, 2011).

Other factors have been theorized as impacting the traditional TAM constructs. In his Ph.D. thesis, Torres (2011) investigated the moderating effects of anxiety and apathy in the personal management of health information. Anxiety was defined as the nervousness involved in using an ePHR, and apathy as the intention to avoid using the ePHR as a result of the anxiety. Torres also included constructs from the theory of planned behaviour (TPB) in his research model, to account for the behavioural control in addition to the perceptions of ease of use and usefulness. He found that anxiety and apathy were not moderating factors for most of the model, but that anxiety moderated the influence of social

norm—the perception that others would approve of the behaviour, from TPB— on intention to use an ePHR. In post-hoc analysis, the anxiety and apathy were tested for influence on intention to use the ePHR. Anxiety had no statistically significant effect, but apathy was a significant predictor of both attitudes and intentions.

2.3.3 Small Scale Studies

Studies of small-scale ePHRs, or prototype ePHRs, work with a somewhat functional system, perhaps unconnected to other data sources or users, or they may be just paper-based. These studies usually involve actual use behaviour, as opposed to simply intention, and decisions made are usually well-informed. In an early study in the United Kingdom, the medical data from general practitioners' offices were combined with data from the patients' dentists to create an integrated patient record for review and evaluation (Jones et al., 1999). A random group of patients in two medical practices were provided with the paper patient-held record (PHR), and a control group was not. The two groups were surveyed and followed up a year later. The group that had the paper PHR was more favourable towards PHRs in general. The patients were able to review the records, and 24 percent discovered errors, and 30 percent discovered omissions, demonstrating the value of PHRs. Samples were taken from two areas of different socio-economic status, but no difference was reported.

In contrast, a study of physicians and patients in Australia (Liaw, 1993) found participants from areas of lower income had less interest in the paper records, both physicians and patients. The patients, as in other studies, reported to being concerned with the privacy and security of their records. Also reporting security and privacy concerns, along with concerns over complexity and accuracy, was a study using three, free to use, public access ePHRs (Liu et al., 2011). The complexity of the systems was eased in some cases, by the ability to personalize the ePHR to reflect the needs of the user.

Understanding of the information has been found to be a barrier of ePHR use in other studies. Therefore an investigation was undertaken in a mental health and substance abuse clinic, investigating if the particular concerns of the patients had a contributing effect on understanding, and thus using an ePHR (Hilton et al., 2012). No barrier effect from the health issues was found, but the basic

computer literacy of the sample population was a limiting factor in usage of the ePHR, as in studies of the general population.

2.3.4 Large Scale Studies

Turning to studies of larger ePHRs, two very large population ePHRs are in operation in the US. One supplies ePHRs to customers of Kaiser Permanente, the other to veterans by the Department of Veterans Affairs (VA). A study of Kaiser Permanente's ePHR users (Silvestre et al., 2009) found that usage continues to grow. The ePHR was perceived as useful, which contributed to the adoption behaviour, as did the perceived quality. The perceived ease of use did not have a statistical influence on the behaviour, even though the users could make an informed judgement on the system ease of use; it was believed that measuring the perceived quality, which also had a positive impact on adoption behaviour, overwhelmed the influence of the ease of use measure.

One study of frequent users of the VA ePHR found that the users were very satisfied, and would recommend the ePHR to others (Nazi, 2009). The study found that the most common complaint with the system, however, was its ease of use, specifically in search and navigation.

A large U.S. national study (Undem, 2010) that oversampled in some demographic areas, such as ePHR usage, to ensure sufficient data for analysis, found that 68 percent of the respondents felt that privacy of their data was the number one concern in using or not using an ePHR, with 40 percent of actual users worried or very worried about the privacy of the data. The respondents felt that the best supplier of an ePHR is the local health organization—healthcare management organization, clinic, or hospital, for example—followed closely by the payer, and then the government; at the bottom of the list was an independent software vendor, such as Microsoft. The reassurances that allowed the survey respondents to use or consider using the ePHR included their trust in their doctor, the reputation of the ePHR, the visible security mechanisms and policies, and legislation.

Demonstrating the effect of education and information transfer on adoption behaviour, a study (North et al., 2011) used three methods of raising awareness of an ePHR in a clinic with patients in three randomized groupings. With the first, they were simply informed of the availability of the ePHR and how to sign up. The second group received an informational pamphlet describing the ePHR, and

the third was shown an instructional video on the ePHR. There was a registration rate of 2.5 percent for the first group after 45 days, 7.1 percent for the second group, and 11.7 percent for the third. After 6 months the retention rate was about 1 percent for the first two groups and 3.5 percent for the third.

In other studies of usage, notable differences were seen in usage demographics. In one study, older patients were more likely to use an ePHR (Tulu et al., 2012), and in another, younger patients were more likely (Ancker et al., 2011), and in a third, there was no age effect (Goel et al., 2011). Similarly, gender had an impact on ePHR usage in one study (Ancker et al., 2011), with women being more likely to use an ePHR, and no impact in another (Whetstone & Goldsmith, 2009). And some found that health status, or health-driven need had no effect on usage of an ePHR (Goel et al., 2011; Whetstone & Goldsmith, 2009), while others found that it did (Ancker et al., 2011).

Finally, the authors of some studies have argued that TAM is not appropriate for evaluating adoption of ePHRs. In a survey, using TAM, of health practitioners adopting ePHRs (Holden & Karsh, 2010), the authors felt that TAM was too flexible and too general to provide meaningful results, and that a process of going back to first principles to develop specific outcomes that matter to healthcare users, patients and providers, should be undertaken. Another set of authors (Winkelman et al., 2005) feel that TAM may not be appropriate for studying ePHR adoption by those with a chronic illness, as TAM is based in logic and derived from perceptions and behaviours within business organizations; they feel that individuals as patients who are being followed through medical practice have little in common with office workers, and the effects of their illness may not allow them to assess situations with the logic that a knowledge worker would apply to assessing an office information system.

There are some valuable studies included in the preceding section, but while a few have tried to capture the calculus of trust—the balancing of trust in the rewards from an ePHR against the risk of exposing personal health data to theft, abuse, or loss—has not been well tested. Some have focused exclusively on perceptions of privacy and trust in an ePHR as part of the study of adoption intention, but there was no interconnection of the constructs. Others did allow the risk and reward to work together in adoption intention, but the focus was narrow—in information quality, for example, not ePHR features and options.

2.4   Trust and Distrust

Trust has been defined by authors in many different fields (Anderson & Dedrick, 1990; Arnulf et al., 2005; Chiaburu & Lim, 2008; Colquitt et al., 2007; Kramer, 1999) as a willingness to open one's self to possible loss based on a belief in the positive actions of another. In this light, trust is the belief of the user that the other parties involved in providing the ePHR and its contents will act in the best interests of the consumer.

Trust is a broad concept that has been investigated by many researchers from many disciplines; Gefen et al (Gefen et al., 2003) lists 42 studies up to 2002, most reflecting the researchers' area of interest: marketing, psychology, sociology, or organizational behaviour. Bigley and Pearce (Bigley & Pearce, 1998) found 116 studies in several disciplines and a recent Google Scholar document search for "Study Consumer Trust" limiting to publication since 2009 returned over 56 000 results. While there does not seem to be a commonality of perspective, the prevailing view is that trust is a multifaceted construct, and it is common to decompose trust factors into personal, or trustor, and institutional, or trustee, components. The personal side involves such factors as beliefs and attitudes, as well as reasoned and thoughtful consideration. The other side of the trust relationship is drawn from the trustor's perspective, relating how the trustee presents to the trustor; factors here typically involve the public face of the trustor, and whether the appearance conforms to expectations and other measures of normal behaviour. Most articles discussing trust in the realm of IS research have settled on the definition of trust from Mayer et al (1995) "the willingness of a party to be vulnerable to the actions of another party based on the expectation that the other will perform a particular action important to the trustor, irrespective of the ability to monitor or control that other party".

Within the literature on trust, the trust behaviours of the trustor break down into two main areas: personal dispositions to trust, and rational trust decisions. Within the disposition to trust area are the trustor's beliefs, attitudes, and opinions regarding trust in general, and the trustee in particular. McKnight and colleagues (McKnight et al., 1998) defines two main factors: faith in humanity and a trusting stance. The former is a belief that people are, by and large, good and reliable, while the latter is a belief that treating people as trustworthy yields better outcomes in interpersonal relationships. The other side of the trustor's antecedents to trust in the trustee are two constructs that rely on considered

thought on the part of the trustor. The first has been referred to as cognitive processes (McKnight et al., 1998) or cognition-based antecedents (Kim et al., 2008). These cognitive trust items are based on reviewing the presentation of the trustee—in the form of a business establishment, Web page, or personal characteristics depending upon the form of interaction—and deciding what level of trust is appropriate in the circumstances. The second cognitive aspect is based upon knowledge, such as past experience, or trusted advice from a third party, regarding the trustworthiness of the trustee. Further refinement of the trusting theory has demonstrated that the environment where the interaction takes place will be a factor, with more socially "upscale" locations yielding higher levels of trust, and higher risk areas generating lower levels of trust attitudes (McEvily et al., 2012).

The other aspects of trust are partly under the control of the trustee. The first is referred to as Situation Normalcy (McKnight et al., 1998). It is a measure of the feeling the trustor gets when interacting with the trustee that everything is normal and as it should be. In the case of a web site, for example, this situation normalcy means that the user interface looks and behaves as one would expect a representative site should look and behave. The second aspect is Structural Assurance (McKnight et al., 1998) referring to the indicators and other visible representations to the trustee that they are what they purport to be; a doctor's stethoscope is an example of such a token in the healthcare field, as is a nurse's uniform. In the case of a web site that one expects to be secure, structural assurance can be the presence of the lock symbol in the browser indicating an encrypted connection, for example.

Lewicki and colleagues (Lewicki et al., 1998) proposed that **distrust** is not the other end of a single axis continuum with trust, but is rather a related and sometimes linked dimension. They defined trust in terms of confident positive expectations of the behaviour of others, and distrust in terms of confident negative expectations of the behaviour of others. McKnight and colleagues (McKnight et al., 2004) adapted existing, established trust instruments to measure trust and distrust to validate the assertions made by Lewicki, McAllister and Bies. From over a thousand study participants, McKnight and his partners found some support for the theory that distrust influences consumer behaviour independently from trust, although not as much as they had expected. This provided support for Lewicki, McAllister, and Bies' hypothesis that there is a

difference in effect between trust and distrust (the measured statistical correlation was -0.38).

In further testing of the trust and distrust distinction, it was shown that discriminant validity occurs between trust and distrust measures (McKnight & Choudhury, 2006), and that trust and distrust differ in what aspect of behavioural intention they predict (McKnight & Choudhury, 2006; McKnight et al., 2004). Many authors studying trust and distrust have pointed out that negative issues, such as distrust, or fears, are weighted higher in evaluating impacts on, and of, a decision (Cho, 2006; Singh & Sirdeshmukh, 2000). For this reason, McKnight and his fellow researchers posited, and found support for the distinction that distrust elements are better predictors of dependent variables that involve higher risk, whereas trust items are better at prediction of dependent variables involving lower risk (McKnight et al., 2003). For example in their study, participants agreed that viewing an eCommerce web site was low risk behaviour, and making a purchase on the site was a high risk activity.

Further evidence of a distinction between trust and distrust was hypothesised and tested in a study using functional magnetic resonance imaging (fMRI) to investigate the brain activity of the test subjects in the midst of evaluating their levels of trust and distrust of fictitious eBay vendors (Dimoka, 2010). The baseline for the test was established in a traditional behavioral study (n=177) that demonstrated the effectiveness of the vendor profiles in establishing trust and distrust. Then a modified presentation was given to a small group (n=15) while the brain of each participant was being scanned in an fMRI machine. The results of the survey portion matched the larger study results, and the fMRI results demonstrated that quite different areas of the brain were involved in the recognition of trusted and distrusted vendors. This further supports the concept that the two constructs are distinct, as different brain processing implies different routes to an opinion, and thus different cognitive and behavioural impacts between trust and distrust.

Trust in Healthcare

In more health-specific research, Abelson et al (Abelson et al., 2009) found deep conflicts in Canadian trust in the medical system. In a set of nine focus groups from three Canadian cities (Hamilton, Montreal, and Toronto), with just over 100 participants in total, the consensus was that Canadians trusted their primary

physicians. However, the focus group participants were distrustful of for-profit units in healthcare, ignoring the fact that Canadian doctors generally function as independent businesses. Where the participants noticed a profit-motive influencing their doctor in his or her actions (extra billing, double scheduling and little time with individual patients in a fee-for-service payment scheme) they trusted the system to identify and rectify the situation; in general, however, they were essentially distrustful of the government's healthcare bureaucracy to do the right thing for them. Some participants saw the system's efforts to ensure a reasonable minimum duration for a patient visit to represent interference with a doctor who was trying to help patients.

In a study of the evolution over time of the concept of trust, it has been found that perceived quality and satisfaction with results are factors that most significantly affected trust after the initial contact (Zahedi & Song, 2008). These factors are consistent with a study of loyalty (Torres et al., 2009) where trust, satisfaction, commitment, and reputation were found to be the key antecedents to loyalty to one's partner in an ongoing trust relationship. But a dark side can affect ongoing trust relationships in cases such as a doctor-patient relationship, where abuse of the doctor's power position in the relationship can lead to domination (Calnan & Rowe, 2006).

The trust between a patient and primary care physician has been identified as a special one (Street et al., 2009) as it can, properly utilized, lead to better health outcomes. Better health outcomes and more clear communication between doctor and patient are selling points of ePHRs for those who can benefit from the data collection and presentation services (Dorr et al., 2007). Trust in the provision of care is engendered through effective communication, since this communication enhances understanding of instructions and symptoms and promotes better agreement between the parties (Street et al., 2009); thus, trust will likely lead to increased adherence of patients to care plans, and better ability to care for themselves. This effect should likely ultimately result in better health and well-being.

Patient-doctor trust works in both directions to achieve better healthcare, as clear communication is supported. Distrust can also play a role in patient-physician interaction. If a physician does not trust the patient, he or she will not accept the patient's descriptions of symptoms or events, and assume that the

patient is looking for drugs or insurance money (Cook et al., 2004); if a patient does not trust the physician, compliance will drop and the patient may search for a new primary care physician (Cook et al., 2004).

Anderson and Dedrick (1990) created a trust measure for the patient-physician relationship, based on an 11 item scale that relates to the areas of fidelity, competence, honesty, and global trust. In the original two studies, and many subsequent ones (Calnan & Rowe, 2006; Hall et al., 2002; Hall et al., 2001), this trust measure was found to be consistently uni-dimensional, and quite robust. A translation from the common North American setting to a European one with a different healthcare provision model detected no change in the overall results (Bachinger et al., 2009), making the trust of one's physician a common one.

Cook and colleagues (Cook et al., 2004) found that patients were generally able to determine the trust or distrust that the physician saw in them and that was then factored into the patients' trust in the physician, as one of the many factors that patients use to determine the trustworthiness of their doctors. In general, Cook et al found that a patient, given a choice, will change doctors if the attending physician does not measure up to the patient's trust expectation. This implies that, in an open environment, a patient who has a choice of doctor will generally trust his or her chosen doctor.

2.5 Risk

Finally, **Perceived Risk** has been studied in many fields related to consumer behaviour as the perception of dangers and uncertainty involved in the relationship with another party; while as many as nine types of risk have been identified (Laroche et al., 2003; Laroche et al., 2004; Lim, 2003), eCommerce studies—upon which this study will build—have narrowed the risks to six: performance, financial, opportunity/time, personal safety and privacy, social, and psychological loss (Featherman & Pavlou, 2003). These issues are forces that prevent a user from immediately adopting or using a system in the adoption model, and cause the potential user to balance the potential exposure they face against their motivations to use the system or enter into a transaction with the other party. In this study of ePHRs, personal safety and privacy is the primary risk that researchers in early adoption have considered, as well as the social and psychological risks (Willison et al., 2007), but these latter two are tied into the privacy and security aspects of ePHRs. It has also been suggested (Sjöberg &

Fromm, 2001) that personal safety perceptions be combined with privacy perceptions in healthcare situations to address concerns over information security failures that could expose private data. While all these factors may be part of risk analysis, most are expected to have little impact on the perception of risk in ePHRs; the reasons follow.

In several studies of health information systems it has been found that the most important risk from the public's perspective is security and privacy risk (Gostin, 1997; Mukherjee & McGinnis, 2007; Smith & Manna, 2004). Patients are concerned that their information may fall into the wrong hands, or be used inappropriately (Willison et al., 2007). Unlike financial situations where data are lost and the institution can make good any losses and issue new accounts, cards, and cheques, health data cannot be reset in the same way and so has a more rigorous requirement on data security and privacy.

Performance risk, psychological risk, and opportunity- or time-loss risk can, in the case of ePHRs, be seen as slightly different aspects of the risk that the ePHR will not perform as expected, or be too difficult to use. This may lead to lost, omitted, outdated, or corrupted information, or other risks related to security of the person through erroneous information, returning the risk source to security and privacy of the data.

It has been suggested that any ePHRs in Canada might have to be paid for by individuals through a subscription-like fee structure. While studies have shown that American consumers are so interested in having access to their health data, they are willing to pay for on-line access to it (Adler, 2006), the risk that ePHR performance failures might lead to financial losses could lead some consumers to perceive a financial risk in an ePHR, slight though it may be. As this risk is slight, and payments are expected to be modest, this financial risk is not likely to be a significant contribution to the perception of risk; a study done in 2009 found that Canadian consumers surveyed would be willing to pay, on average, $1.80 to $4.50 (US) per month for use of an ePHR (Archer & Fevrier-Thomas, 2010).

Social risk is defined as the fear that others would perceive a consumer in a negative sense if an ePHR is used; this is not a serious concern, in and of itself, as some relevant studies (Adler, 2006; Wilson & Lankton, 2004) have found that even a healthy consumer would be willing to use an ePHR. Thus, using an ePHR would not carry a negative perception; it may even carry a positive perception,

as parents using an ePHR for a child with complex health issues may be seen as better parents. However, fear of exposure of a patient's health condition to others not in the patient's circle of care is a social risk, but amplifies the perception of privacy and security risk factors, since some conditions carry a negative social stigma.

ePHRs are services and not products that are being selected. This raises a different category of risk evaluation related to the intangibility of services, in terms of both their physical and mental dimensions (Featherman & Wells, 2004).

2.6 Summary

This chapter set out to define the theoretical foundations for the remainder of the dissertation, by summarizing a cross-section of the existing research on adoption of ePHRs and establishing what is considered to be an ePHR for this investigation. Past studies on adoption of ePHRs have shown that trust is a requirement for adoption of ePHRs, due to the inherent risk of exposing ones personal health information to others online. Potential users are concerned by the potential exposure of their health information through security lapses and privacy breaches, as well as accessibility, accuracy, and literacy issues. While some other risks are involved, privacy and security together comprise the dominant factor. Finally, there may or may not be controlling variables in the adoption process, such as age, gender, income, health status, or education. The next chapter assembles these constructs and variables into a research model to provide the hypotheses for analysis.

3   Research Model

Based on the theoretical foundation and literature presented in Chapter 2, a model incorporating the factors influencing consumer adoption of ePHRs was developed for this dissertation. The model that has been developed, shown in Figure 3.1, uses TAM as a foundation and builds on it. It integrates the trust-distrust parallelism of McKnight et al (McKnight & Choudhury, 2006; McKnight et al., 2004) to capture the trust and risk elements that are thought to play a role in the intention to adopt an ePHR. The model hypotheses and support are presented below.
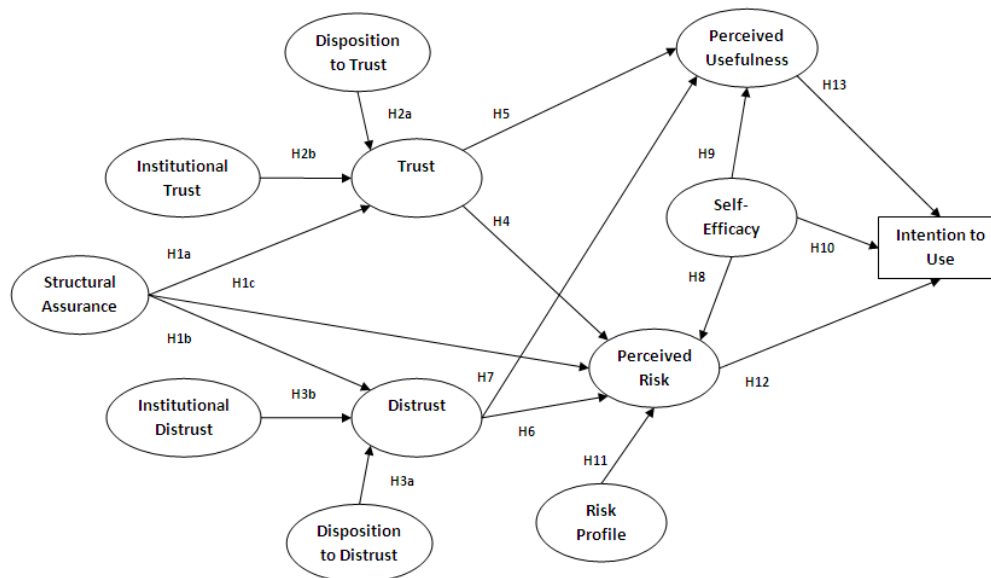
Figure 3.1 Research Model

3.1   Structural Assurances

One of the common factors that eCommerce researchers have reported as a factor that is within the scope of manipulation by the vendor in encouraging consumers to trust the site is the set of structural assurances (Gefen et al., 2003; Kim et al., 2008). These factors include third party seals, privacy and security statements, and information quality. Studies have shown that structural assurances will reduce the perception of risk (Kim et al., 2008; McKnight et al., 2002a) , and raise the level of trust held by the consumer (Gefen et al., 2003; McKnight & Choudhury, 2006). With trust and distrust having a negatively correlated relationship in measures affecting consumer behaviour (McKnight &

Choudhury, 2006), the effect of structural assurances on distrust will be the opposite of that to trust in the model. Thus for this dissertation the relationships between structural assurances and other constructs are captured in the following hypotheses.

Hypothesis 1a: Structural assurances will positively affect Trust in the ePHR.

Hypothesis 1b: Structural assurances will negatively affect Distrust in the ePHR.

Hypothesis 1c: Structural assurances will negatively affect Perceived Risk of the ePHR.

3.2   Antecedents to Trust and Distrust

Many models have several antecedents for trust, but most models agree that fundamentally personal dimensions exist on the part of the trustor as well as institutional or organizational dimensions on the part of the trustee. The personal factors break down into general personality components and perception of the trustee. The general personal components have been alternately termed the disposition to trust or the trusting nature (Gefen, 2000; Kim et al., 2008; McKnight et al., 1998). This nature reflects the attitude of the trustee towards others in general, and the supporting channel such as the Internet and the site operator in more specific terms.

The other antecedent is the perceived nature of the ePHR. In the case of ePHR specific factors, some directly relate to the people's perceptions of the organization providing the ePHR, such as perceptions of the integrity of the business, and would have to be applied separately to any visible third party involved in the operation of the system.

The factor consumer's disposition to trust comes from earlier psychological research in trusting behaviour, and has been shown to be a significant factor in the decision by a buyer to trust an eCommerce site (McKnight et al., 2002b); as previously discussed, an ePHR is a web-based system, where one places personal information, trusting that the provider of the site will treat the information carefully, and render the benefit to the user that is implied in the expected operation of the site. This trust-benefit relationship also applies to an eCommerce site, allowing for building some constructs in ePHR adoption analysis on eCommerce adoption analysis.

Someone who is more trusting—that is, has a higher disposition to trust—is more likely to trust in a given situation than someone with a lower disposition of trust. Therefore, the first antecedent of trust is hypothesised as follows.

Hypothesis 2a: Disposition to Trust will positively affect Trust in the ePHR.

Similarly, the perception of trustworthiness of the company or groups that are behind the eCommerce site has been demonstrated to be a contributing factor to a consumer's trust in the site and their intention to use the site to satisfy their needs (Gefen et al., 2003; Kim et al., 2008; McKnight et al., 2002b). In this dissertation, based on the healthcare environment, there will be one of three possibilities for the ePHR provider (Undem, 2010), a doctors' clinic, the provincial health authority, or the vendor of the system running the ePHR software. The greater the trust in the organization that is providing the ePHR to the consumer, the more the consumer is likely to trust the ePHR. Thus, the second antecedent to trust is hypothesised to be as follows.

Hypothesis 2b: Institutional Trust will positively affect Trust in the ePHR.

The relationship between trust and distrust has been shown to be that of parallel, distinct, and inverted constructs, not opposites on a spectrum (Lewicki et al., 1998; McKnight & Choudhury, 2006). As such, where a trust antecedent exists there will be a similar antecedent to distrust. Therefore the distrust antecedent hypotheses are as follows.

Hypothesis 3a: Disposition to Distrust will positively affect Distrust in the ePHR.

Hypothesis 3b: Institutional Distrust will positively affect Distrust in the ePHR.

3.3 Trust

Trust and risk have a well-defined relationship. When a situation is perceived as risky, but of some value, consumers have been shown to look for signs that the transaction between the parties, of whatever nature, has some factors that can be counted on to either reduce, mitigate, or transfer some of the perceived risk so that the transaction may proceed with the intended benefit to each party; the trust that the consumer has in the other party, or in the legal or societal framework that has been established, documented, or suggested in the arena of the transaction is what reduces the perception of risk in the consumer (Kim et al., 2008; Ratnasingham & Pavlou, 2003; Rousseau et al., 1998). As discussed in

Chapter 2, trust in the ePHR is one part of what allows a user to accept the risk involved to adopt an ePHR.

There has been developed, over time, a concept of the calculus, or calculation, of trust (Huang & Nicol, 2010; Lewicki et al., 1998; Li et al., 2012; Rousseau et al., 1998). The calculation is the measure of the balance of the trust in the situation as compared to the benefits that are expected to accrue to the user. Thus, trusting an ePHR will allow the user to reflect differently on the risks in placing personal health data in the ePHR, reasonably feeling that the ePHR provider will provide a secure ePHR. So, while the risks are still perceived to be there, with a higher level of trust in the ePHR, the fear of loss from those risks is lessened, and the relationship between trust and risk is hypothesized to be as follows.

Hypothesis 4: Trust in the ePHR will negatively affect Perceived Risk of the ePHR.

TAM provides the input to the basic framework using the concept of external variables (Davis et al., 1989), or external stimulus (Davis, 1993). In this case, trust is that external factor, and the theory has the external stimulus affecting both PU and PEOU in the model. Since the current model uses self-efficacy in place of PEOU, a connection there is not supported, but the one to PU exists.

When there is trust in the ePHR, it is believed that, among other considerations, the ePHR will behave as expected, delivering the benefits ascribed to it by the healthcare system. If it performs as expected, then it is more likely to perform the tasks that the user expects it to do, and will be more likely to provide the usefulness expected. Thus the relationship between trust in the ePHR and the PU construct in the model is hypothesized as follows.

Hypothesis 5: Trust in the ePHR will positively affect the Perceived Usefulness of the ePHR.

3.4 Distrust

Distrust is not the same as the antithesis of trust, but is negatively correlated with it. Thus all of the relationships between trust and other factors in the model are paralleled and reversed in effect for distrust, based on McKnight's research (McKnight et al., 2002b; McKnight et al., 2004). The next two relationships in the model are hypothesized as follows.

Hypothesis 6: Distrust in the ePHR will positively affect Perceived Risk of the ePHR.

Hypothesis 7: Distrust in the ePHR will negatively affect the Perceived Usefulness of the ePHR.

3.5 Self-Efficacy

Computer self-efficacy, the self perception of the user's ability to perform a task using a computer, has been studied in the context of adoption of new technology (Hasan, 2007; Yi & Hwang, 2003). Self-efficacy has been cited as a useful measure when the user is not able to use the technology, as it allows the user to judge their ability to use existing skills in a new context (Hsu & Chiu, 2004). It has been shown that users' understanding of the usefulness of a system to allow them to achieve their desired outcomes is increased when they are confident in their ability to use that system (Compeau & Higgins, 1995; Igbaria & Iivari, 1995). Research in adoption of ePHRs has shown that computer self-efficacy has a positive influence on both PU, and on intention to use the ePHR (Richards, 2012). The opposite effect of computer self-efficacy on PU has been seen as well (Hasan, 2007), but was theorized to be a result of exceptional users. It was suggested that high self-efficacy individuals were able to see the flaws in the illustrated system, and so discount the usefulness of the system. It was also suggested that low self-efficacy users could be easily overwhelmed by the system and thus be more concerned with their ability to use the system than its usefulness. In general, the theory points to a positive relationship. In a study of risk in online systems similar to an ePHR, Featherman and Pavlou (2003) integrated risk into a TAM model, with an ease of use construct reducing the perception of risk. They adapted this concept from an earlier study (Moore & Benbasat, 1991) where increased complexity (low ease of use, poor self-efficacy) raised the perceived risk of a system. So, following the theory advanced and empirically tested in those two studies, the relationship between self-efficacy and risk in the research model is as follows.

Hypothesis 8: Computer Self-Efficacy will negatively affect the Perceived Risk of the ePHR.

Following Featherman and Pavlou (2003), and earlier studies mentioned above showing the positive relationship between self-efficacy and the ability to perceive how technology can be useful, increased perception of one's ability to

use an ePHR would increase the ability to determine how the ePHR would affect performance of the tasks desired from it. Therefore the relationship between self-efficacy and PU is hypothesized to be as follows.

Hypothesis 9: Computer Self-Efficacy will positively affect Perceived Usefulness of the ePHR.

Further, a heightened understanding of a system by those with higher computer self-efficacy can be shown to raise the intention to use the system (Hasan, 2007; Hsu & Chiu, 2004; Igbaria & Iivari, 1995) with the comfort in the perception that the users are able to adequately take advantage of the system to satisfy outcome expectations. A high level of ability with an ePHR will increase the confidence that adopting the ePHR would be beneficial, and so the relationship between self-efficacy and intention to use the ePHR is hypothesized to be as follows.

Hypothesis 10: Computer Self-Efficacy will positively affect Intention to Use the ePHR.

3.6   Risk Profile

Similar to disposition to trust and disposition to distrust and their effect on trust and distrust respectively, the perception of risk is influenced by the attitude of the perceiver. Thus, a measure of personal tolerance to risk is included in studies focusing on risk (McKibbon et al., 2007; Pearson et al., 1995) where a more comfortable relationship with risk—a higher value on the scale—reduces the perception of risk in a given situation. A risk accepting person (high risk profile) has a willingness to take risks as a matter of course, while a risk avoiding individual (low risk profile) will act to minimize the possible risks in life. This attitude will affect the ways in which a potential user will assess the inherent risk in an ePHR, causing different individuals to have a different perception of the risks involved.

Hypothesis 11: Risk profile will negatively affect Perceived Risk of the ePHR.

3.7   Perceived Risk

As discussed previously in Chapter 2, the risk of security failures and privacy breaches is the key risk component in the adoption of an ePHR. Several empirical studies have demonstrated that risk is a direct factor in the adoption of technology, with high risk systems being less likely to be adopted (Featherman &

Pavlou, 2003; Nicolaou & McKnight, 2006; Richards, 2012). Risk is a factor that clearly would reduce the potential user's interest in using the ePHR, and so would reduce the likelihood that the potential user intends to adopt the ePHR.

Hypothesis 12: Perceived Risk of the ePHR will negatively affect Intention to Use the ePHR.

3.8   Perceived Usefulness

Perceived usefulness captures the users' perception that the ePHR will allow them to attain their personal goals, or perform better at the tasks that they must complete (Davis, 1989, 1993; Davis et al., 1989). This is the user's perception of the benefit that he or she is expecting to receive by adopting the ePHR. When PU is high, the user expects the ePHR to better provide the health data management and other healthcare improvements that they believe will be the result. If the user is unable to see the value that the ePHR is supposed to provide them, they will not see the ePHR as useful.

This positive relationship between PU and intention to use an ePHR is based on the link in TAM, which has been empirically validated many times, in eCommerce, and in ePHR adoption studies (Featherman & Pavlou, 2003; Gefen et al., 2003; Richards, 2012; Torres, 2011). Therefore the final hypothesis is as follows.

Hypothesis 13: Perceived Usefulness of the ePHR will positively affect Intention to Use the ePHR.

The next chapter will describe the process used to develop and administer the survey used to collect the data required to empirically validate the proposed model.

4   Research Design

This chapter describes the actual process used to gather and screen the responses used to empirically validate the proposed model. The analysis is found in the next chapter. The survey development, data gathering process, pilot test results, and survey distributions are described.

4.1   Research Process

To test the consumer perceptions of potential ePHRs, a standardized approach was needed. The concept of scenarios, where a story is presented to survey participants and their perceptions obtained (Schoemaker, 1993; Wason et al., 2002), has been used in several areas of research into perceptions. Areas beyond marketing and consumer preference, including ethics (Banerjee et al., 1998), security violations (Siponen & Vance, 2010), and misbehaviour (Guo et al., 2011) have used scenarios successfully, demonstrating their effectiveness. After deciding to use scenarios, the next decision is how many scenarios to present to the survey participants. The accepted best practice, to reduce effort by the respondents, to prevent learning bias, and to facilitate the statistical analysis, is to present only one scenario to a participant and analyze differences in responses (Dimoka, 2010; Meyers et al., 2006).

Two dimensions were chosen for manipulation, based on the theory and opportunities for manipulation. To encourage trust in the ePHR, those establishing ePHRs in Canada can only change a few things; one is the presentation of the ePHR, and the other is the visible provider of the ePHR. The theory (Gefen et al., 2003; McKnight et al., 2002b) has three constructs as the antecedents to Trust and Distrust: disposition to trust or distrust, institutional trust or distrust, and structural assurances. Thus, the manipulation of structural assurances, making a site appear secure or unsecure with appropriately displayed items may influence the main study constructs leading to the intention to use. The respondents' disposition to trust and disposition to distrust are, by their nature, not constructs that can be manipulated, but institutional trust and institutional distrust can be manipulated by changing the institution—that is, the visible provider of the ePHR. From the restrictions within the healthcare sector in Canada, the three reasonable possibilities for the provision of an ePHR to the public are a clinic in a tethered—or possibly interconnected network—ePHR, a department within the provincial health ministry offering an ePHR for those participating in the provincial health insurance plan, or a third party provider of

systems and services operating an ePHR under contract, probably to the health ministry. This is, therefore, the second manipulation within the model.

For those reasons, a three by two scenario breakdown was used with the options on one dimension (ePHR sponsor/provider) being one of a government, third-party ePHR vendor, or primary physician's clinic highlighted as the provider of the ePHR. On the other dimension (structural assurances) the options were the inclusion or not of structural assurance items to denote a secured or unsecured web portal. The six scenarios are listed in Table 4.1. Participants were randomly assigned into one of the six scenarios, based on the seconds value (value *modulo* 6, creating six possible group codes) in the time that they started the survey. By having the group assignment change between each participant and the next, it was expected that a relatively uniform distribution would be created as in other studies; testing confirmed a relatively balanced distribution.

Table 4.1 Scenario Breakdown

Provider → **Structural Assurances ↓**	Doctors' Clinic	Provincial Ministry	3rd Party Vendor
No Structural Assurances	Scenario 1	Scenario 3	Scenario 5
Structural Assurances Shown	Scenario 2	Scenario 4	Scenario 6

The primary tool for this study was a Web-based quantitative survey, using a set of approximately 50 statements responded to by participants, on a seven point Likert scale. These statements were derived from constructs in the existing literature that have previously been used to study the factors of interest in this research. In creating the survey questions, it is always better to use or adapt closely related studies looking at comparable subjects as a first source of validity (Boudreau et al., 2001). The statements were re-worded as necessary to reflect an ePHR online portal and its presentation to potential users; as discussed previously, strong parallels exist between eCommerce websites and ePHR portals, providing a fair basis for content and nomological validity (Straub et al., 2004). Table 4.2 below summarizes the source of material for the factors studied here.

Table 4.2 Sources of Survey Material

Factor	Source study	Comments
Trust	McKnight et al 2002, Hall et al 2002, Gefen et al 2003, Hassanein and Head 2004, Kim et al 2008	Covering disposition, beliefs, intentions, and institutional trust
Distrust	McKnight and Choudhury 2006	Each trust item is transformed to distrust as described
Risk	Featherman and Pavlou 2003	Adapted to ePHR, health
Usefulness, Intention	Wilson and Lankton 2004, McKnight and Choudhury 2006	Adapted to ePHRs, health concerns
Self-Efficacy	Marakas et al 1998, Marakas et al 2007	Rules used to create statements on ePHRs, health concerns
Structural Assurances	Gefen et al 2003	Adapted to ePHR, health
Risk Profile	Pearson et al (1995)	Measure of willingness to take risks, unmodified

4.1.1 The Survey

The complete survey is in Appendix A: eHealth Survey. The survey comprised an introduction, a series of images and accompanying text, the survey questions, and a conclusion. The introduction to the survey discussed the possible risks involved in taking the survey, as well as the rights of the participants to withdraw from the survey, as required in the ethics approval process. If a participant clicked on the button at the end of the introduction to go on to the questions, this was deemed consent to the terms of the survey. At the end of the survey, the conclusion thanked them for their time and assured them of confidentiality.

4.1.1.1 Scenario Images

Several images were shown in the survey introduction to demonstrate some of the functionality that an ePHR can provide. These images were presented so that the respondents could judge the usefulness and applicability to their situations, as well as judge the level of trust, distrust, and risk involved in using such a system. The images had a common set of six central images, and each scenario had a unique frame to represent different websites appropriate for the scenario. It was possible for a participant to return to the images at any time while

completing the survey. Images and the frames used appear in Appendix A: eHealth Survey.

The images were taken from a demonstration version of a tethered ePHR in use for patients and their families at Toronto's Hospital for Sick Children. The ePHR was used with the permission of the developers (the *Clarity Health Journal*, by Consulting Cadre International Inc.) for use as a source of images of a functioning and professional ePHR. A fictitious family and some example data were entered into the system and screen-shots taken. The home page, and pages relating to personal ailments, condition selection, condition information, monitoring, and a data chart were chosen as representative. All scenarios received the same images with minor text changes. The scenarios that were to be from a doctor's clinic were relabeled in the images from Clarity Health Journal to "Clinic Health Journal". The provincial and system provider were relabeled as "Provincial Health Journal" or "Prov. Health Journal" depending on the space available in the source image. The changes were done this way to minimize the alteration of the original images.

Each image was introduced in the page of the survey with a few words of text indicating the purpose of the page shown, and some of the features illustrated. The home page was used to show that a family could keep all of their data in one place, if desired, and demonstrated the range of information that could be organized and retained. The ailments page was used to show the medical history of a family member and the readiness of data access. The conditions page was used to show how one would enter data on a specific condition into the personal record, demonstrating the possibility of several methods of finding the desired condition. The information page was used to demonstrate how reliable information on a condition could be presented to the patient. The monitoring page was used to show how medical data could be collected over time to provide a record of progress or deterioration. The data chart page was used to show how data could be entered and presented in chart form.

To create scenarios for structural assurance, a frame to go around the images was designed to look like a web browser on a computer system for each scenario and used for each image in the scenario. The top part of the frame showed an address bar with a web address implying a doctor's clinic, the province, or a system provider as the provider of the ePHR, and either a secure or normal

transport (https or http, with or without a lock symbol). The bottom frame was one of two, either with the structural assurances of a third party security emblem, contact link, and security privacy contact, or with no assurance elements. Each bottom frame was used in common across the scenarios to match either a secure or not secure top frame. A full set of the six scenario frames is reproduced for the first image in Appendix A: eHealth Survey.

4.1.1.2 Trust and Distrust Items

Trust has been studied quite often, particularly in terms of consumer behaviour (summarized well in (Gefen et al., 2003; McKnight et al., 2002b)) and has been determined to have a personal component, the disposition to trust, and an institutional component, the recipient of the trust. Within these, subcategories have been demonstrated (McKnight et al., 2002a) that refine the trust concepts more precisely. For personal trust, the subcategories are identified as benevolence, integrity, competence, and trusting stance; for institutional trust, the subcategories are general trust, benevolence, integrity, and competence. McKnight and his team generated a set of items for each construct; the full instrument comprises 23 items.

With many constructs to investigate in the ePHR research model, some reduction was necessary to lessen the possibility of question fatigue in the respondents leading to withdrawal from the survey (Hinkin, 1995). This also created the requirement to validate the scales prior to the analysis of the results. One item from each of the personal categories was selected, selecting items that had a clear, positive statement of trust; this item reduction method has been used to simplify similar surveys (Gefen et al., 2003; Hassanein & Head, 2004a; Kim et al., 2008). For institutional trust items, the general category was dismissed as non-specific, and the benevolence items were very close to the personal belief in benevolence items. Thus two items were selected from the integrity and competence constructs. Again, clear statements of trust were selected; for example, "I believe that most professional people do a very good job at their work" was selected but "A large majority of professional people are competent in their area of expertise" was not because of the increased qualification and word complexity.

The original McKnight study asked consumers their opinion on Internet vendors, so wording of some of the items needed to be changed to reflect the potential

sources of the ePHR. Instead of referring to Internet vendors, the items referred to "my Doctor's office", "my Provincial Health Ministry", and "the System Administrator" for the three possible ePHR providers in the study. Further, since feedback on the items' text from the pre-test asked if one expected competence from a ministry or merely the staff employed there, the wording was changed to employees or staff members.

The items on trust in the ePHR itself come from another eCommerce study, by Hassanein and Head (Hassanein & Head, 2004a) studying trust in a vendor as influenced by product type. Four of the 10 items in the trust measure used were selected based on their specific content towards eliciting a response to the service supplied, privacy, security, and general trustworthiness. Again, the wording was changed from "the online vendor" to "this ePHR", narrowing the term to just service from product or service, and changing references to a transaction with the vendor to simply "using this ePHR".

This process reduced the measurement of trust in the ePHR, and its antecedents, from over 20 items to 12; for the four institutional trust items there were three variants—one for each of the possible ePHR providers.

Distrust items were derived from the equivalent trust items using the method described by McKnight and Choudhury (McKnight & Choudhury, 2006). The inverted sense was created by applying the word "not" as a verb modifier, and a negative emotion was invoked using words such as "fear", "worry", and "concern" from a thesaurus. This method has been shown to generate the opposite sense from trust, and the emotion-laden impact that distrust has been found to have (Dimoka, 2010; Lewicki et al., 1998; McKnight & Chervany, 2001a; McKnight & Choudhury, 2006).

The order of the items was randomized within their category by assigning numbers to each and generating a random sequence of these. The institutional questions were in the same order in all scenarios to avoid having order confound the response evaluation (Schwartz, 1999).

4.1.1.3 Structural Assurance Items
The structural assurance items were selected from the work of Gefen and his colleagues (Gefen et al., 2003) integrating TAM and trust models. Their study was focused on an online vendor, where those items that consumers had been

told by security experts to look for were part of the study of generating trust in a vendor. For this dissertation, the items were modified from the original to substitute "this ePHR" instead of "the online vendor", and terms were shifted from explicit business to consumer signs to more generic online trust items. For example, instead of referring to the Better Business Bureau, reference was made to third party protection, and reference to a "1-800 number" was replaced by commenting on seeing a way to contact the provider.

4.1.1.4 Perceived Risk Items

The perceived risk items were taken from a study of risk factors in eServices adoption, where all six specific risk facets were studied, along with general risk perception (Featherman & Pavlou, 2003). Using all twenty-five items from the study would be overwhelming as part of a larger study, so focusing the risk to a general risk item and the three privacy risk items made this construct more manageable and consistent. The privacy risk facet was selected as a result of the previous studies on concerns patients had expressed over their health information being in an eHealth system (CHI, 2007; King et al., 2012; Tang et al., 2006; Willison et al., 2007). Two items in the general risk category were combined, taking the explicit risk concept from one and using it to replace the less specific "dangerous" concept. Since the Featherman and Pavlou items were about a generic service for bill payment, the wording was changed to focus on ePHRs in general, for the privacy items, and on this ePHR or similar systems for the general risk item.

4.1.1.5 Risk Profile Items

The risk profile items were taken directly from Pearson and colleagues' study of risk and emergency doctor behaviours (Pearson et al., 1995). The text of the questions was unchanged.

4.1.1.6 Self-Efficacy Items

Self-efficacy is a topic-specific concept, relating specifically to the actions being tested. In this case, the estimation of ability to use an ePHR was based on seeing images of it with explanations. Questions of key usage actions were developed using guidelines in self-efficacy research (Marakas et al., 2007; Marakas et al., 1998), and using the image content that the respondent had seen (discussed in Section 4.1.1.1); these guidelines also suggest using a phrasing template for the questions, so that there is similarity and consistency in the wording; that is to

say, all of the questions would begin with a phrase such as "I believe I would have the ability to...". Also from the same guidelines, the statements were presented in random order, so that a perception of a ranking of difficulty was not imputed.

4.1.1.7 Perceived Usefulness, and Intention to Use Items

Perceived Usefulness and Intention to Use are tightly linked constructs in TAM research, so both sets of items were taken primarily from a study of TAM in eHealth (Wilson & Lankton, 2004). The wording was changed from generic eHealth to "an ePHR" and some emphasis softened ("critical" to "important"). Since only two items assessed intention in the original, a further intent item was taken from another study (McKnight & Choudhury, 2006), and the text modified from the legal advice site studied and its services to "this ePHR" and "manage my health information".

4.1.1.8 Open-ended Questions

Also included in the survey were some open-ended questions that were used to verify that the concepts that are important to the respondents had been captured, even if they were not part of the model. These questions were also used to gather more of the participants' motivations and feelings regarding the trustworthiness of the ePHR and the perceived risks involved in sharing sensitive health data online. The responses to these open-ended questions were analyzed and themes extracted to determine the factors and opinions involved in the participants' decisions.

4.1.1.9 Demographic Items

Standard demographics and control variables including health status—did the respondent or a close family member have a chronic illness and how did they feel on a ten-point scale—and Internet awareness—usage frequency and on-line shopping, for example—were also collected to allow for further study of possible effects. Items collected and categories are listed in Table 4.3.

Table 4.3 Demographic Data Values

Demographic Data	Values
Gender	M=Male F=Female
Age: Please select the range that includes your age	1=18-30 2=31-50 3=51-70 4=Over 70
Region: Please indicate which province or territory you live in.	1=Newfoundland and Labrador, 2=Nova Scotia, 3=New Brunswick, 4=PEI, 5=Quebec, 6=Ontario, 7=Manitoba, 8=Saskatchewan, 9=Alberta, 10=British Columbia, 11=Yukon, 12= Northwest Territories, 13=Nunavut, and 14=Other country
Household income: Please select the category that matches the combined income of everyone in your home	1=Under $25,000 2=$25,000 to $50,000 3=$50,000 to $75,000 4=$75,000 to $100,000 5=$100,000 to $125,000 6=Over $125,000
Education: Please select the entry that best matches the highest level of education you have achieved	1=Some high school 2=Completed high school 3=Some post-secondary (college or university) 4=Completed post-secondary 5=Some post-graduate (Masters, Doctorate) 6=Completed post-graduate
Internet use location: Please indicate where you regularly access the Internet	1=At home only 2=At work or school only 3=At both home and work/school 4=At some other location

Internet usage: Please indicate how many hours you estimate you use the Internet in a week	1=Under 2 hours 2=2 to 5 hours 3=5 to 10 hours 4=10 to 20 hours 5=20 to 40 hours 6=Over 40 hours
Internet shopping: Please indicate how often you purchase items on the Internet	1=Never 2=Rarely 3=Sometimes 4=Often
Personal health: Do you suffer from a chronic or long-term health condition that requires regular treatment and/or medication?	Y=Yes N=No
Personal health status: On a scale of 1 to 10, where 1 is very poor and 10 is excellent, please rate your assessment of your health at this moment	1 2 3 4 5 6 7 8 9 10
Family health: Do you have a close family member who suffers from a chronic or long-term health condition that requires regular treatment and/or medication?	Y=Yes N=No

4.1.2 Survey Participation Requirements

The survey population included English-speaking Canadian adults; no special knowledge or particular demographic segment was expected or preferred. The sample size required was based on survey guidelines for a six-scenario evaluation; it was determined that at least 20 participants per group (Hair et al., 1998) were required for sufficient statistical power in inter-group analysis, resulting in a minimum of 120 participants. Partial Least Squares (PLS) guidelines of ten times the maximum number of predictors in a construct—items in the construct, or connections from antecedents in the model—(Chin, 1998; Roldán & Sánchez-Franco, 2012) indicated that more than 50 participants are required per scenario if detailed analysis using PLS on a per-scenario basis were to be

performed; the self-efficacy construct has the maximum number of 5 items. Thus, a target of 300 participants was established. Since a low response rate is often seen in studies on technology (Sivo et al., 2006), the distribution of calls for participation in the survey needed to be broad enough, and cover enough potential participants to allow for that low return rate.

4.2   Pilot Study Findings

Initially, a convenience group of about 90 people—graduate students and other volunteers approached through university mailing lists and personal contacts— was presented with an early version of the survey to test for clarity and understanding, and to validate the modifications made to the scales to adapt them to the survey. No substantial problems were reported with the survey in content. However, technical issues with the survey software rejected many users, and as a result, too few responses were available to run validation tests. The pilot was abandoned, save for some minor wording adjustments for clarity of information and understanding. Validation of the scales was moved to a later phase of the survey process.

4.3   Data Gathering Process

Upon approval by the McMaster University Research Ethics Board, a survey population was sought through the membership of several chronic disease advocacy and support organizations. Each respondent was asked to pass along the request to at least one generally healthy friend or relative. It was anticipated that using this technique would attract both those medically motivated by some health issue in their lives, and those not motivated in that way (well individuals). To achieve the required sample size, twenty-five organizations with cumulative membership counts totalling well over 10,000 were contacted by mail, and follow-ups made by telephone, garnering support from the *Anaphylaxis Network, Medic Alert Canada, COPD Canada Patient Network*, and *Connect Us*. Notices were placed in the groups' newsletters, websites, and Facebook pages, inviting the reader to go to the survey website. Further requests went out through personal and business contacts. Participants were compensated for their time by placing their names in a draw for gift cards. This survey was active from October 2011 through March 2012.

The survey software stability continued to generate a high dropout rate. A review of the responses indicated that there were insufficient results to begin

analysis. To achieve the required 300 responses, an ethics board approval for a modification was received to use a commercial survey organization to gather more responses. The survey firm provided their own compensation to those participating through the organization. The survey firm sent out e-mail messages to an undisclosed number (for business practice protection reasons) of their contacts, inviting the reader to follow the link to the survey website. After a second round of surveys was collected, the total number of responses was adequate for analysis. This survey process ran from March 7th to March 14th, 2012.

Since the stated purpose of targeting the support organizations for contacts was to ensure that a substantial subgroup either had a chronic disease or health situation that would be supported by the benefits an ePHR can provide, or knew someone in that situation, an open call could have meant a low response in that category. The desired characteristic of chronic disease or knowledge of the requirements of care for a chronic disease was tested and numbers for these demographic values between the two sample groups were found to be very similar.

5   Data Analysis

5.1   Preliminary Data Screening

In the first round of sampling, 86 complete surveys were gathered from 129 visitors to the survey site; this initial group of responses is referred to as the *Health Groups sample*. The data in this group exhibited a completion rate of 64 percent, with 33 percent incomplete and 3 percent being rejected. Data screening for this group consisted of looking for skipped survey questions, as responses were not mandatory during data gathering for this sample. Single and double skipped questions (two responses) were retained, but three or more skipped questions caused the survey response to be rejected. Data from three respondents were rejected for this reason.

The survey organization's call to participate attracted a further 402 participants, generating 314 complete responses; this was close to the goal of 300 participants from this source, in case the two groups could not be integrated. The completion rate for the second round of participants, referred to as the *Survey Organization sample*, was 78 percent, with 22 percent incomplete. Since survey items were mandatory for this group, no rejections were necessary for that reason.

Survey responses were checked for "gaming". This was reported by the survey organization to be a known problem with responders seeking to maximize the rewards for participating. To remove these gaming problems, responses of all, or almost all, one point on the Likert scale such as almost all 1s or 7s, or simple patterns such as 1, 2, 3, 4, etc. were scanned for by both data search and graphing the responses, and when found these survey responses were rejected. There were seventeen such response patterns discovered in the Survey Organization sample, and one in the Health Groups sample.

A total of 379 survey responses were thus available for analysis. Since there was no way to track the number of readers of the notices from the Health Groups sample, and the survey company would not disclose the number of messages sent, it is impossible to record the non-response rate for this study. Of the 131 incomplete responses, only 21 quit after answering at least one question, suggesting a strong desire to complete the survey in the surveyed population.

Demographic questions were optional in both samples, but having too many skipped questions was seen to reduce the quality of possible analysis. The data were coded to determine the number of missing answers in the demographic questions, and if three or more questions were skipped, the entire response was rejected. As can be seen in Table 5.1, a large number of respondents skipped the income question, and many skipped the gender question, but very few other questions were skipped.

There were no survey responses rejected from the Health Groups for missing demographic answers, and 13 responses were rejected from the Survey Organization sample. Once all the screening of the data was completed, 366 valid surveys were used in the analysis.

5.2   Consolidation of Data

With two groups of participants, the careful consolidation of the data is an important consideration. Several tests (Meyers et al., 2006) were performed on the data to ensure that the data were sufficiently invariant between sources. First a general comparison was made. Second, a simple statistical comparison of aggregate construct results was performed. Finally, a full statistical analysis of the survey was performed.

5.2.1   Basic Comparison

The first, most basic test was a simple comparison of the demographic data from the two sets of participants that were captured as part of the survey. While many participants did not answer some of these questions, few failed to answer all of them.

As shown in Table 5.1, the two samples are not incomparable. Note that where a difference existed in one area relative to that region's population (for example Ontario in the region demographic in the Health Groups sample), the spread in the Survey Organization sample balanced it, approximating the broader population that this study was measuring. While the alignment is not ideal, it is an indication that the groups are not too dissimilar, and therefore at the most basic level, the data from the two groups could be combined.

In Table 5.1, the percentage of the demographic questions is based on those answering that question. In the missing category, the percentage is based on those completing the survey. That is, 7 percent of the survey organization's 284

respondents did not answer the gender question. Of the 264 who did answer, 61 percent reported their gender as male and 39 percent reported being female.

Table 5.1 Demographic Data Summary

Variable	Values	Health Groups (N=82)		Survey Organization (N=284)	
		Count	%	Count	%
Gender	Male	38	49	160	61
	Female	40	51	104	39
	Missing	4	5	20	7
Age	18-30	11	13	85	30
	31-50	47	57	66	23
	51-70	18	22	102	36
	Over 70	6	7	29	10
	Missing	0	0	2	1
Region	Maritimes	0	0	20	7
	Quebec	1	1	49	17
	Ontario	75	93	78	28
	West	5	6	135	48
	Missing	1	1	2	1
Household Income	Under $25,000	5	6	24	11
	$25,000 to $50,000	6	8	42	19
	$50,000 to $75,000	7	9	55	25
	$75,000 to $100,000	15	19	47	21
	$100,000 to $125,000	14	18	21	9
	Over $125,000	32	41	34	15
	Missing	3	4	61	21
Highest Education Achieved	Some high school	1	1	6	2
	Completed high school	2	2	38	14

Variable	Values	Health Groups (N=82)		Survey Organization (N=284)	
		Count	%	Count	%
	Some post-secondary	8	10	70	26
	Completed post-secondary	28	34	113	41
	Some post-graduate	13	16	16	6
	Completed post-graduate	30	37	30	11
	Missing	0	0	11	4
Internet location	Home only	19	23	135	48
	Work or school only	1	1	6	2
	Both home and work/school	59	72	140	49
	Some other location	3	4	3	1
	Missing	0	0	0	0
Weekly Internet usage	Under 2 hours	8	10	19	7
	2 to 5 hours	6	7	35	12
	5 to 10 hours	11	13	54	19
	10 to 20 hours	17	21	103	36
	20 to 40 hours	27	33	54	19
	Over 40 hours	13	16	18	6
	Missing	0	0	1	0
Online shopping	Never	15	18	34	12
	Rarely	17	21	80	28
	Sometimes	39	48	123	43
	Often	11	13	47	17
	Missing	0	0	0	0
Personal chronic	Yes	29	36	102	37
	No	51	64	172	63

Variable	Values	Health Groups (N=82)		Survey Organization (N=284)	
		Count	%	Count	%
health condition	Missing	2	2	10	4
Personal health status	Mean	8.06		7.86	
	Missing	0	0	1	0
Family chronic health condition	Yes	53	65	144	53
	No	29	35	130	47
	Missing	0	0	10	4

5.2.2 t-Test Comparisons Between Groups

The second test of the data gathered from the two sources is the Student's t-test between the groups' responses to the survey constructs to determine if there are differences between responses that can be explained by the different groups of responses. Multiple t-tests were performed against the aggregate (formed by averaging response values for items in a construct by respondent) responses for the constructs, using the source as the grouping variable. If a significance value was below 0.05, then the groups could be considered statistically distinct for that variable. As can be seen in Table 5.2, the t-test results show that while three aggregates (in bold) had significant differences, there was no significant difference between the groups' responses to the other nine constructs. This result could be isolated differences, or evidence of a problem in combining the groups. Therefore an investigation of the full impact of the possible difference between groups on all the items considered together as a system was required before proceeding.

Table 5.2 t-Test Results for Aggregate Values between Data Source Groups

Measure (Aggregates)	t-Test Significance
Disposition to Trust	0.122
Institutional Trust	0.430
Trust in the ePHR	0.678
Disposition to Distrust	0.125
Institutional Distrust	0.282
Distrust in the ePHR	0.391
Structural Assurances	0.791
Risk Profile	**0.047**
Perceived Risk	0.316
Self-Efficacy	0.265
Perceived Usefulness	**0.008**
Intention to Use	**0.006**

5.2.3 MANOVA Results

The third test before complete confirmation of data combination was a full MANOVA analysis of the responses for the two groups, compared as a complete system of responses. All of the aggregates were tested against the group that the data came from, to see if there was a statistically significant link between the data group and the aggregate values as a whole. The generally reported single measure for this analysis is the significance value of the Wilks' Lambda test (Meyers et al., 2006); the standard significance interpretation applies to these results, so the value greater than 0.05 confirms the hypothesis that there are two distinct groups represented. All MANOVA fit results, summarized in Table 5.3, returned significances above the accepted 0.05 level, and thus the hypothesis that there are two groups is not supported.

Table 5.3 MANOVA Fit Quality Results for All Aggregates Tested Against Data Groups

	Value	F	Hypothesis df	Error df	Sig.
Pillai's Trace	0.037	1.165	12.000	362.000	0.307
Wilks' Lambda	0.963	1.165	12.000	362.000	0.307
Hotelling's Trace	0.039	1.165	12.000	362.000	0.307
Roy's Largest Root	0.039	1.165	12.000	362.000	0.307

Therefore, there are not two distinct groups, and the data may safely be studied as one group, and not two separate populations. The count of the responses by scenario, ePHR provider, and structural assurances of the two samples combined is shown in Table 5.4.

Table 5.4 Complete and Screened Survey Response Counts by Scenario

	Doctor	**Province**	**Vendor**	**Total**
Not secure	56	64	58	178
Secure	63	65	60	188
Total	119	129	118	366

5.3 Data Validation Analysis

5.3.1 Survey Instrument Validation Tests

When revising the survey scales to create the research survey for this dissertation, certain changes, documented in Chapter 4, were made to established scales. These revised scales should be tested for validity before analysing the data. As the pilot study provided too little data for analysis, the data that were collected in the main study were divided into two samples, one small set to serve as the validation data, and the larger set for the main analysis. This division is in line with other research studies, where a larger sample is divided randomly to test results in a different manner (McKnight et al., 2002b).

Each response was randomly assigned a decimal code value from 0 to, but not including, 7; for example, 3.923521. This divided the collection into seven groups (those with an initial digit of 0, 1, 2 etc.). Each group comprised approximately 50 samples in this manner, as the guidelines for using PLS on this model suggested a sample size of 50 (Chin, 1998). So one group was selected to be the validation sample, and the remainder would be the data analysis sample. Once the division was complete, the validation sample comprised 58 responses and the data analysis sample had 308. The validation sample had 25 percent reporting that they had a chronic health condition, and the analysis sample had 38 percent. The scenario (ePHR provider, and structural assurance) breakdown is in Table 5.5. The first number is the validation sample count and the second is the data analysis sample count. The division of the data is reasonably equitable based on the scenarios, and the representation of those with chronic illness is not unbalanced.

Table 5.5 Survey Response Counts by Scenario After Data Split

	Doctor	Province	Vendor	Total
Not secure	8/48	11/53	7/51	26/152
Secure	11/52	12/53	9/51	32/156
Total	19/100	23/106	16/102	58/308

First number is validation group count, second is data pool count.

Following the guidelines for validating a new survey instrument, several validity tests must be run (Straub et al., 2004). Content validity—that the items are a fair representation of the content from theory—was validated by using content from established instruments. Convergent construct validity—that items in a construct are strongly associated with each other—was tested using the correlations, average variance extracted, and convergent reliability data from a PLS analysis of the model using the validation data (Chin, 2010). The results are shown in Table 5.6, with the square root of the average variance extracted (AVE) for each construct on the diagonal. To show convergent validity, the square root of AVE should be greater than 0.707, and greater than correlations with other constructs (Chin, 2010). Also shown is Composite Reliability (CR), which is a reliability indicator, with good reliability over 0.7 (Chin, 2010). The validation data exhibits convergent validity.

Table 5.6 Validation Data Convergent Construct Validity Test

Construct	Composite Reliability	Disposition to Distrust	Disposition to Trust	Distrust	Institutional Distrust	Institutional; Trust	Intent	Perceived Usefulness	Risk	Risk Profile	Self Efficacy	Structural Assurances	Trust
Disposition to Distrust	.91	.85											
Disposition to Trust	.90	-.73	.84										
Distrust	.95	.49	-.29	.91									
Institutional Distrust	.96	.56	-.33	.56	.92								
Institutional Trust	.91	-.55	.45	-.61	-.83	.84							
Intent	.98	-.18	.12	-.38	-.22	.24	.97						
Perceived Usefulness	.96	-.20	.18	-.31	-.29	.28	.86	.94					
Perceived Risk	.92	.30	-.19	.70	.44	-.52	-.57	-.51	.86				
Risk Profile	.86	.21	-.21	-.31	-.09	.02	.10	.12	-.29	.73			
Self Efficacy	.93	-.13	.09	-.29	-.21	.34	.41	.52	-.33	.00	.86		

Construct	Composite Reliability	Disposition to Distrust	Disposition to Trust	Distrust	Institutional Distrust	Institutional; Trust	Intent	Perceived Usefulness	Risk	Risk Profile	Self Efficacy	Structural Assurances	Trust
Structural Assurances	.91	-.43	.38	-.71	-.48	.58	.53	.50	-.60	-.01	.34	.85	
Trust	.93	-.45	.52	-.51	-.40	.49	.36	.39	-.52	-.04	.24	.63	.88

Discriminant construct validity—that the items discriminate between constructs, that they best represent their own construct and not another—were tested using the loadings and cross-loadings results of a PLS analysis of the model using the validation data (Chin, 2010). The scores bolded in Table 5.7 are the ones where an item is loading on its construct. For discriminant validity, each bolded score should be higher than any in its row, and the bolded scores should be the highest in their column. The bolded scores should ideally exceed 0.70, but 0.50 and higher can be acceptable (Chin, 2010). Note that there is a clear concern with item RP4, from the risk profile construct, and thus the item was removed from the construct. Beyond that, the validation data passes the discriminant construct validity test.

Table 5.7 Validation Discriminant Validity: Item Loadings and Cross-Loadings

Item	ion to Distrust	Distrust	onal Distrust	ion to Trust	Trust	onal Trust	Assurances	Risk	Risk Profile	Self Efficacy	Usefulness	Intent
DD1	**.84**	.44	.43	-.56	-.38	-.39	-.30	.24	.07	.03	-.08	-.11
DD2	**.88**	.51	.47	-.63	-.47	-.52	-.47	.34	.12	-.15	-.15	-.18
DD3	**.86**	.30	.52	-.67	-.32	-.51	-.32	.20	.34	-.21	-.29	-.20
DD4	**.82**	.35	.50	-.65	-.30	-.47	-.31	.23	.28	-.13	-.23	-.14
DE1	.43	**.83**	.51	-.20	-.39	-.48	-.59	.59	-.14	-.30	-.33	-.44
DE2	.44	**.92**	.46	-.32	-.44	-.57	-.64	.57	-.35	-.24	-.14	-.20
DE3	.46	**.96**	.57	-.29	-.55	-.63	-.67	.70	-.30	-.33	-.34	-.38
DE4	.45	**.93**	.49	-.24	-.44	-.53	-.68	.68	-.32	-.18	-.30	-.34
DI1	.56	.43	**.90**	-.44	-.38	-.77	-.38	.40	.05	-.25	-.30	-.21
DI2	.52	.59	**.95**	-.34	-.46	-.81	-.53	.44	-.10	-.21	-.32	-.22
DI3	.52	.59	**.94**	-.25	-.39	-.77	-.50	.47	-.17	-.21	-.28	-.26
DI4	.47	.43	**.91**	-.22	-.21	-.71	-.30	.26	-.06	-.10	-.17	-.08
TD1	-.56	-.30	-.27	**.85**	.42	.38	.30	-.20	-.18	.09	.15	.18
TD2	-.64	-.17	-.21	**.89**	.50	.33	.27	-.11	-.24	.06	.16	.10
TD3	-.64	-.25	-.38	**.83**	.43	.49	.34	-.15	-.16	.17	.19	.07
TD4	-.60	-.26	-.27	**.78**	.38	.33	.40	-.20	-.10	-.04	.09	.06
TE1	-.37	-.34	-.31	.43	**.85**	.42	.50	-.42	-.16	.25	.41	.37
TE2	-.49	-.40	-.41	.51	**.88**	.45	.52	-.45	-.16	.34	.44	.40
TE3	-.34	-.53	-.36	.42	**.88**	.42	.62	-.44	.06	.11	.22	.21
TE4	-.36	-.50	-.32	.47	**.90**	.43	.59	-.50	.11	.13	.30	.28
TI1	-.44	-.57	-.68	.27	.46	**.79**	.53	-.51	.08	.28	.28	.32

Item	ion to Distrust	Distrust	onal Distrust	ion to Trust	Trust	onal Trust	Assuran ces	Risk	Risk Profile	Self Efficacy	Usefuln ess	Intent
TI2	-.46	-.59	-.76	.41	.51	**.92**	.58	-.51	.02	.29	.26	.23
TI3	-.47	-.34	-.65	.43	.21	**.80**	.33	-.27	-.07	.28	.21	.13
TI4	-.51	-.45	-.68	.49	.33	**.85**	.42	-.35	-.03	.31	.17	.06
SA1	-.23	-.61	-.33	.20	.52	.46	**.82**	-.54	.20	.31	.53	.54
SA2	-.42	-.65	-.49	.36	.49	.55	**.92**	-.58	-.05	.30	.46	.46
SA3	-.42	-.54	-.39	.46	.67	.51	**.90**	-.52	-.16	.32	.51	.53
SA4	-.36	-.59	-.40	.27	.45	.46	**.73**	-.39	-.03	.22	.17	.23
PR1	.26	.54	.38	-.18	-.57	-.47	-.51	**.86**	-.07	-.40	-.61	-.63
PR2	.32	.66	.46	-.22	-.50	-.55	-.60	**.94**	-.29	-.34	-.51	-.56
PR3	.29	.67	.39	-.17	-.41	-.50	-.58	**.91**	-.33	-.29	-.35	-.43
PR4	.14	.55	.21	-.07	-.22	-.19	-.32	**.68**	-.37	.04	-.19	-.21
RP1	.15	-.32	-.15	-.17	-.01	.08	.06	-.23	**.79**	.09	.14	.12
RP2	.13	-.12	.02	-.11	.02	.01	-.04	-.20	**.65**	.00	.05	.07
RP3	.15	-.32	-.21	-.18	-.01	.11	.09	-.30	**.81**	.07	.13	.12
RP4	.24	-.12	.14	-.22	-.04	-.13	-.12	-.10	**.36**	-.30	-.13	-.07
RP5	.20	-.21	.00	-.14	-.16	-.02	-.08	-.11	**.84**	-.01	.05	.02
RP6	.16	-.14	.03	-.10	-.06	-.12	-.12	-.19	**.81**	-.07	.12	.07
SE1	-.14	-.22	-.13	.21	.24	.31	.27	-.28	.01	**.89**	.55	.48
SE2	-.08	-.35	-.23	.01	.24	.36	.34	-.32	-.06	**.83**	.38	.27
SE3	-.16	-.36	-.26	.03	.20	.34	.38	-.35	.01	**.88**	.48	.41
SE4	-.02	-.18	-.13	-.06	.08	.23	.23	-.22	.02	**.93**	.42	.31
SE5	-.13	-.11	-.14	.15	.25	.17	.24	-.21	.00	**.74**	.32	.21
PU1	-.20	-.25	-.30	.21	.40	.29	.44	-.53	.01	.48	**.93**	.84
PU2	-.18	-.28	-.21	.16	.35	.23	.46	-.46	.15	.56	**.96**	.81
PU3	-.19	-.34	-.32	.12	.35	.28	.52	-.46	.16	.41	**.93**	.77
IU1	-.23	-.40	-.21	.17	.36	.25	.53	-.57	.07	.42	.85	**.98**
IU2	-.20	-.34	-.21	.16	.37	.26	.49	-.55	.04	.39	.84	**.98**
IU3	-.10	-.36	-.20	.02	.31	.19	.52	-.52	.19	.39	.80	**.95**

Thus, with the exception of the poor performance of the RP4 item, the validation data demonstrate that the survey instrument passes the basic validity checks. The primary analysis may proceed.

5.3.2 Common Method Bias

A number of checks for data validity were run against the data pool before the empirical testing of the model began. Common Method Bias is a potential problem for surveys such as this, where the questions respondents are answering come from the same, common source. The standard test is Harman's one factor test—an unrotated factor analysis (Podsakoff & Organ, 1986). If the first factor in the result accounts for more than half of the variance attributed to the factors with an eigenvector greater than 1, then there is reason to believe that common method bias exists in the data. As Podsakoff and Organ (1986) caution, this analysis method is a simple test metric and does not take into

account the natural correlations that exist between items in the survey. As is shown in Table 5.8, 9 factors meet the eigenvalue threshold that, together, account for 74.1 percent of the variance; the first accounts for only 35.8 percent. Common method bias does not seem to exist based on the factor analysis.

Table 5.8 Factor Analysis Results - Unrotated

Factor	Eigenvalue Total	% of Variance	Cumulative %	Sums of Squares Total	% of Variance	Cumulative %
1	17.558	35.833	35.833	17.558	35.833	35.833
2	4.208	8.588	44.422	4.208	8.588	44.422
3	3.179	6.488	50.91	3.179	6.488	50.91
4	3.117	6.362	57.272	3.117	6.362	57.272
5	2.237	4.565	61.836	2.237	4.565	61.836
6	2.062	4.209	66.045	2.062	4.209	66.045
7	1.555	3.174	69.219	1.555	3.174	69.219
8	1.263	2.578	71.797	1.263	2.578	71.797
9	1.131	2.307	74.104	1.131	2.307	74.104
10	0.973	1.985	76.089			

There is an alternate test for common method bias that uses the research model, modified to add a method construct and turn each item into a single item construct. The relative weights and significances of the paths for the method construct and the model construct are compared for each item. If the method path is significant and larger, then there may be a bias. The square of the loadings may be considered a percentage of variance (Liang et al., 2007). There have been some issues raised with the methodology, but it is could still reveal common method bias in some cases (Chin et al., 2012). From the data presented in Table 5.9, only 8 paths to the method construct were significant (in bold), while all of the connections to the model constructs were highly significant. The highest percentage of variance shown by the significant method paths is 2 percent of variance in the item (PR1 and TE2); all of the other connections were less.

Table 5.9 Common Method Bias Test: Unmeasured Latent Method Construct Results

Item	Model Construct Weight	Significance	Method Construct Weight	Significance
DD1	0.83	p << 0.001	0.04	p > 0.10
DD2	0.76	p << 0.001	-0.02	p > 0.10
DD3	0.84	p << 0.001	-0.07	p < 0.10
DD4	0.87	p << 0.001	0.04	p < 0.10
DE1	0.71	p << 0.001	-0.08	p < 0.10
DE2	1.00	p << 0.001	**0.08**	**p < 0.05**
DE3	0.86	p << 0.001	-0.08	p < 0.10
DE4	0.99	p << 0.001	0.06	p < 0.10
DI1	0.93	p << 0.001	0.06	p < 0.10
DI2	0.86	p << 0.001	**-0.07**	**p < 0.05**
DI3	0.90	p << 0.001	-0.02	p > 0.10
DI4	0.96	p << 0.001	0.03	p < 0.10
IU1	0.98	p << 0.001	0.00	p > 0.10
IU2	0.98	p << 0.001	0.01	p > 0.10
IU3	0.97	p << 0.001	-0.01	p > 0.10
PR1	0.74	p << 0.001	**-0.14**	**p < 0.05**
PR2	0.95	p << 0.001	0.03	p > 0.10
PR3	0.90	p << 0.001	-0.01	p > 0.10
PR4	0.91	p << 0.001	0.13	p < 0.10
PU1	0.87	p << 0.001	0.07	p < 0.10
PU2	0.99	p << 0.001	-0.04	p > 0.10
PU3	0.98	p << 0.001	-0.03	p > 0.10
RP1	0.86	p << 0.001	0.00	p > 0.10
RP2	0.55	p << 0.001	**-0.13**	**p < 0.05**
RP3	0.78	p << 0.001	**0.10**	**p < 0.01**
RP5	0.85	p << 0.001	0.02	p > 0.10
RP6	0.75	p << 0.001	-0.04	p > 0.10
SA1	0.88	p << 0.001	0.03	p > 0.10
SA2	0.94	p << 0.001	-0.05	p < 0.10
SA3	0.89	p << 0.001	0.03	p > 0.10
SA4	0.88	p << 0.001	0.00	p > 0.10
SE1	0.87	p << 0.001	0.06	p < 0.10
SE2	0.90	p << 0.001	0.02	p > 0.10

Item	Model Construct Weight	Significance	Method Construct Weight	Significance
SE3	0.90	p << 0.001	0.03	p > 0.10
SE4	0.96	p << 0.001	**-0.07**	**p < 0.05**
SE5	0.81	p << 0.001	-0.06	p < 0.10
TD1	0.87	p << 0.001	-0.06	p < 0.10
TD2	0.83	p << 0.001	0.00	p > 0.10
TD3	0.83	p << 0.001	0.01	p > 0.10
TD4	0.64	p << 0.001	0.06	p < 0.10
TE1	0.91	p << 0.001	-0.03	p > 0.10
TE2	0.74	p << 0.001	**0.14**	**p < 0.01**
TE3	0.98	p << 0.001	-0.07	p < 0.10
TE4	0.96	p << 0.001	-0.04	p < 0.10
TI1	0.87	p << 0.001	0.01	p > 0.10
TI2	0.79	p << 0.001	**0.11**	**p < 0.05**
TI3	0.95	p << 0.001	-0.07	p < 0.10
TI4	0.94	p << 0.001	-0.06	p < 0.10

From the results of the two tests, the factor analysis and the model analysis, there is no common method bias in the data and the variance is attributable to the constructs.

5.3.3 Data Pool Convergent Validity Test

The test for convergent validity, explained above Section 5.3.1, was repeated for the data pool. The results can be found in Table 5.10. The square root of AVE for each construct is greater than 0.707 and greater than any correlation between that construct and any other (Chin, 2010), and CR is greater than 0.7 for each construct (Chin, 2010). In Table 5.10 the square root of AVE is on the diagonal, and the off-diagonal items are the correlations between the items. As shown, the tests for convergent validity are successful, and the items do, indeed, measure the same concepts within each construct.

Table 5.10 Convergent Validity Test: Average Variance Extracted, Composite Reliability, and Correlations

Construct	Composite Reliability	Disposition to Distrust	Disposition to Trust	Distrust	Institutional Distrust	Institutional; Trust	Intent	Perceived Usefulness	Risk	Risk Profile	Self Efficacy	Structural Assurances	Trust
Disposition to Distrust	.90	.83											
Disposition to Trust	.87	-.62	.79										
Distrust	.94	.46	-.36	.89									
Institutional Distrust	.95	.61	-.35	.51	.91								
Institutional Trust	.94	-.35	.42	-.48	-.67	.88							
Intent	.98	-.28	.36	-.44	-.41	.54	.97						
Perceived Usefulness	.96	-.30	.35	-.52	-.36	.52	.70	.95					
Perceived Risk	.93	.41	-.36	.70	.53	-.52	-.47	-.48	.87				
Risk Profile	.87	-.08	.11	-.20	-.06	.06	.21	.19	-.17	.76			
Self Efficacy	.95	-.27	.29	-.36	-.29	.36	.50	.59	-.31	.21	.89		
Structural Assurances	.94	-.14	.35	-.52	-.30	.50	.55	.51	-.55	.30	.38	.90	
Trust	.94	-.27	.43	-.60	-.42	.62	.63	.56	-.58	.15	.41	.66	.90

5.3.4 Main Data Pool Discriminant Validity Test

The next step in validity checking, discriminant validity, reviewed the loadings and cross-loadings between the individual items and the constructs. In Table 5.11 the rows are the individual items, and the columns are the constructs. The cells that reflect the loadings of the questions on their construct are highlighted. As before, in Section 5.3.1, the items for the construct should be the highest in that construct's column; the highlighted value should be the highest in the row (Chin, 2010). Some guides suggest a minimum threshold of 0.70, but with the weighting scheme used in PLS, a threshold of 0.50 could be considered as long as the row and column rules are met and there is convergent validity for the construct (Chin, 2010). Review of the higher cross-loadings shows them to be constructs that have an expected strong correlation with the item's construct, such as trust items with their respective distrust items. The results are in Table 5.11. The loading that failed to meet the thresholds, specifically RP2 in the Risk Profile item, indicate that there are problems with that item and that it should be dropped from the analysis. Removing RP2 from the model and running the analysis again made no difference to any other loadings. The remaining data

displayed discriminant validity, indicating that the items best measure their construct and not any other.

Table 5.11 Discriminant Validity: Item Loadings and Cross-loadings

Item	Disposition to Distrust	Distrust	Institutional Distrust	Disposition to Trust	Trust	Institutional Trust	Structural Assurances	Risk	Risk Profile	Self Efficacy	Perceived Usefulness	Intent
DD1	**.81**	.38	.48	-.48	-.16	-.27	-.07	.36	.00	-.22	-.22	-.14
DD2	**.79**	.38	.43	-.49	-.22	-.19	-.13	.29	-.15	-.28	-.25	-.27
DD3	**.88**	.43	.60	-.55	-.30	-.36	-.17	.40	-.05	-.20	-.29	-.30
DD4	**.83**	.32	.52	-.55	-.19	-.33	-.10	.31	-.05	-.20	-.20	-.21
DE1	.42	**.76**	.44	-.30	-.49	-.40	-.36	.46	-.09	-.36	-.45	-.37
DE2	.39	**.94**	.42	-.31	-.54	-.42	-.51	.69	-.22	-.30	-.44	-.36
DE3	.43	**.92**	.49	-.36	-.57	-.47	-.49	.65	-.20	-.36	-.52	-.46
DE4	.42	**.94**	.47	-.31	-.54	-.42	-.51	.70	-.20	-.28	-.46	-.38
DI1	.58	.38	**.87**	-.37	-.34	-.57	-.22	.40	-.06	-.23	-.29	-.33
DI2	.54	.51	**.92**	-.28	-.42	-.63	-.31	.51	-.07	-.31	-.38	-.44
DI3	.54	.48	**.91**	-.34	-.42	-.63	-.28	.50	-.05	-.23	-.33	-.36
DI4	.59	.47	**.94**	-.31	-.36	-.61	-.26	.50	-.04	-.27	-.32	-.36
TD1	-.48	-.26	-.26	**.80**	.28	.34	.24	-.25	.13	.23	.29	.28
TD2	-.47	-.28	-.28	**.80**	.32	.35	.31	-.31	.06	.28	.33	.27
TD3	-.55	-.31	-.32	**.85**	.38	.37	.28	-.31	.03	.23	.28	.31
TD4	-.48	-.28	-.25	**.72**	.36	.28	.28	-.27	.16	.20	.23	.28
TE1	-.30	-.50	-.40	.40	**.88**	.53	.54	-.47	.11	.37	.49	.57
TE2	-.31	-.49	-.44	.41	**.86**	.58	.51	-.45	.15	.48	.58	.60
TE3	-.18	-.59	-.34	.36	**.93**	.55	.66	-.58	.13	.30	.47	.55
TE4	-.19	-.56	-.35	.38	**.93**	.58	.65	-.57	.14	.33	.49	.57
TI1	-.30	-.43	-.56	.38	.61	**.90**	.47	-.46	.01	.28	.43	.48
TI2	-.28	-.46	-.59	.33	.63	**.89**	.49	-.52	.08	.31	.49	.53
TI3	-.33	-.38	-.60	.37	.46	**.87**	.39	-.41	.05	.35	.47	.46
TI4	-.34	-.40	-.64	.41	.46	**.87**	.39	-.45	.07	.33	.44	.42
SA1	-.17	-.49	-.26	.35	.61	.44	**.90**	-.53	.29	.33	.45	.48
SA2	-.13	-.47	-.27	.33	.56	.42	**.90**	-.43	.29	.35	.43	.47
SA3	-.12	-.48	-.28	.32	.62	.49	**.91**	-.53	.23	.34	.48	.51
SA4	-.09	-.45	-.25	.27	.58	.45	**.88**	-.49	.26	.34	.47	.51
PR1	.38	.59	.53	-.30	-.55	-.50	-.47	**.85**	-.16	-.34	-.45	-.50
PR2	.39	.63	.48	-.31	-.52	-.50	-.49	**.92**	-.13	-.28	-.45	-.40
PR3	.38	.67	.45	-.40	-.55	-.46	-.54	**.91**	-.18	-.27	-.41	-.39
PR4	.28	.56	.38	-.24	-.40	-.36	-.43	**.81**	-.15	-.21	-.38	-.32
RP1	.02	-.12	.00	.06	.12	.06	.29	-.10	**.85**	.22	.17	.16
RP2	-.10	-.07	-.07	-.02	-.10	-.10	-.07	-.01	**.39**	.01	.02	-.02
RP3	-.10	-.17	-.07	.16	.17	.11	.29	-.16	**.85**	.25	.25	.28
RP5	-.01	-.19	-.03	.13	.16	.05	.32	-.16	**.87**	.11	.14	.15
RP6	-.14	-.17	-.09	.01	.03	-.04	.08	-.14	**.73**	.13	.07	.11
SE1	-.27	-.39	-.29	.29	.39	.35	.38	-.30	.18	**.92**	.58	.48
SE2	-.30	-.33	-.28	.30	.38	.33	.33	-.27	.17	**.91**	.56	.45
SE3	-.26	-.32	-.25	.29	.41	.35	.37	-.31	.18	**.93**	.57	.49
SE4	-.22	-.33	-.26	.23	.32	.27	.29	-.25	.24	**.91**	.49	.40
SE5	-.15	-.22	-.20	.17	.27	.27	.31	-.26	.17	**.77**	.38	.38

Item	Disposition to Distrust	Distrust	Institutional Distrust	Disposition to Trust	Trust	Institutional Trust	Structural Assurances	Risk	Risk Profile	Self Efficacy	Perceived Usefulness	Intent
PU1	-.30	-.52	-.38	.35	.54	.51	.50	-.46	.23	.57	**.93**	.63
PU2	-.28	-.50	-.35	.31	.53	.46	.48	-.47	.15	.55	**.96**	.65
PU3	-.26	-.46	-.32	.34	.54	.50	.47	-.45	.17	.56	**.96**	.69
IU1	-.27	-.44	-.39	.35	.63	.51	.54	-.45	.22	.49	.68	**.98**
IU2	-.30	-.43	-.41	.36	.62	.53	.52	-.47	.18	.49	.68	**.98**
IU3	-.25	-.42	-.40	.34	.60	.53	.53	-.43	.22	.47	.67	**.96**

5.3.5 Cronbach's Alpha

Cronbach's alpha is an alternate test for convergent validity (Straub et al., 2004), and may be more familiar than composite reliability. As shown in Table 5.12, all Cronbach alpha scores are strongly above the threshold of 0.70 (Straub et al., 2004), indicating that all items in the constructs contribute appropriately to the constructs

Table 5.12 Survey Construct Cronbach Alphas

Construct	Cronbach's Alpha
Disposition to Distrust	0.846
Disposition to Trust	0.805
Institutional Distrust	0.931
Institutional Trust	0.909
Distrust	0.914
Trust	0.920
Structural Assurance	0.920
Risk	0.846
Risk Profile	0.845
Self-Efficacy	0.900
Perceived Usefulness	0.945
Intent	0.971

5.3.6 Manipulation Validation

In establishing the six scenarios, the manipulations of showing an unsecured web portal to the ePHR, or a secured one with assurances, and demonstrating an ePHR from a doctor's clinic, the provincial health ministry, or a system provider, certain manipulations of the respondents were used. While conventional manipulation checks were not possible as there were no check variables collected, testing was undertaken to verify that the manipulations were

successful, as follows. The portal presentation was strictly in the form of manipulating the structural assurances, and so the scenarios with assurances present were coded with a 1 and those without with a 0 (zero). In prior research into trust in Canadian healthcare (Abelson et al., 2009), it was clear that doctors were trusted more than the provincial health ministry. It was assumed that a system provider would be less trusted in hosting an ePHR than the province in keeping with research in the United States (Undem, 2010). Thus, the doctor's clinic scenario responses were coded with a 3, the provincial ministry with a 2, and the system provider with a 1 to reflect a diminishment of trustability. Table 5.13 shows the scenario coding.

Table 5.13 Scenario Coding for Manipulation Check

(Security, Provider)	Doctor	Province	Vendor
No Structural Assurances	(0, 3)	(0, 2)	(0, 1)
Structural Assurances Present	(1, 3)	(1, 2)	(1, 1)

A higher security code should positively impact the structural assurances construct, while a higher provider code should positively impact institutional trust and negatively impact institutional distrust. The model was amended with the security variable linked to the structural assurance construct, and the provider variable linked to the institutional trust and distrust constructs, as shown in Figure 5.1.
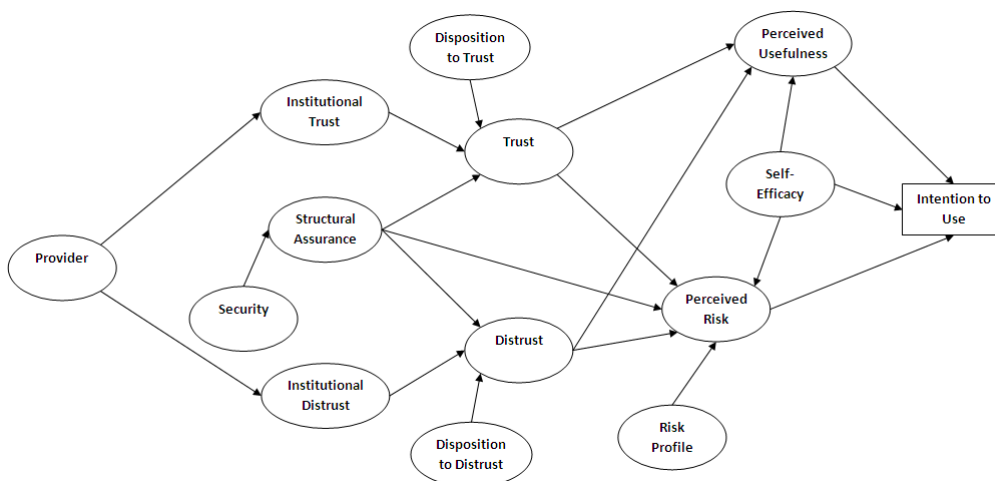

Figure 5.1 Manipulation Validity Test Model without Moderator

When the model in Figure 5.1 was tested with PLS, the provider influence was as expected, but the security influence was not significant, and had a negative impact, as shown in Table 5.14. Hence this model is not reasonable.

Table 5.14 Manipulation Validity Test Results without Moderator

Path	Path Weight	z-score	p<
Security to Structural Assurances	-0.03	0.563	0.6
Provider to Institutional Trust	0.21	3.88	0.001
Provider to Institutional Distrust	-0.20	3.65	0.001

Based on the results reported in the literature survey of Chapter 2, several of the demographic values were investigated to see if they had any effect on the security to structural assurances relationship. None had any effect. When a mean difference test had been conducted on the aggregate scores for the structural assurances construct based on the provider group in the original complete sample of 366 survey responses (Table 5.15), a pattern was found.

As the trust in the ePHR provider decreased, the awareness of the structural assurances generally increased in the scenarios with no structural assurances. In the scenarios with structural assurances the pattern was the opposite. This suggested that the provider was a moderating variable. The pattern is not clear in the data analysis sample, but based on the relationship in the complete data set, there was a reasonable prospect for a test. The model was revised as shown in Figure 5.2, and the analysis re-run.

Table 5.15 Structural Assurances Mean Difference t-tests By Provider, Partial and (Full) Data

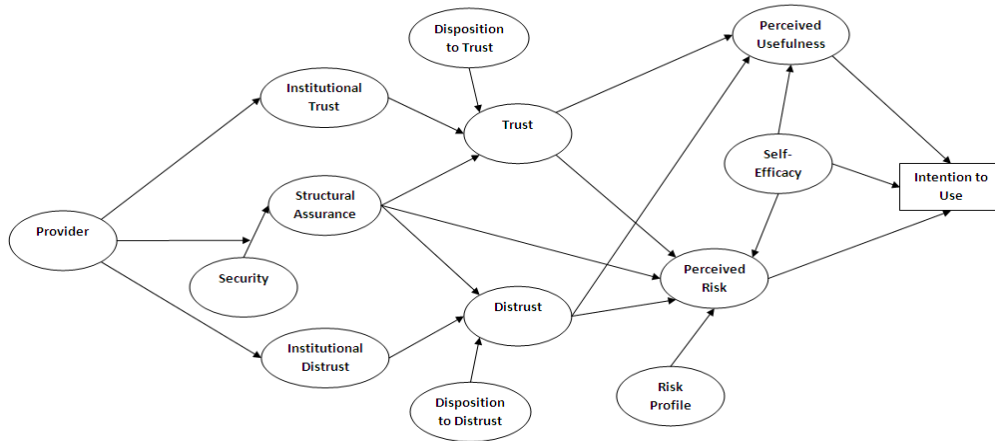| Test Group	Mean: No Security	Mean: Secure	Significance (p<)
Doctor	4.03 (4.09)	4.35 (4.37)	0.179 (0.202)
Province	4.46 (4.41)	4.36 (4.28)	0.623 (0.505)
Vendor	4.41 (4.45)	4.01 (4.03)	0.065 (0.031)

Figure 5.2 Manipulation Validity Test Model with Moderator

The results for the path weight and significance are recorded in Table 5.16. The first path in the table is the standard notation for the path under the influence of the moderator.

Table 5.16 Manipulation Validity Tests with Moderator

Path	Path Weight	z-score	p<
Security to Structural Assurances x Provider	0.37	2.42	0.05
Provider to Institutional Trust	0.21	3.97	0.001
Provider to Institutional Distrust	-0.20	3.67	0.001

This shows that, at the 0.05 probability level, the structural assurance construct is positively impacted by the security variable, when it is moderated by the provider variable. The manipulation tests were successful, indicating that the survey sample has manipulation validity, and thus has meaningful results in terms of the population responding to the scenarios. This means that the manipulations had an effect and that the model results may be considered useful to predict behaviours based on the differences between scenarios.

5.4   Research Model Hypothesis Testing

5.4.1   Overview

To test the proposed model, Structural Equation Modelling (SEM) was used, specifically the Partial Least Squares (PLS) technique using SmartPLS (Ringle et al., 2005). Another widely used SEM modelling approach (LISREL), uses covariances to attempt to minimize the differences between observations and an established model, relying on normal distributions in the data (Roldán & Sánchez-Franco, 2012). PLS was chosen as the normality of the distributions of the underlying statistics was not guaranteed as shown in Table 5.17, where most of the constructs exhibit either skewness or kurtosis, or both (Chin, 1998); guidelines for skewness and kurtosis are conservative at ±0.5 and relaxed at ±1.0 (Meyers et al., 2006).

Table 5.17 Descriptive Statistics of Constructs

Construct (N=308)	Mean	Std. Dev.	Skewness Statistic	Kurtosis Statistic
Trust in the ePHR	4.86	1.16	-0.58	0.46
Disposition to Trust	5.30	0.79	-0.63	0.15
Institutional Trust	5.10	1.01	-0.86	0.95
Distrust in the ePHR	3.73	1.32	-0.12	-0.69
Disposition to Distrust	2.91	1.03	0.71	0.02
Institutional Distrust	3.17	1.26	0.61	-0.31
Perceived Risk	3.85	1.30	0.03	-0.68
Risk Profile	3.78	1.30	-0.17	-0.69
Structural Assurances	4.28	1.14	-0.40	0.28
Self-Efficacy	5.53	0.97	-1.08	2.83
Perceived Usefulness	5.28	1.08	-0.91	1.28
Intention to Use	4.82	1.38	-0.74	0.49

PLS was also selected because the requirements for measurement scales are not as restrictive permitting interval and ratio scales (Chin, 1998), and this was exploratory theory development or theory extension (Chin, 1998; Reinartz et al.,

2009). Further, PLS has a lower threshold for the number of responses needed for statistical strength and reliability, and with analysis of the scenarios potentially dividing the sample size by six, the ability to generate results with small data sets was important. Specifically, the guideline is ten times the maximum number of predictors (items or antecedents) of any variable, which in this case is five, for the self-efficacy construct with 5 items, and the Intention to Use, with 5 antecedents. Thus, a sample size of over fifty is preferred, but care must be exercised in interpreting the data to avoid overstating the statistical power (Marcoulides & Saunders, 2006); based on the factor loadings (most in the 0.9 range from Table 5.11) and correlations (for connected constructs, most in the 0.5 range, from Table 5.10), statistical power of the tests can be satisfactory (above 0.8) with sample sizes as small as fifty.

5.4.2 Hypothesis Testing

Running the full model (seen in Figure 3.1) with the complete data set in SmartPLS (bootstrapping with 308 cases, 500 iterations, 10e-5 abort criteria on analysis) the R^2 value for the Intention to Use was 0.52. This indicates that 52 percent of the variance in the Intention to Use dependent variable was explained by the model; suggested guidelines for both path weights and R^2 values are that 0.19 is a weak result, 0.33 is a moderate result, and 0.67 is a strong result (Chin, 1998). Thus a relatively strong result from the model was found, and 15 of the 17 paths in the model were determined to be significant. The path weights and R^2 values are shown in Figure 5.3.
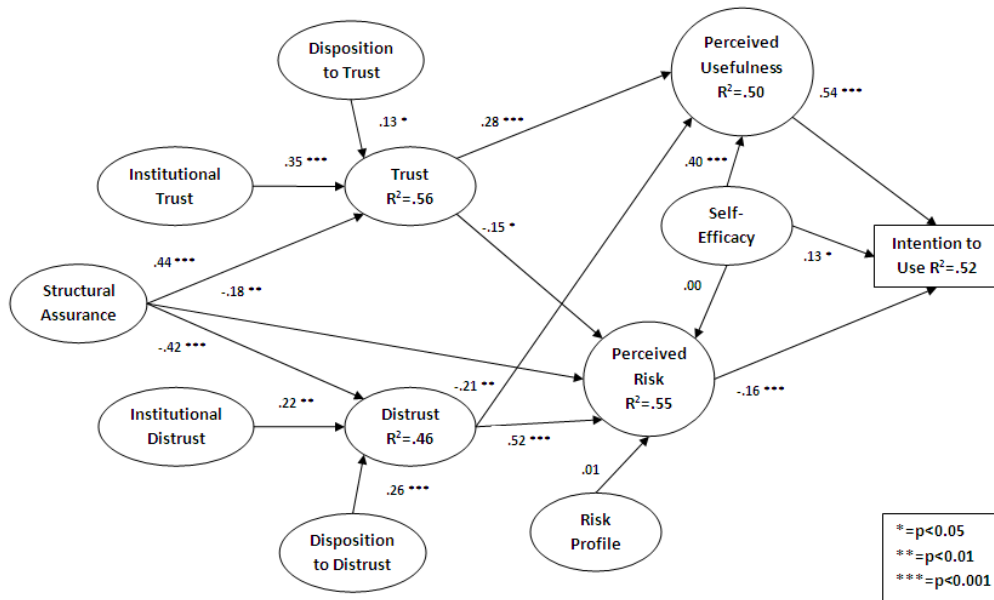
Figure 5.3 Research Model Showing Path Weights and R² Values

Looking at the individual hypotheses in Table 5.18, it can be seen that the structural assurances are moderately influencing the trust and distrust in the ePHR illustrated in the questionnaire, but they were less of an influence on the perceived risk where the connection was weak. The trust and distrust antecedents influenced their respective constructs as expected, and the trust and distrust constructs influenced the perceived risk appropriately, with a high moderate impact from distrust, as expected (McKnight et al., 2003), and a weak impact from trust. Trust and distrust both influenced PU, but the strength was weak. Self-efficacy did not have an effect on the perceived risk, but did influence the PU at a moderate level. Self-efficacy had a very weak influence on the intention to use the ePHR. The perceived risk had a weak negative influence on the intention to use the ePHR. Risk profile had no influence on the perceived risk while PU had a strong relationship with the intention to use the ePHR.

Table 5.18 Path Weights and Validity from Hypothesis Testing

Hypothesis	Value	p <	Valid?
Hypothesis 1a: Structural Assurances + → Trust	0.44	0.001	**Yes**
Hypothesis 1b: Structural Assurances - → Distrust	-0.42	0.001	**Yes**
Hypothesis 1c: Structural Assurances - → Perceived Risk	-0.18	0.01	**Yes**
Hypothesis 2a: Disposition to Trust + → Trust	0.13	0.05	**Yes**
Hypothesis 2b: Institutional Trust + →Trust	0.35	0.001	**Yes**
Hypothesis 3a: Disposition to Distrust + → Distrust	0.26	0.001	**Yes**
Hypothesis 3b: Institutional Distrust + → Distrust	0.22	0.01	**Yes**
Hypothesis 4: Trust - → Perceived Risk	-0.15	0.05	**Yes**
Hypothesis 5: Trust + → Perceived Usefulness	0.28	0.001	**Yes**
Hypothesis 6: Distrust + → Perceived Risk	0.52	0.001	**Yes**
Hypothesis 7: Distrust - → Perceived Usefulness	-0.21	0.01	**Yes**
Hypothesis 8: Self-Efficacy - →Perceived Risk	0.00	0.95	No
Hypothesis 9: Self-Efficacy + → Perceived Usefulness	0.40	0.001	**Yes**
Hypothesis 10: Self-Efficacy + → Intention to Use	0.13	0.05	**Yes**
Hypothesis 11: Risk Profile - → Risk	0.01	0.90	No
Hypothesis 12: Perceived Risk - → Intention to Use	-0.16	0.001	**Yes**
Hypothesis 13: Perceived Usefulness + → Intention to Use	0.54	0.001	**Yes**

Another view of the influence on the respondents' intention to use the ePHR is the Total Effects results from the PLS analysis. This is the effect of the each construct in the model on Intention to Use the ePHR, factoring in the correlations between constructs, and the influence of the weights and significance of the links connecting each construct to the Intention dependent construct. Table 5.19 shows the list of constructs and their effects; also included is their statistical significance. Note here that the trust and distrust antecedents have very little effect on intention, while trust and distrust themselves have a weak total effect on intention to use the ePHR. The perceived risk and structural assurances constructs have weak influence on intention, while risk profile has none at all. Finally, self efficacy and perceived usefulness were the only constructs with a moderate total effect on intention to use the ePHR.

Table 5.19 Total Effects of Model Constructs on Intention to Use the ePHR

Total Effects Relationship	Value	p <	Valid?
Disposition to Distrust -> Intention to Use	-0.05	0.01	**Yes**
Disposition to Trust -> Intention to Use	0.02	0.05	**Yes**
Institutional Distrust -> Intention to Use	-0.04	0.01	**Yes**
Institutional Trust -> Intention to Use	0.06	0.01	**Yes**
Structural Assurances -> Intention to Use	0.19	0.001	**Yes**
Distrust -> Intention to Use	-0.20	0.001	**Yes**
Trust -> Intention to Use	0.18	0.001	**Yes**
Risk Profile -> Intention to Use	0.00	0.9	No
Perceived Risk -> Intention to Use	-0.16	0.001	**Yes**
Self-Efficacy -> Intention to Use	0.34	0.001	**Yes**
Perceived Usefulness -> Intention to Use	0.54	0.001	**Yes**

Table 5.20 shows the effect of constructs on other constructs further "downstream" (to the right) in the model. It is quite clear that perceived usefulness has the most effect on the intention to use the ePHR. Self-efficacy also has an important effect on intention, and rather strongly on PU, but none on perceived risk. Trust has a discernible effect on intention, but more of an effect on PU, and little on risk. Note that distrust has about the same effect on intention, little on PU, and almost a strong effect on perceived risk. The relationships between trust and distrust and the three other main constructs confirms the earlier findings of McKnight et al. Structural assurances also have a moderate negative influence on perceived risk, but only a weak influence elsewhere.

Table 5.20 Total Effects on Other Constructs

Total Effects	Intention to Use		Perceived Usefulness		Perceived Risk	
	β	p <	B	p <	B	p <
Disposition to Distrust	-0.05	0.01	-0.06	0.05	0.14	0.01
Disposition to Trust	0.02	0.05	0.04	0.05	-0.02	n.s.
Institutional Distrust	-0.04	0.01	-0.05	0.05	0.12	0.01
Institutional Trust	0.06	0.01	0.10	0.01	-0.05	n.s.
Structural Assurances	0.19	0.001	0.21	0.001	-0.47	0.001
Distrust	-0.20	0.001	-0.21	0.01	0.52	0.001
Trust	0.18	0.001	0.28	0.001	-0.15	0.05
Risk Profile	0.00	n.s.			0.01	n.s.
Self-Efficacy	0.34	0.001	0.40	0.001	0.00	n.s.
Perceived Risk	-0.16	0.001				
Perceived Usefulness	0.54	0.001				

5.4.3   Post-hoc Analysis

5.4.3.1 Testing Risk Profile Significance

To explore possible causes for the non-significant connection, and explore possible relationships a partially saturated model was tested in PLS. Risk profile, which had no detectable effect on risk, was tested as a possible antecedent to all of the other constructs, and a link to self-efficacy was discovered, supported by some other research (Agarwal et al., 2000; Krueger & Dickson, 1994; Livingstone & Helsper, 2010); those who were more likely to take risks were also more willing to try new things, and believe themselves capable of managing the new technology. The past studies cited also found a correlation between risk-taking and self-efficacy, in that experience allowed risk avoidance or mitigation. Risk profile also demonstrated a statistically significant link to structural assurances, and disposition to trust, but no theoretical support was found for those relationships.

5.4.3.2 Trust and Distrust Cross Connections

In another test, the antecedents of Trust in the ePHR and the antecedents of Distrust in the ePHR were cross connected to the other construct (that is Trust antecedents to Distrust and *vice versa*). This test was done to verify if there is a differing effect for trust antecedents versus distrust antecedents. If trust and distrust are opposites, then the switching of antecedents should have little to no effect. Table 5.21 summarizes the results of the test. The Institutional constructs had a significant effect on their opposite subsequent constructs, but with Institutional Trust having a lesser effect when acting as an antecedent to Distrust than in the base model. The Disposition constructs were of less significance when connected to the alternate construct, with a sizable change in the effect of Disposition to Distrust in the alternate configuration. This supports the notion that distrust is not the opposite end of a spectrum from trust, as has been argued or assumed in the past (McKnight & Chervany, 2001a; Ullmann-Margalit, 2002), but recently has been proven false in other contexts (Dimoka, 2010; McKnight & Choudhury, 2006). By behaving differently in an alternate model, the difference in the constructs can be seen.

Table 5.21 Effects of Swapping Trust and Distrust Antecedents

	Associated Construct		Alternate Construct	
Total Effects	**β**	**p <**	**β**	**p <**
Disposition to Distrust	0.26	0.001	-0.05	n.s.
Disposition to Trust	0.13	0.01	-0.13	0.05
Institutional Distrust	0.22	0.01	-0.22	0.001
Institutional Trust	0.35	0.001	-0.24	0.001

5.5 Analysis of Mean Differences between Scenarios

One of the research questions in this dissertation asks if a difference exists in intention to use an ePHR depending on the organization that was presented as the provider of the system. The options were an ePHR from a doctor's clinic, the provincial health ministry, or a third party system provider on behalf of the provincial ministry. To determine whether a difference exists, several independent sample t-tests were executed to compare the means between the groups broken down by provider of the ePHR.

An additional research question in this dissertation asks if a difference exists in intention to use an ePHR based on structural assurances. An additional comparison was made between those presented with an ePHR displaying structural assurances and those without structural assurances to answer the research question.

5.5.1   Between Doctors' Clinic and Provincial Health Ministry

Table 5.22 summarizes the results of the mean difference t-test between the group of responses from those presented with an ePHR provided by a doctors' clinic compared to those presented with an ePHR supplied by the provincial health ministry. The difference was significant with better than 95 percent confidence. Those responding are more likely to intend to use the ePHR if it is presented as coming from a provincial health ministry than from a doctors' clinic.

Table 5.22 Mean Differences t-Test Between Doctor and Provincial Provider

Data Element	Source	N	Mean	Std. Dev.	Sig.
Aggregate Intent to Use	Doctor	102	4.74	1.408	0.025
	Province	110	5.14	1.206	

5.5.2   Between Doctors' Clinic and Third Party Vendor

Table 5.23 summarizes the results of the mean difference t-test between the group of responses from those presented with an ePHR provided by a doctors' clinic compared to those presented with an ePHR supplied by a third party on behalf of the provincial health ministry. The difference was not significant. The two groups are equally likely to intend to use an ePHR.

Table 5.23 Mean Differences t-Test between Doctor and Third Party Provider

Data Element	Source	N	Mean	Std. Dev.	Sig.
Aggregate Intent to Use	Doctor	102	4.74	1.408	0.399
	3rd Party	102	4.57	1.464	

5.5.3   Between Provincial Health Ministry and Third Party Vendor

Table 5.24 summarizes the results of the mean difference t-test between the group of responses from those presented with an ePHR provided by the provincial health ministry compared to those presented with an ePHR supplied

by a third party on behalf of the provincial health ministry. The difference was significant with better than 95 percent confidence. Those surveyed who were presented with an ePHR from the province are more likely to intend to use an ePHR than those presented with one from a third party, despite the statement that the third party is acting on behalf of the provincial ministry.

Table 5.24 Mean Differences t-Test Between Provincial and Third Party Provider

Data Element	Source	N	Mean	Std. Dev.	Sig.
Aggregate Intent to Use	Province	110	5.14	1.206	0.002
	3rd Party	102	4.57	1.464	

5.5.4 Between Structural Assurances and No Structural Assurances

Table 5.25 summarizes the results of the mean difference t-test between the group of responses from those presented with an ePHR without structural assurances compared to those presented with an ePHR with structural assurances. The difference was not significant at any level. There is no difference in intended use of an ePHR between the two groups based on the presence of structural assurances.

Table 5.25 Mean Differences t-Test Between With and Without Structural Assurances

Data Element	Source	N	Mean	Std. Dev.	Sig.
Aggregate Intent to Use	Without	156	4.80	1.365	0.785
	With	158	4.84	1.394	

5.5.5 Summary of Mean Difference Test Results

The survey respondents were more likely to intend to use an ePHR if it was provided by the provincial health ministry than either of the other options, and the difference was statistically significant. There was no significant difference in intention to use an ePHR between the groups seeing an ePHR from a Doctor's clinic or a third party vendor.

There was no statistically significant difference in intention to use an ePHR between those presented with structural assurances on the images and those not presented with structural assurances. It is possible that the importance and meaning of the structural assurances was missed, or that the value was diminished by the influence of the provider in the respondents' assessments.

5.6 Analysis of Control Variable Effects

The study collected a large number of demographic variables for potential use as control variables. Some of these variables may have an effect on the results, and thus should be tested. The testing consists of two steps: determining which variables may have an effect, and testing the strength and significance of that effect.

For the purpose of these tests, the province variable was recoded into a region value, with all provinces east of Quebec in one group, Quebec, Ontario, as their own groups, and provinces west of Ontario as another group. There were no responses from the territories or outside of Canada.

5.6.1 Determination of Effects

To determine which control variables may have an effect, two different tests using PLS were employed. The first test was testing the effect size of the control variable on the model constructs. The effect size is a ratio comparing the R^2 of the model with a control variable and the R^2 without it (Chin, 1998). This was done by adding each control variable in turn to the PLS model, establishing a connection to each construct in the model, and running a PLS analysis. The effect size, f^2, was then calculated for each construct and the overall results tabulated. The guidelines for f^2 are that an effect of 0.35 is large, 0.15 is moderate, and 0.02 is small; anything less than 0.02 is inconsequential (Chin, 2010). Since a substantial number of responses with no income value were recorded, and a t-test measured a difference in overall intent in this group from the rest, the absence of an income response was treated as an additional control variable. The results are tabulated in Table 5.26, with values above the threshold in bold font. Only a few relationships had any notable effect, and only a very few rose above the small effect level. Specifically, the age control variable demonstrated an effect on both disposition to trust and disposition to distrust, and the internet shopping control variable had an effect on self-efficacy; these were the only relationships that demonstrated more than a minimal effect.

Table 5.26 Effect Sizes for Control Variables

f^2	DD	DT	D	ID	IT	IU	PU	R	SE	SA	T
Gender	0	0	0	0	0.01	0	0	0	0.01	0.01	0
Age	**0.04**	**0.09**	0	0	0	0	0	0.01	0.01	0	0
Region	0	0	0	0	0.01	0	0	0	0	0	0
Income	0.01	0.02	0	0.01	**0.02**	**0.04**	**0.03**	0	**0.03**	0.01	0
Income Missing	0	0.01	0	0	**0.02**	0.01	0.01	0	**0.03**	**0.02**	0
Education	**0.02**	**0.03**	0	0.01	0	0	**0.03**	0	**0.02**	0	**0.02**
Internet Location	0	0.01	0.01	0	0	0	0	0	0	0	0
Internet Usage	0.01	0	0	0	0	0	0	0.01	**0.03**	0	0.01
Internet Shopping	0.01	0	0	0	0	0	0	0	**0.09**	0	0
Personal Health	0	0	0	0.01	0.01	0	0	0	**0.02**	0	0
Health Status	0	0	0.01	**0.02**	0.01	0	0	0	0	0	0
Family Health	0	0.01	0	0	0.01	0	0.01	0.01	0	**0.03**	0

DD=Disposition to Distrust, DT=Disposition to Trust, D=Distrust, ID=Institutional Distrust, IT=Institutional Trust, IU=Intention to Use, PU=Perceived Usefulness, R=Perceived Risk, SE=Self Efficacy, SA=Structural Assurances, T=Trust

The second test proceeded in a similar way, with each control variable being added to the model in turn, with a connection to each construct, and a standard PLS analysis performed; the results were reviewed, looking for significant paths. The results are summarized in Table 5.27 with significant paths highlighted in bold font. Again, only a few relationships were significant. The relationships between the age control variable and the two disposition constructs were highly significant, as was the relationships between the Internet shopping variable and Self-efficacy, and family member with a chronic illness and structural assurances. A small number are moderately significant, but few have actual weight values that approach the recommended small size level of 0.19 (Chin, 1998).

Table 5.27 Effects of Control Variables on Model Constructs

Weights	Stat	DD	DT	D	ID	IT	IU	PU	R	SE	SA	T
Gender	β	.03	.02	.04	-.02	.07	.02	.00	-.05	.10	.09	.01
	p <	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.
Age	β	**-.20**	**.28**	-.02	-.05	-.01	.04	.05	-.07	-.09	.02	-.03
	p <	.001	.001	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.
Region	β	-.05	.03	.03	.02	-.07	.01	.03	.01	.04	.00	-.04
	p <	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.
Income	β	-.10	**.15**	**-.02**	-.10	**.15**	**.14**	**.13**	-.01	**.16**	.10	.03
	p <	n.s.	.05	-.02	n.s.	.01	.01	.01	n.s.	.01	n.s.	n.s.
Income Missing	β	.03	-.11	.03	.07	**-.13**	-.07	-.06	.01	**-.17**	**-.15**	-.05
	p <	n.s.	n.s.	n.s.	n.s.	.05	n.s.	n.s.	n.s.	.05	.01	n.s.
Education	β	**-.12**	**.16**	.00	-.08	.04	-.01	**.12**	-.02	**.14**	-.01	**-.10**
	p <	.05	.01	n.s.	n.s.	n.s.	n.s.	.05	n.s.	.01	n.s.	.01
Internet Location	β	.06	**-.12**	.06	.00	.00	-.04	.05	.02	.05	-.07	.00
	p <	n.s.	.05	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.
Internet Usage	β	-.10	.00	-.01	-.01	-.01	.00	-.02	-.07	**.18**	-.05	.06
	p <	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	.01	n.s.	n.s.
Internet Shopping	β	-.08	.06	-.02	-.04	.01	.04	-.02	-.01	**.28**	.06	.01
	p <	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	.001	n.s.	n.s.
Personal Health	β	.04	.00	-.02	-.09	.10	-.04	-.01	-.01	**.13**	.06	-.02
	p <	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	.05	n.s.	n.s.
Health Status	β	-.05	.05	.09	**-.13**	**.12**	-.01	-.01	-.03	.01	.01	-.03
	p <	n.s.	n.s.	n.s.	.05	.05	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.
Family Health	β	.07	.07	.01	.01	.07	-.01	.08	.05	.03	**.17**	-.05
	p <	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	.001	n.s.

DD=Disposition to Distrust, DT=Disposition to Trust, D=Distrust, ID=Institutional Distrust, IT=Institutional Trust, IU=Intention to Use, PU=Perceived Usefulness, R=Perceived Risk, SE=Self Efficacy, SA=Structural Assurances, T=Trust

5.6.2   Testing of Relevant Effects

Any connection between a control variable and a construct that showed even a small effect size (more than 0.02) or a statistically significant path was then tested for effect on the hypotheses in a second two-stage test (Liang et al., 2007). In the first step, each control variable was connected, one at a time, to only those constructs that it demonstrated an effect on in the determination tests or significant effect in the path tests, and a PLS analysis was run. The results were reviewed to measure any change in the significance of the model

relationships, or a change in the R^2 of the Intention to use the ePHR dependent variable—that is, the model's overall explanation of variance. There were some minor shifts in significance, and some slight changes to path weights or R^2 values. No change exceeded 0.01, which is a negligible change.

The second stage added all of the highlighted connections together to the model and another PLS analysis was performed. Changes between the controlled and uncontrolled model were tested for, and none were found.

No material changes to the hypotheses or explanation of variance in the model were found in either step. Thus, none of the control variables had a discernible effect on the model or the constructs.

5.7   Analysis of Responses to Open-ended Questions
A collection of open-ended questions was posed as part of the study to allow a richer picture of the opinions of the survey population to unfold. These questions involved positive and negative factors surrounding Intention to Use an ePHR, as well as perceived risks, key decision considerations, as well as what organization they felt should be operating the ePHR; the exact text of the questions and the relationship with the rest of the survey can be found in Appendix A: eHealth Survey. The number of non-responses to the questions was the same for each of the questions, at just over 15 percent, but not all of these were the same in each question; that is, not responding to one question did not mean that the person did not respond to all questions.

5.7.1   Factors Leading to Intention to Use
The first question asked the study participants, "What factors would lead you to you consider using an ePHR similar to the one shown here?". The responses were reviewed to find themes and common responses. The nineteen categories are described in Table 5.28 and the response counts are summarized in crosstab format by scenario in Table 5.29. The percentage is based on the total of the survey participants responding in each column for the no-answer (N/A) category, and based on the total less the N/A responses for the rest; that is the percentage of actual responses.

Table 5.28 Themes in Responses to Concerning the Use of an ePHR

Theme	Description
Data	Collecting all data in one location is important
Ease	Ease of use
Security	Looking for security in the system
Need	Personal need
Content	Access to specialized content by using an ePHR
Interest	Personal interest, managing health
Coordinate	Coordination between health providers
Privacy	Looking for privacy in the system
Mobile	Availability of data on mobile devices, or alternate locations
Trust	ePHR is provided by a trusted organization
Required	Health provider requests or mandates it
Time	Saves time for patient or provider
Communication	Assists in communication with health providers
Won't	Will not use the system
Value	The system is cost-effective
Unsure	Not sure without more information
Access	Ability to access health services is enhanced
Available	When the system is available for use, will use it
N/A	No answer or indecipherable

Table 5.29 Crosstab of Responses for Factors Leading to Use of an ePHR

Theme	Scenario 1 Doctor, No SA	Scenario 2 Doctor, SA	Scen. 3 Province, No SA	Scen. 4 Province, SA	Scen. 5 Vendor, No SA	Scen. 6 Vendor, SA	Total
Data	13 (28%)	16 (35%)	18 (32%)	25 (45%)	11 (21%)	13 (28%)	**96 (32%)**
Ease	6 (13%)	12 (26%)	11 (20%)	7 (13%)	9 (17%)	7 (15%)	**52 (17%)**
Security	8 (17%)	7 (15%)	8 (14%)	6 (11%)	12 (23%)	7 (15%)	**48 (16%)**
Need	7 (15%)	10 (22%)	9 (16%)	9 (16%)	6 (11%)	6 (13%)	**47 (15%)**
Content	4 (9%)	6 (13%)	7 (13%)	6 (11%)	10 (19%)	5 (11%)	**38 (13%)**
Interest	5 (11%)	8 (17%)	6 (11%)	6 (11%)	6 (11%)	6 (13%)	**37 (12%)**
Coordinate	7 (15%)	7 (15%)	4 (7%)	9 (16%)	6 (11%)	1 (2%)	**34 (11%)**
Privacy	2 (4%)	3 (7%)	3 (5%)	4 (7%)	9 (17%)	3 (7%)	**24 (8%)**
Mobile	5 (11%)	2 (4%)	5 (9%)	6 (11%)	2 (4%)	3 (7%)	**23 (8%)**
Trust	3 (6%)	4 (9%)	2 (4%)	1 (2%)	1 (2%)	4 (9%)	**15 (5%)**
Required	3 (6%)	4 (9%)	1 (2%)	4 (7%)	1 (2%)	1 (2%)	**14 (5%)**
Time	1 (2%)	5 (11%)	1 (2%)	4 (7%)	0 (0%)	3 (7%)	**14 (5%)**
Comm-unication	1 (2%)	2 (4%)	0 (0%)	4 (7%)	1 (2%)	2 (4%)	**10 (3%)**
Value	2 (4%)	1 (2%)	3 (5%)	0 (0%)	1 (2%)	2 (4%)	**9 (3%)**
Unsure	1 (2%)	2 (4%)	1 (2%)	0 (0%)	3 (6%)	1 (2%)	**8 (3%)**
Access	0 (0%)	0 (0%)	2 (4%)	3 (5%)	0 (0%)	1 (2%)	**6 (2%)**
Available	0 (0%)	1 (2%)	1 (2%)	1 (2%)	1 (2%)	1 (2%)	**5 (2%)**
Won't	3 (6%)	0 (0%)	2 (4%)	2 (4%)	1 (2%)	2 (4%)	**10 (3%)**
N/A	9 (16%)	17 (27%)	8 (13%)	9 (14%)	5 (9%)	14 (23%)	**62 (17%)**

Theme	Scenario 1 Doctor, No SA	Scenario 2 Doctor, SA	Scen. 3 Province, No SA	Scen. 4 Province, SA	Scen. 5 Vendor, No SA	Scen. 6 Vendor, SA	Total
Total	56	63	64	65	58	60	366

The concept of bringing all of their data together was the most mentioned factor overall, and highest in almost all scenario groups.

I like that it has all your information in one place, I can easily access medication information, doctors appointments, results etc. When a doctor just scribbles notes on a pad you may or may not totally understand what is being said or done on your behalf, this looks like it'll give the patient time to go over conditions/resolutions on their own time and possibly enhance their ability to take control of their medical needs.

It would help me manage my health in a way that covers all areas of health. The food logbook, blood glucose records and A1C, height/weight graphs. it incorporates all aspects of health and displays it in more visual ways!!! This looks like a very beneficial site to use for me, as i am always striving to be healthier. Having type 1 diabetes and ADHD is hard to enough manage, but having a website where you can manage both together would be awesome!

I do not have any existing health problems, but I think it's important for my doctors to be able to see my history, especially if I move locations.

This bringing data together is an opinion found elsewhere (Moen & Brennan, 2005); the interest is derived from the desire to maintain control over personal health issues by having all the data to present to a healthcare practitioner as required to best use the time in an appointment. A secondary impetus found by Moen and Brennan (2005) for this factor was for patients to be able to move between practitioners over time, either from a complex health situation or other non-health factors; moving jobs or residences are examples of non-health issues.

Presenting and using health data in an easy to use system was the next most commonly reported factor overall.

The ease of having accurate, trusted information regarding health, especially my own personal health database, at the click of a mouse.

Ease of Use - it would need to be easily accessible online, with an intuitive user interface.

Complete ease of use. I need to be able to enter any of a wide variety of traditional and alternative lab tests, including those requested by naturopaths or not listed as funded by health insurance.

Medical information can be intimidating, and contextual explanations can ease concerns and reduce stress, leading to better outcomes (Street et al., 2009). Also, some data presentations can aid understanding trends and changes over time, such as weight, blood sugar, or blood pressure, for example.

A secure system was raised as a required factor for the survey respondents to consider using an ePHR as the third most prevalent response overall.

I need to be certain, 100% certain, that my health information will not be given out without my knowledge and that hackers could not get my information.

I would need to see that there are stringent precautions and acccess / login protocols to ensure the security of my information.

I would need more info on how it works and what makes it secure...how many people will have access to my info?

This factor, as was the privacy factor, was mentioned as a feature that the respondents were expecting in the ePHR, without which they would not consider using the system. Security, is a common concern regarding personal health information (King et al., 2012; van der Linden et al., 2009; Willison et al., 2007), and has resulted in many forms of legislation to protect health data in many countries of the world.

As has been shown in other studies (Flynn et al., 2009; Wang et al., 2004) and repeated here, personal need for or personal interest in the benefits that an ePHR may provide will be an important consideration for many who know of the difficulties in dealing with a complex health situation. Beyond that, having valued content, such as screened and validated health information, or tools to manage health data, is an important factor for 13 percent of the respondents.

As I get older forgetting certain information and keeping appointments is more of a problem

Having a medical condition that requires frequent conveyance of information to my doctor, as using the ePHR could be a more convenient way to do so, as compared to making frequent visits to his office.

The ability to use an ePHR to coordinate between healthcare providers, often given as a reason for patients to consider using an ePHR, was reported as important by 11 percent, but privacy assurances, usually important, were only mentioned by 8 percent.

Several clearly stated that they would not use the system at all, and several more were unwilling to speculate on using an ePHR without more information.

5.7.2 Factors Inhibiting Use

The second open-ended question asked the participants, "What factors would cause you to consider <u>not</u> using an ePHR similar to the one shown here?". The themes discovered in the responses are summarized in Table 5.30. Table 5.31 lists the counts and percentages for each theme, broken down by scenario. As before, the percentage of the no-answer (N/A) category for each column is based on the total responses, and the remainder of the percentages are based on the actual response count for each column.

Table 5.30 Themes in Responses to Factors Preventing Use of an ePHR

Theme	Description
Security	Concern over security in the system
Privacy	Concern over privacy of the data
Trust	Concern over trust in participants
None	Text says none or similar
Usage	Concern that the system will not be used by desired health providers
Ease	Concern over ease of use
Accuracy	Concern over accuracy of information
Access	Concern over accessibility
Content	Concern that the desired content is not available
Trouble	Concern over trouble caused by the system
Interest	No personal interest

Theme	Description
Need	No personal need
Time	Concern that it would waste time
Unsure	Not sure without more information
Cost	Concern over the cost of use
Understanding	Concern that the information would be misunderstood
Would	Would use the system
N/A	No answer or indecipherable

Table 5.31 Crosstab of Responses to Factors Inhibiting Use of an ePHR

Theme	Scenario 1 Doctor, No SA	Scenario 2 Doctor, SA	Scen. 3 Province, No SA	Scen. 4 Province, SA	Scen. 5 Vendor, No SA	Scen. 6 Vendor, SA	Total
Security	20 (43%)	17 (38%)	20 (35%)	21 (37%)	21 (40%)	23 (49%)	**122 (40%)**
Privacy	14 (30%)	14 (31%)	20 (35%)	12 (21%)	19 (36%)	15 (32%)	**94 (31%)**
Trust	8 (17%)	2 (4%)	7 (12%)	4 (7%)	7 (13%)	4 (9%)	**32 (10%)**
None	3 (6%)	1 (2%)	4 (7%)	9 (16%)	4 (8%)	3 (6%)	**24 (8%)**
Usage	3 (6%)	3 (7%)	4 (7%)	6 (11%)	1 (2%)	5 (11%)	**22 (7%)**
Ease	2 (4%)	4 (9%)	3 (5%)	4 (7%)	5 (9%)	3 (6%)	**21 (7%)**
Accuracy	4 (9%)	3 (7%)	4 (7%)	2 (4%)	4 (8%)	3 (6%)	**20 (7%)**
Access	4 (9%)	6 (13%)	1 (2%)	0 (0%)	3 (6%)	5 (11%)	**19 (6%)**
Content	2 (4%)	2 (4%)	4 (7%)	3 (5%)	4 (8%)	1 (2%)	**16 (5%)**
Trouble	2 (4%)	2 (4%)	0 (0%)	4 (7%)	2 (4%)	3 (6%)	**13 (4%)**
Interest	2 (4%)	1 (2%)	3 (5%)	3 (5%)	2 (4%)	0 (0%)	**11 (4%)**
Need	1 (2%)	1 (2%)	2 (4%)	5 (9%)	0 (0%)	2 (4%)	**11 (4%)**
Time	3 (6%)	1 (2%)	2 (4%)	4 (7%)	0 (0%)	1 (2%)	**11 (4%)**

Theme	Scenario 1 Doctor, No SA	Scenario 2 Doctor, SA	Scen. 3 Province, No SA	Scen. 4 Province, SA	Scen. 5 Vendor, No SA	Scen. 6 Vendor, SA	Total
Unsure	1 (2%)	3 (7%)	2 (4%)	0 (0%)	2 (4%)	1 (2%)	**9 (3%)**
Cost	2 (4%)	1 (2%)	1 (2%)	1 (2%)	1 (2%)	0 (0%)	**6 (2%)**
Under-standing	1 (2%)	2 (4%)	1 (2%)	1 (2%)	0 (0%)	0 (0%)	**5 (2%)**
Would	1 (2%)	0 (0%)	1 (2%)	1 (2%)	0 (0%)	0 (0%)	**3 (1%)**
N/A	9 (16%)	18 (29%)	7 (11%)	8 (12%)	5 (9%)	13 (22%)	**60 (16%)**
Total	**56**	**63**	**64**	**65**	**58**	**60**	**366**

Security and privacy were mentioned most often overall, and most in each scenario group; response counts were substantially lower for all other response themes.

> *Fear of hackers gaining access to the information. In today's day and age, everyone gets hacked, from the gov't to credit card companies. Our medical information would not be any less vulnerable not matter how well set up the system is.*

> *I have no problem using this system. The only time I would have a doubt if information came forth that indicated that security had been breached.*

> *I dont like that so many people would potentially be able to access private medical data (technicians, etc that have nothing to do with my doctor or the doctor's immediate personnel*

> *If I were not able to determine who would see the information.*

> *I'm concerned about access by government officials or other parties who have no business viewing my health information, which i view as private and between my health care provider and me.*

Concern over trust in the organization providing the ePHR was the next highest response, at 10 percent of responses, compared to over 30 percent for the first two issues.

Access to the database by Insurers. Lack of confidence in the 3rd party Administrator. Absence of a neutral overseer to keep the Administrator and medial users honest.

If the design does not look professional and therefore implies lack of credibility to me.

knowing how unorganized and incompetent the medical fields is in Quebec is, i would be very hesitant

Like to see a "track record" elsewhere

Interestingly, trust was mentioned much more often in scenarios with no structural assurances than scenarios with structural assurances. This is further evidence that structural assurances are important to developing trust in system users.

For the scenarios with structural assurances, the third most common responses were split between several themes. Those seeing an ePHR supplied by the provincial health ministry indicated that they had no concerns.

Those seeing a doctors' clinic ePHR were concerned with being able to access the system. This response is supported by some of the comments raised in the last open-ended question when the respondents were asked who they preferred to run the system (see Section 5.7.5); several responses indicated that they did not trust their doctor and the staff in the clinic to run a sufficiently robust ePHR.

Accessibility was also the third most mentioned theme for those seeing a system vendor supplied ePHR, tied with the concern that the health providers that they wished to deal with were not using the ePHR.

1. Lack of Convenience - if information cannot be easily accessed by doctors with whom the patient does not have a previous history...4. Lack of Accessibility - the user does not have the maximum amount of freedom, and cannot access all information, define new information, or update that information at will.

It was only adopted by one or two health providers.

If there were multiple providers/carriers/options.   It needs to be standardized provincially (if not federally).

My physician doesn't even have a computer in her office.

- not having all of my medical team partners on board

Again, not knowing who the provider was and thus not trusting the system to be available was mentioned in the last open-ended question. The concern that a provider was not using the ePHR could reasonably be explained by the lack of apparent connection between a healthcare provider and an ePHR provider; the connection is obvious between a doctor and a doctors' clinic. The usage theme was also fairly common in the provincial health ministry scenario, so the real connection between the doctor and the ministry—and the incentives proposed to encourage adoption (Ludwick & Doucette, 2009b; Ludwick et al., 2010)—is not apparent to the public opinion captured in the sample.

5.7.3   Risk Perceptions

The third open-ended question asked the study participants, "What do you feel are the risks in using an ePHR similar to the one shown here?". The themes expressed in their responses have been summarized in Table 5.32. Table 5.33 contains the counts and percentages for each theme by scenario and overall. The no-answer (N/A) category has a percentage based on the total responses for each column and the remainder are based on the actual response count.

Table 5.32 Themes in Responses to Perception of Risks in using an ePHR

Theme	Description
Hackers	Mention of hackers in the response
Security	General mention of security concerns
Exposure	Mention of data made available to inappropriate people
Privacy	General mention of privacy concerns
Accuracy	Mention of data errors, corruption, or treatment of it
Access	Misuse of data by groups not authorized or expected
Online	Mention of threat from data being online
Fraud	Fraudulent use of data by others
Failure	Mention of system (software or hardware) failure
None	Text says none or similar
Few	Risks downplayed or deemed of little significance

Theme	Description
Trouble	Problems in medical staff-patient relations exposed by the ePHR
Trust	Mention of trust towards system or supplier
Unsure	Person uncertain in some way
Usage	Lack of use by patient or not used by desired practitioner
Block	Inability to access/change own data
Time	Wasting time on ePHR
Redo	Having to re-enter data
Cost	Wasting money on ePHR
Duplication	Having data in multiple locations, perhaps different
N/A	No answer or indecipherable

Table 5.33 Crosstab of Perception of Risks in Using an ePHR

Theme	Scenario 1 Doctor, No SA	Scenario 2 Doctor, SA	Scen. 3 Province, No SA	Scen. 4 Province, SA	Scen. 5 Vendor, No SA	Scen. 6 Vendor, SA	Total
Hackers	15 (34%)	12 (25%)	16 (28%)	8 (14%)	11 (21%)	11 (23%)	**73 (24%)**
Security	7 (16%)	12 (25%)	14 (25%)	11 (19%)	9 (17%)	8 (17%)	**61 (20%)**
Exposure	8 (18%)	8 (17%)	8 (14%)	9 (16%)	15 (28%)	4 (8%)	**52 (17%)**
Privacy	8 (18%)	8 (17%)	10 (18%)	5 (9%)	12 (23%)	6 (13%)	**49 (16%)**
Accuracy	8 (18%)	6 (13%)	3 (5%)	9 (16%)	9 (17%)	8 (17%)	**43 (14%)**
Access	5 (11%)	5 (10%)	3 (5%)	6 (11%)	6 (11%)	4 (8%)	**29 (9%)**
Online	3 (7%)	5 (10%)	4 (7%)	5 (9%)	3 (6%)	5 (10%)	**25 (8%)**
Fraud	4 (9%)	3 (6%)	3 (5%)	5 (9%)	5 (9%)	4 (8%)	**24 (8%)**
Failure	4 (9%)	1 (2%)	2 (4%)	4 (7%)	6 (11%)	4 (8%)	**21 (7%)**
None	3 (7%)	3 (6%)	4 (7%)	6 (11%)	2 (4%)	2 (4%)	**20 (7%)**
Few	1 (2%)	2 (4%)	1 (2%)	3 (5%)	4 (8%)	4 (8%)	**15 (5%)**

Theme	Scenario 1 Doctor, No SA	Scenario 2 Doctor, SA	Scen. 3 Province, No SA	Scen. 4 Province, SA	Scen. 5 Vendor, No SA	Scen. 6 Vendor, SA	Total
Trouble	2 (5%)	3 (6%)	0 (0%)	4 (7%)	2 (4%)	3 (6%)	**14 (5%)**
Trust	1 (2%)	2 (4%)	2 (4%)	4 (7%)	2 (4%)	2 (4%)	**13 (4%)**
Unsure	2 (5%)	2 (4%)	2 (4%)	1 (2%)	3 (6%)	2 (4%)	**12 (4%)**
Usage	2 (5%)	1 (2%)	2 (4%)	1 (2%)	2 (4%)	1 (2%)	**9 (3%)**
Block	1 (2%)	0 (0%)	0 (0%)	0 (0%)	1 (2%)	3 (6%)	**5 (2%)**
Time	0 (0%)	0 (0%)	0 (0%)	1 (2%)	0 (0%)	3 (6%)	**4 (1%)**
Redo	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2 (4%)	1 (2%)	**3 (1%)**
Cost	0 (0%)	0 (0%)	1 (2%)	0 (0%)	1 (2%)	0 (0%)	**2 (1%)**
Duplication	0 (0%)	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	**1 (0%)**
N/A	12 (21%)	15 (24%)	7 (11%)	8 (12%)	5 (9%)	12 (20%)	**59 (16%)**
Total	**56**	**63**	**64**	**65**	**58**	**60**	**366**

Hackers being able to access and possibly change personal health data in an ePHR was the most commonly given risk category overall.

Digital stored data can be hacked as shown by some of the hacking stories.

IDENTY THEFT HACKERS CAN ABSOLUTY GET ANYTHING AND I DO MEAN ANYTHING THEY WANT AND THAN YOU ARE LEFT TO PICK UP THE PIECES OF YOUR SO CALLED LIFE!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!

My most private information could be exposed to hackers.

This was not one of the top concerns, though, for those who were presented with an ePHR with structural assurances operated by the provincial health ministry; it was also of less than top concern for those presented with a third party provided ePHR without structural assurances, where it was the third most mentioned.

Security issues were raised next most often overall, but the ranking varied between scenarios from most mentioned to fifth most common. Usually closely associated in prevalence of response was a risk of privacy breaches, resulting in a fourth highest percentage overall, but also varying in priority between scenarios.

1. Storage - I am not confident that an ePHR administered by a first or third party will take the necessary precautions to keep my information safe. This could include even simply security breaches such as storage of passwords in plaintext, unsanitized SQL queries, or more elaborate attacks.2. Fraud - Since the Ontario Health Card is often used as a form of identification, I am concerned that the information stored with an ePHR could be used to commit identity fraud.

If I don't have security precautions to protect my userid and password, someone could stole my information and use it. However, I don't see any intrinsic risk on using the ePHR

information security - although I recognize that this can be mitigated

The risk of exposure of private data, as a result of security faults or privacy breaches, was assessed to be third most mentioned risk overall, also with variance between scenarios.

more info you put out there the more chance you have of some one getting your info? but if some one did get my info what would it be used for??

Insurance interests and employers getting access to personal health information.

Many of the other perceived risks mentioned were common concerns in online information situations. The risk raised that is most specific to ePHRs, mentioned by 14 percent overall, is the concern that the data would not be accurate, either through corruption or error, and would prove difficult to correct, or would result in mistakes in treatment.

THERE ARE TOO MANY RISKS AT THIS POINT WITHOUT RECEIVING MORE INFORMATION AS TO OUR PRIVACY & WHO CAN ACCESS INFORMATION.

OR WHO CAN CHANGE THIS INFORMATION WHICH COULD CAUSE ERRORS. FILES CAN BE CHANGED SO MUCH MORE EASILY WITH THIS SYSTEM THAN WITH A HARD COPY.

maybe the wrong persons file being pulled or missed information (ie something like an allergy not be added) There are the same risk with this as with anything and it is not so much in the system as it is in the people using them or hacking them etc.

an error or bug in the system may make a doctor think I need a treatment that I don't need

Information getting tampered with, lost or stolen.

one mis-type could lead to miscommunication; especially when just learning how it all works

This issue of accuracy has been raised before (Staroselsky et al., 2006), specifically indicating that encouraging patient input is important to improve and maintain accuracy.

5.7.4   Critical Decision Factors

The fourth open-ended question asked the participants, "What would be the most important factor in your decision to plan to use or not use an ePHR similar to the one shown here?". The identified themes are listed in Table 5.34. Table 5.35 contains the counts and percentages for the themes, overall and by scenario. The no-answer (N/A) category has a percentage based on the total responses for the individual columns and the remaining percentages are based on the actual response count for the column.

Table 5.34 Themes in Responses of Critical Decision Factors for Using or Not Using an ePHR

Theme	Description
Security	Security issues in the ePHR
Privacy	Privacy issues in the ePHR
Data	All data collected in one place by the ePHR
Trust	Trust in the operation of the ePHR
Ease	Ease of use of the system
Usage	ePHR is used by appropriate professionals

Theme	Description
Manage	Able to manage one's health using the ePHR
Need	Need to manage complex health issues
Available	Availability and accessibility for the patient
Content	Availability of certain content in or through the ePHR
Benefit	Provides benefit; explained or clear
Cost	Value received for the user
Required	Required or health provider recommended
Unsure	Person uncertain
Would	Would use an ePHR
Support	Support of the system by relevant organizations
None	Text says none or similar
Time	Saves time for patient or health provider
Access	Access to care enhanced through ePHR
Relation	Factors in relationship with health provider; help or hinder
N/A	No answer or indecipherable

Table 5.35 Crosstab of Key Factors Given to Use or Not Use an ePHR

Theme	Scenario 1 Doctor, No SA	Scenario 2 Doctor, SA	Scen. 3 Province, No SA	Scen. 4 Province, SA	Scen. 5 Vendor, No SA	Scen. 6 Vendor, SA	Total
Security	14 (31%)	21 (41%)	18 (31%)	15 (25%)	14 (27%)	16 (36%)	**98 (32%)**
Privacy	7 (16%)	5 (10%)	12 (20%)	11 (19%)	9 (18%)	10 (22%)	**54 (17%)**
Data	4 (9%)	7 (14%)	5 (8%)	5 (8%)	9 (18%)	2 (4%)	**32 (10%)**
Trust	4 (9%)	5 (10%)	6 (10%)	3 (5%)	5 (10%)	8 (18%)	**31 (10%)**
Ease	1 (2%)	6 (12%)	5 (8%)	7 (12%)	6 (12%)	3 (7%)	**28 (9%)**
Usage	3 (7%)	1 (2%)	6 (10%)	6 (10%)	7 (14%)	5 (11%)	**28 (9%)**
Manage	4 (9%)	9 (18%)	2 (3%)	5 (8%)	2 (4%)	5 (11%)	**27 (9%)**
Need	5 (11%)	3 (6%)	2 (3%)	4 (7%)	4 (8%)	6 (13%)	**24 (8%)**

Theme	Scenario 1 Doctor, No SA	Scenario 2 Doctor, SA	Scen. 3 Province, No SA	Scen. 4 Province, SA	Scen. 5 Vendor, No SA	Scen. 6 Vendor, SA	Total
Available	2 (4%)	3 (6%)	7 (12%)	7 (12%)	2 (4%)	2 (4%)	**23 (7%)**
Content	1 (2%)	6 (12%)	2 (3%)	4 (7%)	4 (8%)	1 (2%)	**18 (6%)**
Benefit	2 (4%)	1 (2%)	3 (5%)	4 (7%)	4 (8%)	2 (4%)	**16 (5%)**
Cost	2 (4%)	2 (4%)	4 (7%)	1 (2%)	3 (6%)	1 (2%)	**13 (4%)**
Required	2 (4%)	2 (4%)	0 (0%)	4 (7%)	1 (2%)	2 (4%)	**11 (4%)**
Unsure	1 (2%)	2 (4%)	3 (5%)	0 (0%)	3 (6%)	1 (2%)	**10 (3%)**
Would	1 (2%)	0 (0%)	1 (2%)	2 (3%)	2 (4%)	1 (2%)	**7 (2%)**
Support	0 (0%)	1 (2%)	1 (2%)	2 (3%)	2 (4%)	1 (2%)	**7 (2%)**
None	2 (4%)	0 (0%)	1 (2%)	1 (2%)	0 (0%)	2 (4%)	**6 (2%)**
Time	1 (2%)	1 (2%)	0 (0%)	2 (3%)	1 (2%)	1 (2%)	**6 (2%)**
Access	0 (0%)	0 (0%)	1 (2%)	2 (3%)	1 (2%)	1 (2%)	**5 (2%)**
Relationship	1 (2%)	0 (0%)	1 (2%)	0 (0%)	1 (2%)	0 (0%)	**3 (1%)**
N/A	11 (20%)	12 (19%)	5 (8%)	6 (9%)	7 (12%)	15 (25%)	**56 (15%)**
Total	**56**	**63**	**64**	**65**	**58**	**60**	**366**

One in three overall, 32 percent, mentioned security of the system as the most important factor in their decision to use or not use an ePHR, with about half as many indicating that privacy of the data was critical. Security was the factor most mentioned in all scenarios, with privacy second in all but one scenario.

> *I will wait a little longer and see if their system is secure by waiting to see if other users lose their privacy information.*

> *Security and hence the confidentiality of the information. Much information is already stored in Hospital Information Systems such as X-Rays,CT's, MRI's*

etc. and at Pharmacies. Making this information open to exploitation might be unpopular.

Transparency - if the organization that administers the ePHR is transparent in its security procedures (i.e. they present proof that security procedures have been implemented and have hired 'White Hat' security experts to test their system.

Full disclosure of the following:- The exact rules for when parties other than my health care provider may access my profile.- Logging and reporting of every person who accesses my profile (date, stamp and reason for access logged). - Transparency: When third parties access my profile I should know about, i can log in to my profile and see who accessed it and when and for what reason (i might be ok with employee numbers instead of names but definitely would prefer names)- a protocol by which I can challenge the reasons people view my profile (i.e. I can call up said agency and ask for an explanation).- Clearly defined rules (and proof of enforcement of said rules) for breach of protocol for unauthorized access to my file

Assurance that I would be in control of who could access any, some or all of the information. It looks like something I would like to use for MY own record keeping, not necessarily share with just any service provider. I don't want some part time employee at the pharmacy having access to my information (for example).

 In the unique scenario—a doctors' clinic providing an ePHR with structural assurances—privacy was only mentioned by 10 percent of those responding, much lower than several other factors. In that scenario group, the ability to use the ePHR to manage one's health was the second most mentioned critical decision factor.

to be able to keep track of any health condition and to be able to use the information to see the progress good or bad

Decision to use would be based on it's usefulness in keeping me healthy. A decision not to use would be based on real security issues, not perceived ones.

Most important factor would be how i can manage my diabetes on a site that includes all aspects in the management of Diabetes along with other medications i am taking (i.e. weight, food diary, blood glucose logbook, etc)

The third most mentioned factor overall was the ability to gather all of one's personal health data in one place for ease of verification or presentation to a new healthcare provider. Trust in the system and the institution was only slightly less mentioned in the overall responses. Each of these factors was only ranked in the top three in two of the six scenario groups.

to have all medical history info in one place for easy access. these days it is very hard to find a doctor and to get appointments to see the doctor.

To have all my records together and my physician or emergency personnel having access. Also being able to access my own information

Reassurances of the quality and capability of the IT provider responsible for hosting the system.

Hearing from real, trusted people (doctors, friends that have used it) that this is a reliable source.

The variation in the responses by scenario after the top two responses was broad. In the six scenarios, six individual themes had the third ranking in a scenario. These included the data gathering (doctor with structural assurances) and trust (third party provider with structural assurances) critical factors previously mentioned. The potential ease of use of the system was given as critical by 12 percent of those presented with an ePHR from the province with structural assurances. The usage of the ePHR by the health professionals involved in the respondents' care was critical to 14 percent of those presented with a third party provider with no structural assurances. Personal need to manage a complex health situation was considered critical by 11 percent of those presented with the scenario of a doctors' clinic provided system with no structural assurances. Respondents presented with either of the scenarios involving an ePHR from the provincial health ministry gave the availability and accessibility of the system to the public as critical in 12 percent of the responses.

5.7.5 Preferred ePHR Provider

The final open-ended question asked the study participants, "Who do you see as your preferred primary sponsor in an ePHR; your doctor, your provincial health ministry, or a system provider? Who would be your second choice? Why would you rank them that way?". The response groups are summarized in Table 5.36 by scenario; in the responses, there was either a selection (First), a statement stating they were unsure of their response (Unsure), explicitly stating no selection (None), or there was no answer (N/A). These four rows total to 100 percent. In many responses, a second selection was made (Second Provided), and reasons given (Reason Provided). These were subsets of the First Provided category; the percentages for the Second Provided and Reason Provided entries are based on the totals in the bottom row.

Table 5.36 Crosstab of Top-level Provider responses by Scenario

Response	Scenario 1 Doctor, No SA	Scenario 2 Doctor, SA	Scen. 3 Province, No SA	Scen. 4 Province, SA	Scen. 5 Vendor, No SA	Scen. 6 Vendor, SA	Total
First Provided	41 (73%)	42 (67%)	53 (83%)	56 (86%)	48 (83%)	40 (67%)	**280 (77%)**
Second Provided	29 (52%)	35 (56%)	35 (55%)	44 (68%)	35 (60%)	31 (52%)	**209 (57%)**
Reason Provided	31 (55%)	26 (41%)	39 (61%)	42 (65%)	37 (64%)	24 (40%)	**199 (54%)**
Unsure	2 (4%)	3 (5%)	4 (6%)	2 (3%)	3 (5%)	4 (7%)	**18 (5%)**
None	2 (4%)	0 (0%)	1 (2%)	1 (2%)	0 (0%)	1 (2%)	**5 (1%)**
N/A	11 (20%)	18 (29%)	6 (9%)	6 (9%)	7 (12%)	15 (25%)	**63 (17%)**
Total	**56**	**63**	**64**	**65**	**58**	**60**	**366**

There were 280 responses that selected a first choice of ePHR provider, and 209 that selected a second choice. In Table 5.37 the specific choices are tabulated by scenario and overall. The percentages are based on the selection counts, so the first three rows, representing doctor, province, or vendor respectively as first choice, are grouped, totalling 100 percent, and the next three rows are another group, again, totalling 100 percent (some totals may not add to 100 as a result of rounding). The doctors' clinic is rated first by half of those giving a first choice,

with the province being selected second by about half of those giving a second choice.

Table 5.37 Crosstab of ePHR Provider Choices by Scenario

Provider	Scenario 1 Doctor, No SA	Scenario 2 Doctor, SA	Scen. 3 Province, No SA	Scen. 4 Province, SA	Scen. 5 Vendor, No SA	Scen. 6 Vendor, SA	Total
Doctor 1st	24 (59%)	13 (31%)	31 (58%)	29 (52%)	27 (56%)	17 (43%)	**141 (50%)**
Province 1st	14 (34%)	23 (55%)	17 (32%)	16 (29%)	13 (27%)	20 (50%)	**103 (37%)**
Vendor 1st	3 (7%)	6 (14%)	5 (9%)	11 (20%)	8 (17%)	3 (8%)	**36 (13%)**
Total 1st	**41**	**42**	**53**	**56**	**48**	**40**	**280**
Doctor 2nd	7 (24%)	15 (43%)	9 (26%)	11 (25%)	7 (20%)	11 (35%)	**60 (29%)**
Province 2nd	15 (52%)	12 (34%)	19 (54%)	22 (50%)	19 (54%)	11 (35%)	**98 (47%)**
Vendor 2nd	7 (24%)	8 (23%)	7 (20%)	11 (25%)	9 (26%)	9 (29%)	**51 (24%)**
Total 2nd	**29**	**35**	**35**	**44**	**35**	**31**	**209**

Finally, 199 responses included reasons for the selection that they made, with a total of 312 identifiable reasons for those selections. The themes are in Table 5.38, the crosstab results by scenario are in Table 5.39.

Table 5.38 Themes in Provider Selection Reasons and Their Meanings

Theme	Description
Trust	Trust is a factor in the selection
Data	Data already in hand is an issue
Account	Accountability for the data is an issue
Experience	Experience and expertise in handling/securing data is an issue
Privacy	Privacy of information is an issue
Security	Security of data is an issue
Access	Access to data is an issue
Person	Personal relationship is an issue
Standards	Application or enforcement of standards is an issue
Outcomes	Work towards health outcomes is an issue

Theme	Description
Conflict	Conflict between entities within the system is an issue
Time	Concern regarding time usage in the system is an issue
Usage	Use of the system is an issue

The 'Answers' row gives the number of actual responses with reasons for that column, the 'Total' row is the total number of reasons given by that group, and the percentages are based on that value.

Table 5.39 Crosstab of Themes in Provider Selection Reasons by Scenario

Theme	Scenario 1 Doctor, No SA	Scenario 2 Doctor, SA	Scen. 3 Province, No SA	Scen. 4 Province, SA	Scen. 5 Vendor, No SA	Scen. 6 Vendor, SA	Total
Trust	11 (23%)	6 (12%)	11 (19%)	15 (24%)	16 (27%)	6 (17%)	**65 (21%)**
Data	7 (15%)	8 (16%)	9 (16%)	8 (13%)	6 (10%)	3 (8%)	**41 (13%)**
Account	6 (13%)	6 (12%)	6 (11%)	8 (13%)	6 (10%)	7 (19%)	**39 (13%)**
Experience	5 (11%)	5 (10%)	5 (9%)	7 (11%)	11 (18%)	4 (11%)	**37 (12%)**
Privacy	3 (6%)	6 (12%)	7 (12%)	5 (8%)	5 (8%)	5 (14%)	**31 (10%)**
Security	5 (11%)	7 (14%)	7 (12%)	6 (10%)	2 (3%)	4 (11%)	**31 (10%)**
Access	6 (13%)	4 (8%)	4 (7%)	5 (8%)	6 (10%)	3 (8%)	**28 (9%)**
Person	3 (6%)	1 (2%)	6 (11%)	6 (10%)	7 (12%)	3 (8%)	**26 (8%)**
Standards	1 (2%)	4 (8%)	1 (2%)	1 (2%)	0 (0%)	1 (3%)	**8 (3%)**
Outcomes	0 (0%)	2 (4%)	0 (0%)	1 (2%)	0 (0%)	0 (0%)	**3 (1%)**
Conflict	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (2%)	0 (0%)	**1 (0%)**
Time	0 (0%)	0 (0%)	1 (2%)	0 (0%)	0 (0%)	0 (0%)	**1 (0%)**
Usage	0 (0%)	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	**1 (0%)**
Answers	31	26	39	42	37	24	**199**
Total	**47**	**50**	**57**	**62**	**60**	**36**	**312**

As shown in the model results, trust as a consideration in a patient's decision to use an ePHR system was given most often as a reason overall, and one of the top three reasons for individual scenarios. Some of that trust is based on who is operating the system, and who is accessing the data contained within it. While many cited their trust in their doctor, and an existing personal relationship, many others added the more pragmatic assertion that they did not trust their doctors to run a secure and stable ePHR system with the benefits that would be useful to patients.

> *My doctor will be the primary sponsor. I trust her, and only this way I know she will use it and I'll be encouraged to provide the information for her. Second choice, provincial health ministry. Although, I'm concerned that this sponsor may not have buy-in from my doctor to adopt and use this kind of system.*

> *Doctor, then Prov Health Min, then Sys provider -- a doctor has name and can held accountable, a Prov Health Ministry may have a name, but nowadays are quite nameless and blame and don't take responsibility when the chips are down. System Provider is even worse than Prov health ministry.*

> *1. Doctor--an issue of trust & use 2. Health Ministry--admin capability 3. System Provider--unknown folks*

> *Provincial Health registry no interest in the other options. Doctor lacks the resources and a third party would have financial incentives to use the data.*

> *I would prefer for a system provider to be the primary sponsor since this is what they specialize in. I would have the provincial ministry as a second choice as I feel they would have better resources than my doctor to handle a system like this.*

> *1- Doctor2- provincial health3- system provider** ranked by whom I trust most*

> *This is a tough question. I guess it has to be a health data intstituteas an arm of the health ministry, with the system provider as #2. While my doctor may be very competent in his way, I would not want him to be responsible for security/access.*

I suppose my first choice would be the health ministry. They seem like they might be the least biased AND trustworthy. It is a tough call though and I don't have a strong opinion on it however.

The experience and expertise factor that was reported by about 12 percent reflects the logic of having a provider of an ePHR who knows what they are doing to secure the data, assure access to those authorized, and keeping the data private. This led some respondents to select a provider that they did not fully trust but exemplified the better alternative; this further reflects the balancing of trust, distrust, and perception of risks in a system with identifiable benefits to the users.

The second overall reason for selecting an ePHR provider was that the provider selected already had the data, so is in the best position to work with it and ensure that it is in the ePHR accurately.

1)Doctor - I trust my Doctor and know who to phone when there are issues
2)Provincial Health Authority - keep all records together, for easy reference.

1: my doctor --- he already has all this information 2: Health Ministry --- they are in at least some sense accountable to the public, and have a duty to act in the public good 3: System provider --- at the bottom of the list as commercial companies are amoral, and are only as trustworthy as the people running them, who can be changed at any time via e.g., shareholder votes. Witness the 2008 world financial crisis, in which the corporations (e.g., banks) responsible for a huge amount of distress disavowed responsibility, and were unable to be held to account in any significant way.

doctor 1 health ministry 2 because the doctor should be the one entering all the info

1. my doctor because he has the facts about me. 2. the PHM since they have access to all myh records3 computer agency

My personal preference would be family doctor as he/she knows all one's diseases, medications, and health problems anyway.Second choice would be provincial health ministry for somewhat similar reasons as my first choice.

Doctor, then province, because they already have the information.

The third overall reason given for choosing a provider was that the provider was accountable, or could be held to account for problems in the system.

provincial first, they have to answer to the public, then my doctor, who is already supposed to keep my medical information private

provincial ministry first since they should be accountable. system provider next should they have the tools to make it efficient

I would say that a system provider would manage the safety of the data well if under strict contract and penalties for violations. Next the provincial government under the same strict access rules. The doctor could enter and access data but to manage it safely and efficiently would be doubtful as they are not in that business

1st - provincial MOHLTC - because they have the greatest accountability to the public to ensure security and privacy, and the have the power to enforce those regulations.   2nd - Primary care provider (NP or MD) - because if they had permission to access the tool; the information could be used to enhance your health care strategies to ensure better outcomes.

1. Provincial health ministry - high accountability 2. Doctor - personal trust

a system provider because their sole responsibility is to the security of the data. the provincial health ministry is too vulnerable to politics for me to feel secure

Other noteworthy responses were, unsurprisingly, security and privacy, and pre-existing needs to access the data to be found in the ePHR in the course of normal operations.

1) doctor - as long as it is used by the doctor and myself and no one else2) provincial health - as long as the information is used by the government and not private companies (drug companies etc)

Provincial health ministry first, doctor second because the province deals with a lot of personal data already and does a good job keeping it secure.

1. System Provider 2. Provincial Health Ministry Number 1, for system security Number 2, overall continuity of the system requirements (input) through out the province. The Doctors shouldn't have to worry about the "system". All he/she should have to do is input the information.

I think the government should be in charge of security of data and no one else.

my primary would be computer systems because they are installing the system with latest software. Second would be the doctors under patient confidentiality.

Again, broad variation was seen in the rankings between the different scenario groups. While the majority listed trust most often, two scenario groups did not, listing it second and tied for third. The theme covering data already in hand by a provider did not apply to the third party scenarios, so was not given much notice by those groups. Accountability was not considered as important as other factors in the scenarios lacking structural assurances for the province and third party systems. Security, privacy, and access (proper and malicious) to the data were considered important in several scenarios. Lack of any personal relationship was considered important by those presented with a third party system lacking structural assurances.

6   Discussion and Conclusions

This investigation was undertaken to answer the following research questions using the hypotheses expressed in the research model and supporting analysis.

1. What are the trust and distrust related factors involved in a consumer's decision to use or not use an electronic personal health record and how do they influence the consumer's intention to use an ePHR?

2. What is the consumer's perception of risk in sharing personal health information online and how does this influence the intention to use an ePHR?

3. Is there a difference in the intention to use an ePHR if the ePHR is provided by a doctor's clinic, the provincial health authority, or a system vendor?

4. How does the presence or absence of traditional structural assurances influence the consumer's intention to use an ePHR?

6.1   Key Findings

6.1.1   Research Questions

6.1.1.1   Trust and Distrust Factors

The hypotheses regarding the antecedents of trust and distrust in the revised model were shown to be correct, with the constructs being influenced by personal dispositions and by the opinions of the institution presenting the ePHR, and also by the structural assurances presented or not on the portal for the ePHR. Trust in the ePHR was weakly influenced by disposition to trust ($\beta=0.13$, $p<0.05$) and moderately by trust in the institution ($\beta=0.35$, $p<0.001$). Distrust in the ePHR was moderately influenced by both disposition to distrust ($\beta=0.26$, $p<0.001$), and distrust in the institution ($\beta=0.22$, $p<0.01$). Both trust and distrust in the ePHR were moderately to strongly influenced by structural assurances ($\beta=0.44$, $p<0.001$ and $\beta=-0.42$ $p<0.001$ respectively), positively for trust and negatively for distrust, as hypothesized. The model explained 56 percent of the variance in the trust in the ePHR, and 46 percent of the distrust in the ePHR; while the survey scale for trust and distrust was significantly reduced from the over 20 items, it was still capable of accounting for about half of the variation in responses.

In turn, trust and distrust in the ePHR influenced the perceived risk and usefulness of the ePHR. Trust moderately influenced perceived usefulness (β=0.28, p<0.001), while distrust had a moderate, negative effect on perceived usefulness (β=-0.21, p<0.01). Distrust, however, had a strong effect on the perceived risk of the ePHR (β=0.52, p<0.001), while the influence of trust was negative and only a small effect (β=-0.15, p<0.05). Again, about 50 percent of the variance in the perceived usefulness (R^2=0.50) and perceived risk (R^2=0.55) results are explained by the model.

6.1.1.2 Risk Perception

Perceived risk had only a small, negative effect on the intention to use an ePHR (β=-0.16, p<0.001), and the effect of perceived usefulness was strong (β=0.54, p<0.001).

The main perceptions of risks perceived and reported on in the open-ended questions by those who responded were common online risks: attacks by hackers, insufficient security, privacy breaches and the associated exposure of private data, and other potentially fraudulent misuses of the information. Also reported were concerns over patients' accessibility of the system, both from getting access to the portal, and from failures in the system hardware or software. The accuracy of the health information, imagined difficulties in getting it corrected, and possible mistakes in treatment based on inaccuracies were perceived risks reported that were specific to ePHR systems.

6.1.1.3 Differences in Intention between Groups

The observed variation in mean differences between the three organizational sources of the ePHR images in the survey demonstrated that there is a difference in intended adoption for an ePHR presented as being provided by the provincial health ministry as compared to the other possible sources. This was in spite of the stated preference by half of those responding in the open-ended questions that they would prefer an ePHR system provided by a doctors' clinic. It would appear that what the respondents ask for and what they respond to in images are markedly different. There was no difference in stated intention to use an ePHR based on the presence or absence of structural assurances.

6.1.2 Trust and Distrust are Different Concepts

While both trust in the ePHR and distrust in the ePHR had effects on the respondents' intention to use the ePHR, there was a difference in the strengths

of the relationships and the statistical significance of the links involving trust and distrust in the model, thus supporting the belief that trust and distrust are different concepts operating in different dimensions rather than opposite ends of a spectrum. The effects of trust operated primarily, and with high statistical significance, through perceived usefulness (β=0.28, p<0.001 as compared to β=-0.15, p<0.05 for the risk path from trust), while distrust was seen significantly impacting the perception of risk (β=0.52, p<0.001 as compared to (β=-0.21, p<0.01 for the PU path from distrust), as suggested by McKnight and Choudhury (McKnight & Choudhury, 2006).

If trust and distrust were at the opposite ends of a spectrum, then by the nature of their creation, the closely associated items of each construct's antecedents would work equally well to influence the trust and distrust latent variables. In fact this was not the case, with lower path weights and reduction in statistical significance in the links from trust's antecedents to distrust and *vice versa* as compared to the normal connections in the model. For example, when disposition to distrust is connected to distrust in the model, it has a path weight of 0.26, and p < 0.001. If it is associated with trust instead, then it is not a statistically significant link, and the weight drops to 0.05. Other changes were not as severe, but the differences were apparent.

6.1.3 Canadians' Relationships with the Healthcare System Are Complex

As reported in another study on the attitude of Canadians towards the participants in the healthcare system (Abelson et al., 2009) many feelings and contradictions are expressed in the attitudes of patients in the system. While most trust their doctor, they do not trust him or her in everything, such as running a system to support an ePHR. When presented with an example ePHR, and asked if they intended to adopt an ePHR like it, more were willing to adopt the ePHR from the provincial health ministry than the other options. However, when the respondents were asked, in an open-ended question, who their first choice was to provide them with an ePHR, 50 percent chose the doctor.

While the government is looked upon with some distrust, it is considered to be an important participant in providing health resources, including managing the data that are required to manage healthcare. And finally, while many companies can be looked upon as providing examples of good business practice, few citizens

would be willing to surrender personal health information to them without assurances of privacy and security protection; the third-party system vendor, nominally the most professionally equipped to supply and operate an ePHR was the first choice of only 13 percent of the respondents in the open-ended questions.

This variation suggests that the consideration of the organization providing an ePHR and scrutiny of the details of that ePHR are complex, with substantial variation in what is important between individuals. While fairly obvious requirements are common, once those are addressed further breakdown of important features will require more input from the public before a highly satisfactory system can be put into use.

Any changes, such as introducing ePHRs, will be met with this complex set of feelings and opinions. Asking for input does not necessarily result in a useful answer as the discrepancy between the results of two different survey methods demonstrates. The context and definitions in any research in this area must be made quite clear to respondents to ensure clear results.

6.1.4 Some Risks Appear To Be Tolerable In the Face of Other Risks

As discussed, health information is not like financial information where losses can be reinstated and unauthorized access cut off when discovered; loss of information can lead to permanent consequences. Canadians' interest in Internet shopping, where financial information is exchanged for convenience and breadth of selection, may or may not lead to an interest in using the Internet to access personal health data. This study found that many are indicating that, if they trust the supplier (institutional trust has a moderate effect on trust, $\beta=0.35$) and do not distrust the mechanism provided (structural assurances moderately affect both trust and distrust $\beta=0.44$ and $\beta=-0.42$ respectively), they would be willing to use an online ePHR portal. The rewards of ease of accessing past information and the hope of easier access to appropriate medical personnel are strong incentives to take advantage of an ePHR, in the view of those who responded. In the calculus of trust and risk, the assessment that the ePHR could be useful in serving a need of the consumer can be seen to outweigh the risks (perceived usefulness has a path weight of 0.54 for its relationship with intention to use the ePHR, whereas perceived risk has only a weight of 0.16). For ePHRs to have the ascribed value to society, they will need to be used by large numbers

but, to date, voluntary adoption of these systems has been low. Certain clearly perceived value in terms of convenience or improved access will need to be created and publicized if sufficient adoption is to take place in the face of the perceived risks.

6.2   Contributions to Research

This dissertation developed and empirically tested a model that explains over 50 percent of the consumer intentions to adopt an ePHR. The results incorporate the interlinked concepts of trust and distrust, and balance them against the perceived risk in placing personal health information online in a portal-based ePHR. The impact of the provider and the presence of structural assurances were also investigated.

In developing a model, a reduced trust and distrust scale was created and validated, providing the possibility of including these constructs in a larger model without risking survey fatigue in the participants.

6.2.1   Further Evidence that Trust and Distrust Are Different

Most studies looking for a difference between trust and distrust have focused on some aspect of eCommerce and set up trustable and untrustworthy sources to test (Dimoka, 2010; McKnight & Chervany, 2001b; McKnight & Choudhury, 2006; McKnight et al., 2002a). This study dealt with eHealth in realistic, potential scenarios, and the attendant differences in consequences from loss of privacy and the more personal nature of health data as opposed to the financial data required for online sales. The asymmetry of effects on other latent variables in the model and the differences in significance of the antecedents on the opposite construct support the conclusion that the two concepts are distinct and not opposite ends of a spectrum of feeling towards a system.

6.2.2   The Calculus of Trust in Health Information

The perception of risk in providing and accessing ePHRs reported in this study was moderate, but intention to use the ePHR was strong despite this. More than a third of all those responding to the question of what would prevent them from using an ePHR like the one shown, reported that security and privacy of data was a serious concern, but less than ten percent said that they would not use the system. The ability to access all of their data in one place, potential access to specialized content, the ability to ease coordination between providers, and the chance to save time and gain more useful contact with providers were all cited as

positive determinants towards using an ePHR system such as the one illustrated in the study.

6.3   Implications for Practice

6.3.1   Enlist Doctors in Swaying Public to Use

As the most trusted provider in this study—quantitative results notwithstanding, when the respondents were asked for a choice in the open-ended questions, the doctor was the provider most associated with trust—and a highly trusted member of the healthcare system (Abelson et al., 2009), the family doctor is in a position to assist in patient transition to using ePHRs. The physician's recommendation can allow users to have the confidence that the system is legitimate, and the doctor is in a position to use the patient's health status to define the benefits and conveniences that use of an ePHR will provide to the user. Of course, the physician and his or her office staff will need to use the system as well for this to be meaningful, but many incentives have been suggested to assist the government agencies to encourage adoption by doctors and barriers to implementation are well understood (Boonstra & Broekhuis, 2010; Ludwick & Doucette, 2009a; Ludwick & Doucette, 2009b; Ludwick et al., 2010; Simon et al., 2007; Tang et al., 2006)

6.3.2   An ePHR Must Be a Clearly Secure Site

Security of the data stored in an ePHR is important to a large portion of the participants in this study. As previously discussed, health information and consequences of its loss or accidental disclosure are different from financial information. Most banks appear to use "good-enough" security; that is, the cost of the security system is balanced by the cost to the bank of a security breach. In many cases, reissuing of cheques, moving customers' money to a new account, and reinstating lost balances are relatively low cost compared to the scale of a highly secure system. However, security does come at a cost, with onerous identification systems and changing passwords that can lead many users to compromise their own access to the system. A useful and trusted system will need to be seen to be secure, and have features to assure ease of access for those authorized, but not so troubling that the system will frustrate users.

6.3.3   Privacy of Health Data

A recurring theme in the responses to the open-ended questions was that of privacy of data within the system. This theme reflects past studies and the

impetus behind the many health information privacy laws in countries around the world. The ability to specifically allow or deny access to data, control additional uses of the data, and track who has accessed personal information have been raised in the past (Agrawal & Johnson, 2007; King et al., 2012; Willison et al., 2007), and confirmed in the Canadian context.

6.4 Limitations and Future Research

6.4.1 Limitations

This study only involved English-speaking participants from within the Canadian healthcare system, and the possible solutions put forward in that context. The Canadian healthcare system is similar in many ways to other systems in the world, coming as it does, from the Beveridge model of national health systems developed in Britain and spread to many parts of the world from there (Walberg et al., 2008); it is, however, one of only a few that have such a strong monopoly on service. These factors might mean that this study's findings may be generalizable to other similar systems, but there is a risk that the characteristics of the Canadian system will prevent that possibility.

Some confusion was evident in the open-ended question responses, such that the participants may have been answering the questions with a misconception of what was meant by the source of an ePHR, and thus the implications of that role. Further explanation of sources and possible expansion of options in that area might yield different responses and thus offering differences in the support for the hypotheses tested here. Further, the manipulation validation indicated that there was some lack of awareness of the variation in structural assurances. A specific manipulation check question or questions should be included in future studies.

The measurement of intention to act, while shown to be highly correlated with actual action when the conditions have been tested, is still only a related measure, and not the actual measure of behaviour. Further, the intention was to be formed based on static images, rather than based on a realistic demonstration system, thus not allowing for an interactive assessment of the true personal value of an ePHR system. While behavioural intention has repeatedly correlated well with actual use in TAM studies, the difference between intention and action could prove to be a notable one when such

systems are actually put into production, rendering some of these findings unhelpful.

Finally, all of the respondents accessed the survey online. While the survey involved an online portal system, this created a bias towards those comfortable with online systems. A future study utilizing a functional ePHR system could be taken into settings where those expected to benefit from ePHRs would be found, such as a long term care facility or community centre, and those not active on the Internet could be tested. Also, no effort was made to filter out those familiar with ePHRs; there is no reason to believe that their opinions are any less valid than those with no knowledge, and their numbers are currently low. As usage grows, subsequent studies should include experience with ePHRs as a control variable, at least.

6.4.2 Future Research Directions

The post-hoc analysis brought out some contradictions in the findings that merit further study. In particular, the apparent lower trust in a secure portal from a third party system provider than in an unsecured portal from such a source requires more investigation to determine the cause of this contradiction; is this a simple aberration in the current study's data, or is it a repeatable result? A study to test this, and collect the data that would give the reasons why the potential users of an ePHR system would respond that way would prove useful to those setting up ePHR systems and other equivalent collections of sensitive data on the Internet.

Continued testing of the trust and distrust differences, and the relationships between those constructs with risk and usefulness in new contexts could be beneficial to those contemplating offering online services. Software as a service, "cloud" based services, and other online data stores and sources all use the trust of the participant to overcome the inherent risks, and the potential usefulness to overcome the distrust in placing valuable information online. Testing whether or not the relationships hold in other circumstances can provide useful information for cloud computing and other online services.

The relationships discovered between an increase in a person's willingness to take risks and an increase in reported self-efficacy, and risk-taking and confidence in structural assurances were discovered during the testing of partially saturated models. These findings have little support available, and while

the relationships make sense from a logical perspective, more testing is needed to determine if they hold in a wider context, or are artifacts of the nature of this study.

6.5 Conclusions

This research set out to discover the trust and distrust factors involved in members of the public forming an intention to use an ePHR system, differences in intention to use an ePHR depending on its origin, and the risk factors perceived in adopting it. An initial research model was created involving the constructs of Trust, Distrust and Perceived Risk, with antecedents from prior eCommerce research, and embedded in a framework based on the Technology Adoption Model (TAM). This model was validated in an empirical study involving 308 subjects. The complex relationship between patients and the healthcare system in Canada, previously documented (Abelson et al., 2009) was demonstrated in that a clear preference was shown statistically in the intention to use an ePHR construct by the scenario groups presented with an ePHR from the provincial health ministry as a provider compared to family doctors or a third party vendor as providers, but in an open-ended question, half of those stating a preference selected a system from their doctor as a first choice. Finally, common online data exposure concerns such as security and privacy were raised as risks in placing personal data on line, but responses also included concerns over accessibility and accuracy of the data.

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Appendix A: eHealth Survey

The participants were randomly assigned into one of six (6) groups. A specialized introduction was shown to each group, orienting them to the content of an ePHR, and showing them images from one of six possible source/assurance combinations. There was no restriction on how the quotas were filled, tight randomization (changing every second, in rotation) leading to an approximately equal sized population sample in each category.

Table A.1 Scenario List and Description

Scenario Number	Description
1	Clinic source, Standard presentation with no structural assurances
2	Clinic source, Secure presentation with visible structural assurances
3	Province source, Standard presentation with no structural assurances
4	Province source, Secure presentation with visible structural assurances
5	Vendor source, Standard presentation with no structural assurances
6	Vendor source, Secure presentation with visible structural assurances

Introduction Text

In the following text, the phrase "local doctor's clinic" was present for scenarios 1 and 2. For scenarios 3 and 4, the phrase was "your provincial health ministry", and for scenarios 5 and 6 it was "a third party system administrator on behalf of the provincial health ministry". The images for all the scenarios are presented for the first image, in numerical order by scenario number to illustrate the 6 frames; for the remaining images, only the image for the doctor's clinic with no structural assurances is shown. The apparent Internet Explorer window frame for each image in a scenario is exactly the same, and only minor textual variances exist in the image: Clinic Health Journal and CHJ in images for scenarios 1 and 2 are replaced by Provincial (or Prov.) Health Journal and PHJ for the remainder of the

scenarios. Each participant would only see the images from the set for the assigned scenario.

Title lines in bold in the tables for the questions are for clarification here, and were not shown to the respondents.

Welcome

This survey is limited to those who are 18 years of age or older, please.

Thank you for your interest in this study, which should only take about 20 to 25 minutes. Your opinions will help our understanding of public confidence in health information systems. There are no right or wrong answers; we want your honest opinions.

When you click the *Next* button at the bottom of this page you will start the survey. At the beginning you will be shown a number of images. Several questions are based on your opinions of these images. Later on, you can click the *Images* button on any survey page to open a new window to see them again. However, on some browsers, this may cause problems for you.

You are under no obligation to continue or complete the study. However, leaving the survey early will cause you to forfeit any rewards that you may earn by completing it. If you experience problems with the survey, please contact the support group at Research Now.

Thank you again for your interest in this study. By proceeding to answer the questions, you are consenting to participate in the survey. Please click the *Next* button to begin.

Survey Introduction

Other than you, the user-patient who owns the content of the electronic personal health record, or ePHR, there may be three other significant participants in the ePHR: medical professionals (or their staff), your provincial health authority, and possibly a third party system administrator (such as IBM or Telus). Any one of these might provide the system, software and associated security.

You have been randomly assigned into one of six possible groups, and the survey that follows is tailored for your specific group. In the next few pages you will be shown sample images of an ePHR for a person with some health concerns, clearly shown as being provided to you by a **local doctor's clinic**, and demonstrating some of the features to be found in an ePHR. As you look at the images and answer the questions, please imagine that it is your own ePHR where you must store important personal and private information, so that you may establish your feeling of trust in the system and your perception of risk involved in providing your information to this ePHR.

You will have an opportunity to return to this explanation and the example images at any time while you answer the questions in the survey.

Sample ePHR Images

This first image shows a sample home page for an ePHR, demonstrating the breadth of information that can be kept and organized. Most systems have the capability to manage several ePHRs from one login as long as consent is given—for example, a complete family as shown.

Figure A.1 Home Page Treatment for Doctor's Clinic, No SA

Figure A.2 Home Page Treatment for Doctor's Clinic, with SA

Figure A.3 Home Page Treatment for Provincial Ministry, No SA

Figure A.4 Home Page Treatment for Provincial Ministry, with SA

Figure A.5 Home Page Treatment for System Vendor, No SA

Figure A.6 Home Page Treatment for System Vendor, with SA

It can be difficult to keep track of medical issues and the dates that activity occurred, but those details are important contributions to a full medical history for your health providers. Here is an example of an ePHR capturing important facts.
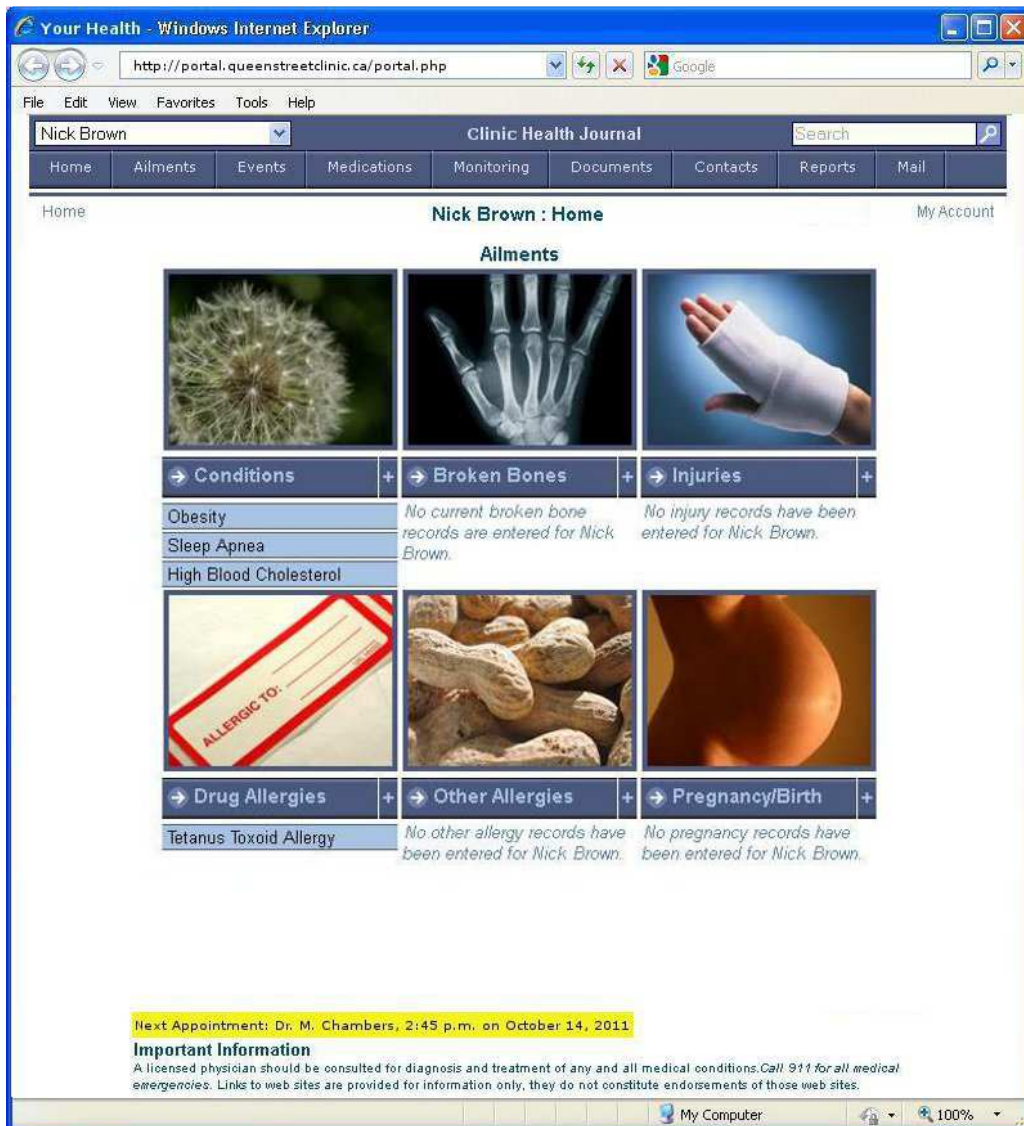
Figure A.7 Ailments Page Treatment

There are many possible conditions, drugs, tests, and other factors in a medical history. An ePHR can make it easier to record the correct data, as shown in this condition selection example.

Figure A.8 Conditions Page Treatment

While the Internet can provide you with useful information, there are also sources that may not be as reliable. An ePHR can filter the information and provide you with links to reliable information for your conditions, as shown here.

Figure A.9 Information Page Treatment

Medical data is often gathered over time, by the patient, for later communication with a medical practitioner. It may be regular blood-glucose readings, blood pressure, or other periodic information. Some systems also provide interfaces to allow you to transfer data automatically from electronic devices you may have at home. An ePHR can hold and organize that information as shown here.

Figure A.10 Monitoring Page Treatment

Finally, it may be easier to see trends or exceptions in graphical format, so an ePHR can provide a graph of your data.

Figure A.11 Data Chart Page Treatment
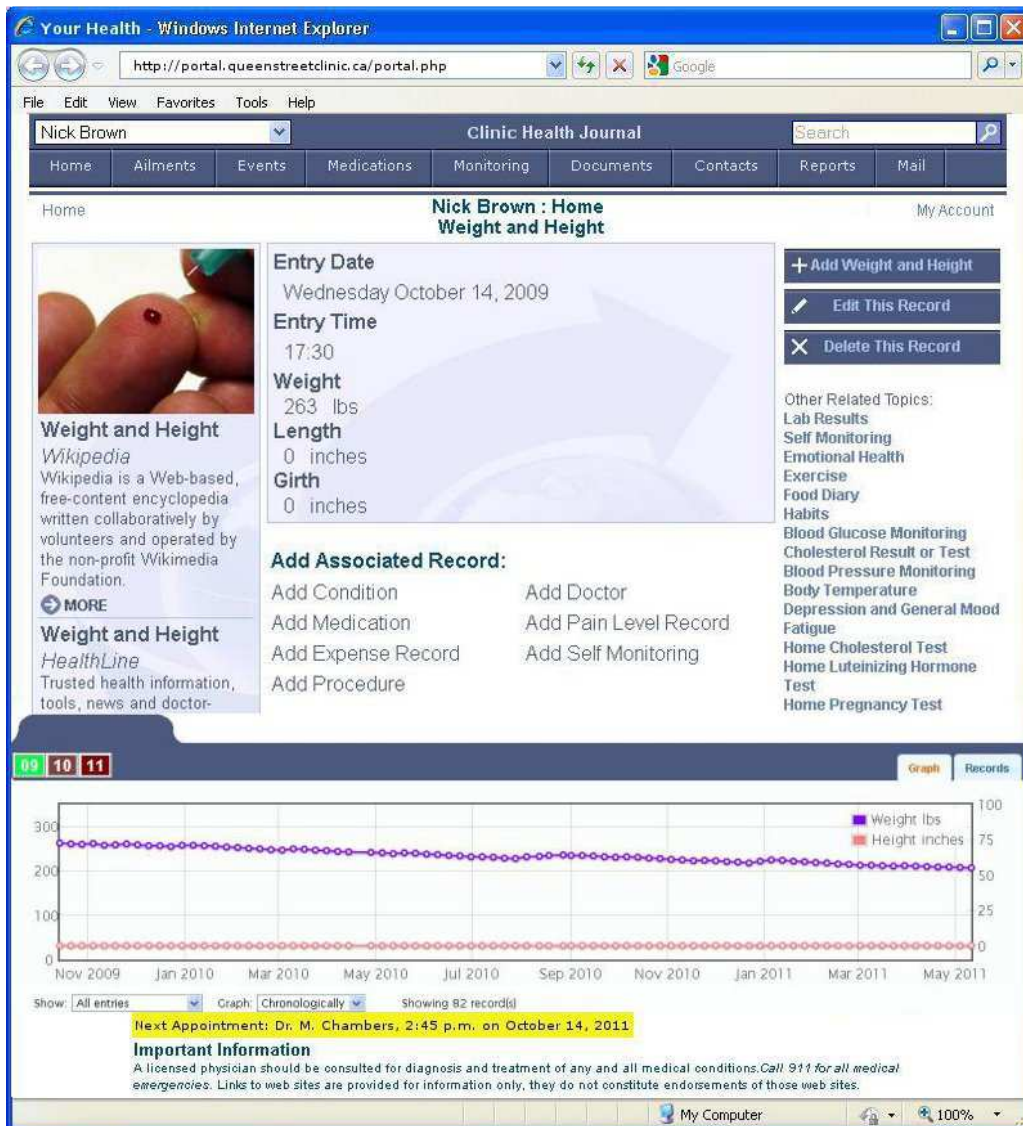
You may want to keep this page open as you fill in the survey for convenient review of the images; you will want to look for the title "ePHR Survey Introduction" in the tab or window/task list. You can also reopen it at any time by using the Instructions button found on every page.

Please return to the survey page now by clicking on the tab or window/task labelled "Trust and risk assessment".

Confidentiality, Risks, and Withdrawal

The data gathered in this survey will be kept in the strictest confidence and stored securely away from the possibility of misuse. No personally identifiable information will appear in any papers related to the study, nor are any names available to the researchers. It is unlikely that taking this survey will cause any harm to you, or expose you to any form of threat or embarrassment. You may withdraw from the study at any time by closing the survey, either by clicking on the "exit and clear survey" button which appears on every survey page, or by simply closing the browser tab or window. Any data you have provided will be discarded as incomplete, but you will not be eligible for any compensation from Research Now.

Contacts

If you have any concerns regarding this survey, contact Research Now and they can put you in contact with the researchers if necessary.

Survey Questions

The measurement items in the following tables are all assigned using 7 point scales: strongly disagree = 1, disagree=2, disagree slightly=3, neutral=4, agree slightly=5, agree=6, strongly agree=7. *Unless noted, all participants answer all questions.*

	1 = Strongly disagree 4 = Neutral 7 = Strongly agree						
Trust in the ePHR							
I feel that this ePHR is trustworthy.	1	2	3	4	5	6	7
I believe that this ePHR will deliver a service that meets my expectations.	1	2	3	4	5	6	7
I feel confident that by using this ePHR my privacy will not be compromised.	1	2	3	4	5	6	7

	1 = Strongly disagree 4 = Neutral 7 = Strongly agree						
I believe that this ePHR will keep my information secure.	1	2	3	4	5	6	7
Disposition to Trust							
Most of the time, people care enough to try to be helpful, rather than just looking out for themselves.	1	2	3	4	5	6	7
I think people generally try to back up their words with their actions.	1	2	3	4	5	6	7
I believe that most professional people do a very good job at their work.	1	2	3	4	5	6	7
I usually trust people until they give me a reason not to trust them.	1	2	3	4	5	6	7

Groups 1 and 2 answer the first set (Doctor), groups 3 and 4 answer the second (Province), and groups 5 and 6 answer the third (System Administrator)	1 = Strongly disagree 4 = Neutral 7 = Strongly agree						
Institutional Trust in my Doctor's Office							
I am comfortable relying on my Doctor's office to meet its obligations to this ePHR.	1	2	3	4	5	6	7
I feel fine providing personal information to my Doctor's office since it generally fulfills its agreements.	1	2	3	4	5	6	7
In general, many of my Doctor's office staff members are likely to be competent at serving their customers.	1	2	3	4	5	6	7

Groups 1 and 2 answer the first set (Doctor), groups 3 and 4 answer the second (Province), and groups 5 and 6 answer the third (System Administrator)	1 = Strongly disagree 4 = Neutral 7 = Strongly agree						
Many of my Doctor's office employees are likely to do a capable job at meeting customer needs.	1	2	3	4	5	6	7
Institutional Trust in my Provincial Health Ministry							
I am comfortable relying on my Provincial Health Ministry to meet its obligations to this ePHR.	1	2	3	4	5	6	7
I feel fine providing personal information to my Provincial Health Ministry since it generally fulfills its agreements.	1	2	3	4	5	6	7
In general, many of my Provincial Health Ministry's staff members are likely to be competent at serving their customers.	1	2	3	4	5	6	7
Many of my Provincial Health Ministry's employees are likely to do a capable job at meeting customer needs.	1	2	3	4	5	6	7
Institutional Trust in the System Administrator							
I am comfortable relying on the System Administrator to meet its obligations to this ePHR.	1	2	3	4	5	6	7
I feel fine providing personal information to the System Administrator since it generally fulfills its agreements.	1	2	3	4	5	6	7
In general, many of the System Administrator's staff members are likely to be competent at serving their customers.	1	2	3	4	5	6	7
Many of the System Administrator's employees are likely to do a capable job at meeting customer	1	2	3	4	5	6	7

Groups 1 and 2 answer the first set (Doctor), groups 3 and 4 answer the second (Province), and groups 5 and 6 answer the third (System Administrator)	1 = Strongly disagree 4 = Neutral 7 = Strongly agree
needs.	

	1 = Strongly disagree 4 = Neutral 7 = Strongly agree
Distrust in the ePHR	
I am concerned that this ePHR will not deliver a service that meets my expectations.	1 2 3 4 5 6 7
I am worried that my privacy will be compromised during or after using this ePHR.	1 2 3 4 5 6 7
I fear that this ePHR will not be trustworthy.	1 2 3 4 5 6 7
I am troubled that this ePHR will not keep my information secure.	1 2 3 4 5 6 7
Disposition to Distrust	
I suspect people generally do not try to back up their words with their actions.	1 2 3 4 5 6 7
I usually distrust people until they give me a reason to trust them.	1 2 3 4 5 6 7
I am concerned that most professional people do not do a very good job at their work.	1 2 3 4 5 6 7
I suspect that most of the time people do not care enough to try to be helpful; they are just looking out for themselves.	1 2 3 4 5 6 7

Groups 1 and 2 answer the first set (Doctor), groups 3 and 4 answer the second (Province), and groups 5 and 6 answer the third (System Administrator)	1 = Strongly disagree 4 = Neutral 7 = Strongly agree						
Institutional Distrust in my Doctor's office							
It troubles me that many of my Doctor's office's employees may do a poor job at meeting customer needs.	1	2	3	4	5	6	7
I worry when providing personal information to my Doctor's office since it generally does not fulfill its agreements.	1	2	3	4	5	6	7
I am uncomfortable relying on my Doctor's office to meet its obligations to this ePHR.	1	2	3	4	5	6	7
I am concerned that, in general, many of my Doctor's office's staff members may be incompetent at serving their customers.	1	2	3	4	5	6	7
Institutional Distrust in my Provincial Health Ministry							
It troubles me that many of my Provincial Health Ministry's employees may do a poor job at meeting customer needs.	1	2	3	4	5	6	7
I worry when providing personal information to my Provincial Health Ministry since it generally does not fulfill its agreements.	1	2	3	4	5	6	7
I am uncomfortable relying on my Provincial Health Ministry to meet its obligations to this ePHR.	1	2	3	4	5	6	7
I am concerned that, in general, many of my Provincial Health Ministry's staff members may be incompetent at serving their customers.	1	2	3	4	5	6	7

Groups 1 and 2 answer the first set (Doctor), groups 3 and 4 answer the second (Province), and groups 5 and 6 answer the third (System Administrator)	1 = Strongly disagree 4 = Neutral 7 = Strongly agree						
Institutional Distrust in the System Administrator							
It troubles me that many of the System Administrator's employees may do a poor job at meeting customer needs.	1	2	3	4	5	6	7
I worry when providing personal information to the System Administrator since it generally does not fulfill its agreements.	1	2	3	4	5	6	7
I am uncomfortable relying on the System Administrator to meet its obligations to this ePHR.	1	2	3	4	5	6	7
I am concerned that, in general, many of the System Administrator's staff members may be incompetent at serving their customers.	1	2	3	4	5	6	7

	1 = Strongly disagree 4 = Neutral 7 = Strongly agree						
Perceived Risk							
This ePHR and similar systems would be risky to use.	1	2	3	4	5	6	7
The chances are high that using an ePHR would cause me to lose control over the privacy of my personal information.	1	2	3	4	5	6	7
My signing up for and using an ePHR would lead to a loss of privacy for me because my personal information may be used without my knowledge.	1	2	3	4	5	6	7
Internet hackers (criminals) might take control of my	1	2	3	4	5	6	7

Perceived Risk	1 = Strongly disagree 4 = Neutral 7 = Strongly agree						
identity if I use an ePHR.							

Risk Profile	1 = Strongly disagree 4 = Neutral 7 = Strongly agree						
I enjoy taking risks.	1	2	3	4	5	6	7
I try to avoid situations that have uncertain outcomes.	1	2	3	4	5	6	7
Taking risks does not bother me if the gains involved are high.	1	2	3	4	5	6	7
I consider security an important element in every aspect of my life.	1	2	3	4	5	6	7
People have told me that I seem to enjoy taking risks.	1	2	3	4	5	6	7
I rarely, if ever, take risks when there is an alternative.	1	2	3	4	5	6	7

Structural Assurances	1 = Strongly disagree 4 = Neutral 7 = Strongly agree						
I feel safe conducting business with this ePHR because I am protected by a third party.	1	2	3	4	5	6	7
I feel safe conducting business with this ePHR	1	2	3	4	5	6	7

Structural Assurances	1 = Strongly disagree 4 = Neutral 7 = Strongly agree						
because I can easily contact someone if there is a problem.							
I feel safe conducting business with this ePHR because I see it has a policy on security and privacy of information.	1	2	3	4	5	6	7
I feel safe conducting business with this ePHR because its address is well-known and reputable.	1	2	3	4	5	6	7

Self-efficacy	1 = Strongly disagree 4 = Neutral 7 = Strongly agree						
I believe I would have the ability to access my data on the ePHR.	1	2	3	4	5	6	7
I believe I would have the ability to find my next scheduled appointment on the ePHR.	1	2	3	4	5	6	7
I believe I would have the ability to find information on the ePHR.	1	2	3	4	5	6	7
I believe I would have the ability to access the ePHR on the Internet.	1	2	3	4	5	6	7
I believe I would have the ability to update my data on the ePHR.	1	2	3	4	5	6	7

	1=Strongly disagree 4 = Neutral 7=Strongly agree						
Perceived Usefulness							
Using an ePHR will support important aspects of my health care.	1	2	3	4	5	6	7
Using an ePHR will enhance my effectiveness in managing my health care.	1	2	3	4	5	6	7
Overall, an ePHR will be useful in managing my health care.	1	2	3	4	5	6	7
Intent to Use Imagine that this was a real system and you were being offered an opportunity to use it to manage your health.							
I intend to use this ePHR.	1	2	3	4	5	6	7
I predict I will use this ePHR.	1	2	3	4	5	6	7
Given the need, I intend to use this ePHR to manage my health information.	1	2	3	4	5	6	7

Open-ended Questions

In order to capture as much of your opinions and feelings, there are a few open-ended questions. These questions will serve to confirm or expand upon your answers from the questionnaire. Please answer as completely and clearly as you can.

What factors would lead you to you consider using an ePHR similar to the one shown here?

What factors would cause you to consider <u>not</u> using an ePHR similar to the one shown here?

What do you feel are the risks in using an ePHR similar to the one shown here?

What would be the most important factor in your decision to plan to use or not use an ePHR similar to the one shown here?

The primary sponsor is the agency that provides the computer systems used to store the electronic data, and provides the security of and access to that data. Who do you see as your preferred primary sponsor in an ePHR; your doctor, your provincial health ministry, or a system provider? Who would be your second choice? Why would you rank them that way?

Demographic Questions

In order to classify some of your responses into groups, please answer the following demographic questions. For each item, please select the choice that you feel best fits your situation.

Gender	M=Male F=Female
Age: Please select the range that includes your age	1=18-30 2=31-50 3=51-70 4=Over 70
Region: Please indicate which province or territory you live in.	1=Newfoundland and Labrador, 2=Nova Scotia, 3=New Brunswick, 4=PEI, 5=Quebec, 6=Ontario, 7=Manitoba, 8=Saskatchewan, 9=Alberta, 10=British Columbia, 11=Yukon, 12= Northwest Territories, 13=Nunavut, and 14=Other country
Household income: Please select the category that matches the combined income of everyone in your home	1=Under $25,000 2=$25,000 to $50,000 3=$50,000 to $75,000 4=$75,000 to $100,000 5=$100,000 to $125,000 6=Over $125,000
Education: Please select the entry that best matches the highest level of education you have achieved	1=Some high school 2=Completed high school 3=Some post-secondary (college or university) 4=Completed post-secondary 5=Some post-graduate (Masters, Doctorate) 6=Completed post-graduate

Internet use location: Please indicate where you regularly access the Internet	1=At home only 2=At work or school only 3=At both home and work/school 4=At some other location
Internet usage: Please indicate how many hours you estimate you use the Internet in a week	1=Under 2 hours 2=2 to 5 hours 3=5 to 10 hours 4=10 to 20 hours 5=20 to 40 hours 6=Over 40 hours
Internet shopping: Please indicate how often you purchase items on the Internet	1=Never 2=Rarely 3=Sometimes 4=Often
Personal health: Do you suffer from a chronic or long-term health condition that requires regular treatment and/or medication?	Y=Yes N=No
Personal health status: On a scale of 1 to 10, where 1 is very poor and 10 is excellent, please rate your assessment of your health at this moment	1 2 3 4 5 6 7 8 9 10
Family health: Do you have a close family member who suffers from a chronic or long-term health condition that requires regular treatment and/or medication?	Y=Yes N=No

Completion Information
Thank You

This completes the survey. Thank you for your time. Your data has been saved and added to the anonymous survey results.

The data gathered in this survey will be kept in the strictest confidence and stored securely away from the possibility of misuse. Only the researchers will be

able to access the data, and only for the purpose of determining the public's views on ePHR systems as defined here. No personally identifiable information will appear in the final documents, nor will individual names be listed in any data collection associated with the study.

You may now return to the Research Now site to conclude your participation.